Cultural and Religious Values of Caregivers at End of Life Care: The Case of Hospice Ethiopia Palliative Center, Addis Ababa Ethiopia

By: Mahlet Endalku Beshah

A Thesis Submitted to School of Social Work, Addis Ababa University Presented in Partial Fulfilment of the Requirements for the Degree of Master of Social Work

Addis Ababa University

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July 2017

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This is to certify that the thesis prepared by Mahlet Endalku, entitled *Cultural and Religious Values of Caregivers at End of Life Care: The Case of Hospice Ethiopia Palliative Center* and submitted in partial fulfillment of the requirements for the Degree of Master of Arts (Social Work) complies with the regulation of the University and meets the accepted standards with respect to originality and quality.

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Declaration

I declare that *Cultural and Religious Values of Caregivers at End of Life Care: The Case of Hospice Ethiopia Palliative Center* is my own work. All the sources that I have used or quoted have been indicated. I have acknowledged by means of reference and that this work has not been submitted before any others degree at any other institution.

Mahlet Endalku Beshah

Signature: ____________________________

Date: ________________________________

Place: Addis Ababa University, Ethiopia

Abstract

Death and dying issue is what we humans find inevitable but most uncomfortable topic to discuss. In a country like Ethiopia, such topics are taken as a taboo and feared to talk about death and dying from the religious and cultural value we hold. This thesis is a qualitative exploratory case study aimed at cultural and religious values of caregivers at end of life care. The caregivers are both family and professional caregivers who provide care for people on the verge of death. The tools for primary data collection were in-depth interviews and observation in order to gain in-depth information. Purposive sampling technique was used to select participants leading to three professional caregivers and eight family caregivers. The finding of this study indicated that cultural and religious values have a great contribution while caring for people at the verge of death. It is important to give values as it has impact on the action of caregivers. In addition, the availability and use of social support has a great contribution and there are family members who are suffering lacking such support. Due to the cultural and religious values, family members have experienced lives that are stressful in care giving. Therefore, the finding has a good contribution for social work implication as the school of social work should incorporate courses that would give social workers a great skill and knowledge of palliative care. Regarding to practice, it is quite important to work with like-minded organization as to plan trainings, seminars and experience sharing programs. The finding showed that there is a lack of social work intervention in the area and it is important to study the view of clients themselves in the service provision. As the Ministry of Health is now giving attention to palliative care having the unit under its umbrella, there should be funding and human resources that could benefit for the quality of service provision and addressing large number of people.

Key Words: End of life Care, Cultural Values, Palliative Care and Religious Values

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Acronyms

AIDS- Acquired Immune Deficiency Syndrome

ESSSWA- Ethiopian Society of Sociologists, Social Workers and Anthropologists Association

HIV- Human Immune Virus

MOH- Ministry of Health

MSW- Masters of Social Work

NASW- National Association of Social Work

NCPC- National Council of Palliative Care

NSW- National Social Work

TB- Tuberculosis

WHO- World Health Organization

Chapter One

Introduction

1.1 Background of the Study

End of life care is a point in life that people on the verge of death require the gentlest and comfortable environment. It is my belief that when people are reaching to their death, it is important to attend them in ways they want without our own beliefs and attitude. As human beings, the attitude we have towards death might affect our approach for the care we owe our loved ones, as we usually think of life after death for them and how we would end up losing them. End of life can be understood as a continuum of events starting with the diagnosis of one or more serious illnesses or injury. Each of these conditions has a trajectory, some more predictable than others. The range of illnesses relevant to end-of-life decision making encompasses the leading causes of death in the population such as cardiovascular disease, pulmonary disease and cancer (Schuklenk, Delden, Downie, McLean, Upshur& Weinstock, 2011).

The practice of end of life care is now being common as there are lots of people approaching the required care. Through the advancement of technology and social transformation, it is possible to find clients admitted to this care. Older adults with age related health problems as well as patients including children who are terminally ill are those treated at end of life care. Diseases requiring palliative care for adults are mostly Alzheimer’s and other dementias, cancer, cardiovascular diseases (excluding sudden deaths), cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, HIV/AIDS, kidney failure, multiple sclerosis, Parkinson’s disease, rheumatoid arthritis, drug-resistant tuberculosis (TB). The care includes children when they are diagnosed with cancer, cardiovascular diseases, cirrhosis of the liver, congenital anomalies (excluding heart abnormalities), blood and immune disorders, HIV/AIDS, meningitis, kidney diseases, neurological disorders and neonatal conditions (Worldwide Palliative Care Alliance, 2014).

Caregivers are the ones who provide support to someone who needs help. It does not matter how many hours per week are spent providing support. Caregivers may live with the person they are caring for, providing assistance with daily needs, or may visit the person weekly or call regularly. Being a caregiver involves an investment in time, energy and support (National Hospice and Palliative Care Organization, 2005). On a different line there are also paid caregivers are hired to keep the patients' safe and pain free. They look after his or her well-being. Unlike the family or unpaid caregivers, these caregiver and care recipient might form a bond over time, but it is important that paid caregivers maintain professional boundaries. They should not become involved in familial or financial conversations and decision-making (Family Caregiver Alliance, 2016). When we think of end of life care, it is possible to think of the cultural and religious components as well as it equally matters like clinical treatment. Bennett (2012) showed that how we let our clients to make decisions on organ donation, placed to be cared at and priorities are influenced by cultural and religious values.

Dying people needs special attention as they feel depressed and anxious. It is also important to care for their physical pain as they need intensive follow up. It is quite possible finding people on their death bed requesting for time alone with friends and families and make conversation with religious community (National Institute on Aging, 2012).

Cass, Lowell, Christie, Snelling, Flack, Marrnganyin& Brown (2002), explained the importance of communication in end of life care. They noted that there should be common understanding as to consider the background, histories, languages and cultures between families and staff. Relating to this point, the issue of ethics is also important point to consider at end of life care. Murray & Jennings (2005) suggested that our approach to death and dying in health care has been excessively rationalistic and that end-of-life decision-making has been excessively individualistic, with too much emphasis on autonomy instead of caring, family solidarity, love, mutual respect and attentiveness.

The service of end of life care also considers family members on how they can handle themselves after the death of their loved one. It is shown by Singg (2009), that family members as well as patients pass through stages of denial, anger, bargaining, depression, and acceptance as to consider letting go their family member and their death for the patients too.

Cultural and religious value plays a great role at end of life care as we need to consider the interest of patients. We tend to neglect the substantial differences in the way people of different cultures perceive, experience and explain illness and death. Often, it is likely to find patients and health-care workers falling under the pressure of unspoken assumption about health, illness and dying as they are from different cultural backgrounds (Jecker, Carrese& Pearlman, 1995). When we see end of life care these days it is visible that spiritual care is also considered a basic lead of palliative care. The spiritual component is vital to be cared of as to make holistic palliative care. But it is important to first consider and distinguish the dying person’s spiritual, religious and existential needs as to make appropriate intervention (Scott, Thiel &Dahlin, 2008).

The purpose of this study was to explore the views of caregivers at end of life care through the eyes of cultural and religious values. This study indicated how our Ethiopian culture can contribute to the care we provide and how to incorporate religious aspects at end of life care. It also implied to give a baseline for the caregivers as family members who are unpaid and caregivers as professionals.

1.2 Statement of the problem

There have been many researchers who conducted studies on End-of-life care. Through my search of the literature, I have found researches conducted on cultural and spiritual view towards end of life care, strategies and principles in end of life care, loss and grief, palliative care and its challenges and role of social workers in end-of-life care. Sissay (2016) conducted a study on knowledge and attitude of nurses towards palliative care in government health hospitals in Addis Ababa. The result showed that there is poor knowledge about palliative care but most nurses have favorable attitude towards it. Nurses' level of education, working department, years of working experiences, experience in caring chronically ill patient and in service training of palliative care had significant association with their attitude towards palliative care. This is to mean that when the nurses have a longer work experience and early exposure to palliative care, they tend to have a positive attitude towards the care for their patients. The working department is the situation that if they have not been placed to get the chance to care for such patients at end of life care, they might have no understanding for the service. The training and the level of education similarly affects how they would respond to their patient at end of life care.

Similarly, nurses' knowledge, practice and associated factors towards pediatrics palliative care in Addis Ababa government hospitals was studied by Alemnesh (2014) and found that caring for someone with a life-limiting condition can be challenging on both an emotional and practical level. This study showed knowledge, practice, and training deficit of nurses to give pediatrics palliative care.

Bosma, Johnston, Cadell, Wainwright, Abernathy, Feron, Kelley & Nelson (2008) explored role of social workers in Canada Palliative care. They indicated that the Canada social workers' competencies such as advocacy, assessment, care delivery, care planning, community capacity building, evaluation, decision-making, education and research, information sharing, interdisciplinary teamwork, and self-reflective practice.

It is often said that appreciating differences in others helps us better understand ourselves, and that this is what ultimately unites humankind. Nobel Peace Prize winner Kofi Annan said, “We may have different religions, different languages and different colored skin, but we all belong to the same human race.” The same is true for End-of-Life our cultures, ethnicities and faiths may differ, yet End-of-Life is something we will all experience (Passare, 2013).

Jones (2002) examined that choices involving end of life medical treatment decisions may be more related to ethnicity and culture than to age, education, socio economic status, or other variables. It is noted that despite the living differences we make in education or wealth at the end of the day all human beings are the same in facing death. The cultural values we hold affect us more than the differences we make in age, education or social status. Thus it is essential for healthcare providers to recognize the basic values, principles and assumptions of western medicine and bioethics as they are historically situated and culturally determined.

When we understand culture from an individual lens we should look beyond his/her ethnicity and give attention to other learned beliefs and values that evolve over a person’s life. Cultural diversity is associated with differing belief systems regarding death and dying in Australian culture. General practitioners are challenged to provide medical care within the context of an individual’s bio-psychosocial needs. Despite disparate beliefs, universal care (i.e. the needs all patients require despite their cultural diversity such as provision of comfort, appropriate communication, self-determination and informed decision making) needs valued at the end of life include the provision of comfort, appropriate communication between the patient and doctor, respect for spiritual beliefs, and the opportunity for the dying person to say goodbye (Clark & Phillips, 2010).

In Hindu's perspective, large number of families and friends tend to get closer to the dying person. It is likely to whisper religious words or Mantra into the ears of the dying person. Usually, family members like to stay with the patient when they are dying. A thread with religious significance may be tied around the wrist or neck by a priest. The person may choose to lie on the floor in order to be close to Mother Earth when they die. In this regard it is noted that nurses need to be sensitive to their needs and feelings and allow at least one female relative to stay with them (O'Connor &Sellick 2010).

Campbell & Amin (2014) gave well illustrated knowledge on the importance of traditional practices around illness, dying, death and bereavement in a rural Zulu (South Africa) community. Traditional healers have knowledge of local traditional practices, referred to as indigenous knowledge. In the study, the benefit of the traditional healers' involvement was the provision of psychological care for patients as they were the first practitioners to introduce the care thinking about the whole person.

Nursing care and responsibilities to the dying patient and their family do not end with the death of the patient. Potential loss and grief issues should be assessed upon admission of the patient, and bereavement care should continue after their death. Like all healthcare professionals, nurses must recognize and respond to their own grief in order to provide quality palliative care to the dying patient and their family (Matzo, Sherman, Lo, Egan & Rhome, 2003).

Ayers (2014) conducted a study on management of emotions in caring for the dying. The study contributes knowledge and understanding as it offers evidence surrounding non-disclosure of cancer diagnosis, prognosis and dying in Addis Ababa predominantly by family members. The new contribution it gave is that the study gave new insight and explored caring for the dying person from ethnographic point of view. It showed a way how to provide novel insight into care behavior, through presenting evidence of the emotional work surrounding the new concept of ‘accompanied dying’. Accompanied dying illustrates how the family offers their ‘companionable presence’ to offer emotional support and care to their dying loved one. This is done by family care givers showing deference to the person who is dying through the emotional work. Finally, the priority of emotional care to the dying person by family and hospice staff as emotional care is expressed through action in our society. This explains that how practitioners respond emotionally to their clients is the reflection of the norms in the society.

In the previous paragraphs a lot have been said on end of life care as it is part of the palliative care. When we are caring for the person on the verge of death we also consider the loss and grief management. Looking through the issue from different points, it was possible to gain the knowledge of end of life care from different cultural and religious perspectives. I was also interested to find related research conducted on this area but I could not find any through my review of literature. I was looking forward to know on how our society responds to end of life care, as palliative care is newly introduced in our society. Even if the practice is now emerging and there are two centers in the city, only two researches have been conducted on palliative care and social work perspective is missing in both researches. As to fill the existing knowledge gap it was my interest to explore cultural and religious values of caregivers at end of life care. This would also serves as a baseline for caregivers and service providers from multidiscipline to be aware of our own culture and religion that would impact professionals when we care for people at end of life care.

1.3 Research Questions

What are the services given at end of life care?

How do caregivers explain cultural values at end of life care?

How do caregivers explain religious values at end of life care?

What are the impacts of religious and cultural values on the action of caregivers?

How do caregivers communicate with family members and clients when they are on the verge of death?

What are the experiences of caregivers at end of life care?

1.4 Research Objectives

1.4.1 General Objective

Exploring the cultural and religious values of caregivers at end of life care

1.4.2 Specific Objectives

To explore the service provision at end of life care for both clients and family members

To explore the explanation of caregivers towards end of life care in their cultural values

To explore the explanation of caregivers towards end of life care in their religious value

To find out the impacts of cultural and religious values on the actions of caregivers

To investigate the communication between professional caregivers, clients and family members

To explore the experiences of caregivers at end of life care

1.5 Scope of the Study

This study is delimited to assess the care provided for clients and family members at end of life care. It covered the communication between caregivers and clients as well as family members. As it is going to explore only from the side of caregivers, it is delimited from assessing the clients’ point of view on religion and culture at end of life care. The study incorporated the views and experiences caregivers have for their clients as they are on the verge of death. It also studied how professional caregivers address the needs of caregivers as family members. It also studied how caregivers’ particularly family members will await loss and grief. Concerning all this, the study is limited its scope at exploring caregivers’ cultural and religious value towards death and dying at end of life care at Hospice Ethiopia center.

1.6 Significance of the study

Death despite its timely occurrence, it affects both who is on the verge of dying and those who are caring for the person. As a social learning theory explains, how we interact with the environment affects how we respond to life phenomena. In line with that, how we approach death as people on the verge of dying and as people caring for them is affected by how we perceived the meaning of death.

This research would help caregivers to value their care for their significant others or clients to see their wishes and needs despite the image created as thinking of death. An in-depth study of caregivers’ religious and cultural value would help both clients and caregivers for death preparation and grief management respectively. It will also help practitioners especially social workers in palliative care to consider bio-psychosocial and spiritual model in their service provision as it would make the service worthwhile for a country like Ethiopia. It will benefit practitioners from multidiscipline as well to incorporate the issue of culture and religion in their service provision.

As this research also studied on a palliative care providing center, it would help to introduce palliative care in Addis Ababa and largely to Ethiopia as well in contextualizing it with our culture. Lastly it will serve as a baseline for future researchers to study on the area as to fill the knowledge gap by studying end of life care from different points of view.

1.7 Theoretical Frameworks

The theoretical framework is the foundation from which all knowledge is constructed (metaphorically and literally) for a research study. It serves as the structure and support for the rationale for the study, the problem statement, the purpose, the significance, and the research questions. The theoretical framework provides a grounding base, or an anchor, for the literature review, and most importantly, the methods and analysis (Grant & Osanloo, 2014). Similarly, Wilkinson (1991) showed the importance of having theoretical frameworks in research as it helps readers to understand how it is related to other research.

For undertaking this research, I chose four theories in which can be related with my idea. The first one is the systems perspective as in which we can understand about interrelationships and how one affects the other. It would also helped me to understand participants of the study with that of their interaction with the environment. Using the ecological perspective as well can benefit the research to see from where problems and different understandings arise as a product of interaction of psychological, social, economic, political and physical forces in which help to assist clients at different level. Family stressor is the other framework I used for studying this research. This theory helped me to support my research area to see how the change that occurs in one family affects the others. Especially as the theory is explained in relation with the availability of resources and means, it is possible to understand the stressful situation in the family. Here also it is possible to look whether the family can adapt the change in the family situation or not.

Lastly the Bio-Psychosocial and spiritual model is taken into account as it makes practitioners' service holistic. Currently, the integration of these four elements in service provision is taken as most effective and best for clients. As we are working with human beings, it is not possible to neglect one of these elements in studying their social problem. It is also possible to note that, not only for assessing a certain problem when we are intervening as well we need to use these elements as resources. Thus with all the above mentioned elements being highly used while the researcher was undertaking the study and especially as the aim is exploring the values of caregivers towards death and dying through cultural and religious values the concept of the last theory was very vital and supportive.

1.7.1 Systems Perspective

Systems theory emphasizes reciprocal relationships between the elements that constitute a whole. These concepts also emphasize the relationships among individuals, groups, organizations, or communities and mutually influencing factors in the environment (Payne, 1997). Systems theories focus on the interrelationships of elements in nature and shows how one depends on the other. It also shows how the system is affected when the one is not functioning well. Anderson, Carter & Lowe, (1999) also explained systems theory is a way of elaborating increasingly complex systems across a continuum that encompasses the person-in environment. It also enables us to understand the components and dynamics of client systems in order to interpret problems and develop balanced intervention strategies, with the goal of enhancing the "goodness of fit" between individuals and their environments.

1.7.2 Ecological perspective

The present thinking on the ecological approach suggests that the primary premise explaining human problems is derived from the complex interplay of psychological, social, economic, political and physical forces. This perspective allows the practitioner to effectively treat problems and needs of various systemic levels including the individual, family, the small group, and the larger community. The client's ecosystem is the interrelationships and conglomeration of these ecologies. It consists of the self, family, the neighborhood, and the entire community. Consequently, the client's ecosystem is composed of numerous overlapping systems including the family, the workplace, and the community, as well as other critical subsystems unique to each client (Pardeck, 1998).

1.7.3 Family Stress Theory

Boss (2002), explained stress is a normal part of family experience, in light of the inevitability that the family will grow and develop, causing change to occur within the family system. This change, which can be either positive or negative, is essentially equivalent to family stress. The impact of change on the family depends upon how adequately a family either manages or adapts to stress and how effectively the family's resources allow them to cope. Generally, family stress becomes problematic when the level of stress causes a disturbance within the family system or its individual family members. Wilmoth (2009) explained the ABC's as for A is the stressor event is defined as an occurrence, positive or negative, that either changes or has the potential to change the family system. B stands for the family resource which are assets that help the family prevent or buffer an event from causing a crisis state and assist the family in problem solving to enhance the family's coping strategies. Family resources are the individual members, the collective family and the community. These meaning are the C in the model in which explains family's perception, appraisal, or assessment of a stressor event, are interpretations and views that the family has collectively formed while interacting with one another. On a similar case, Patterson (2002) showed how families construct meanings about the stressor, family identity, and their worldview. Some situations become sources of stress only because they are perceived by the family to be stressful.

1.7.4 Bio-psychosocial and spiritual model

According to Frankel, Quill & McDaniel (2003), the bio-psychosocial approach systematically considers biological, psychological, and social factors and their complex interactions in understanding health, illness, and health care delivery. Lukoff, Turner, & Gackenbach (1995), showed how transpersonal-spiritual-religious perspective integrates with approaches like psychodynamic, behaviorist, humanistic, cognitive, biological, evolutionary, and sociocultural. Human nature is not a finished product, but the sort of consciousness meant to change, evolve and develop. It is now in a state of transition, one of many, as is demonstrated by the striking increase of interest in things "spiritual" in modern times.

1.7.5 Spiritual Model

Spirituality is a fundamental element of human experience. It encompasses the individual's search for meaning and purpose in life and the experience of the transcendent. Spirituality also encompasses the connections one makes with others, his or herself, nature, and to the sacred realms, inside as well as outside of traditional religion. Viewed in this way, spirituality is an important component of quality of life and may be a key factor in how people cope with illness, experience healing, and achieve a sense of coherence (Puchalski, Ferrell & Virani, 2009). The diagnosis of chronic or life-threatening illness can lead to spiritual struggles for patients. The turmoil may be short for some patients and protracted for others as individuals attempt to make sense of the reality of their diagnosis with what gives them value and meaning in life. The journey may result in growth and transformation for some people, distress and despair for others, and both for many people (Pargament, Koenig, Tarakeshwar & Hahn, 2004).

1.7.6 Existentialist

The existentialist is interested in helping the client find philosophical meaning in the face of anxiety by choosing to think and act authentically and responsibly. According to existential therapy, the central problems people face are embedded in anxiety over loneliness, isolation, despair, and, ultimately, death. Creativity, love, authenticity, and free will are recognized as potential avenues toward transformation, enabling people to live meaningful lives in the face of uncertainty and suffering. Everyone suffers losses (e.g., friends die, relationships end), and these losses cause anxiety because they are reminders of human limitations and inevitable death. The existential therapist recognizes that human influence is shaped by biology, culture, and luck. Existential therapy assumes the belief that people's problems come from not exercising choice and judgment enough--or well enough--to forge meaning in their lives, and that each individual is responsible for making meaning out of life. Outside forces, however, may contribute to the individual's limited ability to exercise choice and live a meaningful life (Sandra, 1999)

1.8 Limitation of the Paper

This paper has its own limitation as it only assessed the cultural and religious values from the side of caregivers. It is limited as it did not see the clients' and society's view. It is also limited as it made the data collection from one center and it cannot make generalization. It is also limited in its sample size as the data was from few number of cases.

1.9 Organization of the Paper

This paper has six chapters. The first chapter includes the introduction, statement of the problem, research objective, and research questions. It also incorporates the scope, significance, and presents the operational definitions of important terms used in the study. As the introduction it gives insights about end of life care and how culture and religion play significant role in service provision. The second chapter presented the literature review which shows about different findings about palliative care. It explained about end of life care treatment, communication and ethical issues as well as cultural and religious values. The third chapter shows the methods that were employed in the study; how data were collected and analyzed, data quality assurance and ethical considerations. The data presentation was indicated in chapter four followed by chapter five presenting major themes that were emerged from the qualitative data gatherings. The emerged themes showed how cultural and religious values are incorporated in the service delivery at end of life care. In this chapter comparison and contrasting has been done with the previous findings on the area. The last chapter shows the conclusion and the social work implications.

1.10 Operational Definitions

Caregivers- these are the family members (such as parents, siblings, children, grandchildren…) who would care for clients as well as the professional caregivers who are health officers and nurses.

Cultural Value- The commonly held standards of what is acceptable or unacceptable, important or unimportant, right or wrong, workable or unworkable. Social support is taken as one manifestation and society’s response the second one.

Clients- individuals who are admitted to get the home to home services resulting from their terminal illness (cancer patients, HIV patients and/or age related health problems).

Death- which is not by accident but rather death occurring resulting from terminal illness

End of life care- the treatment and care provided for people when they are on the verge of dying such as physical, emotional and spiritual care. It is also the care given to the family members as to know how to understand loss and grief management and to allow them to make informed decision.

Palliative care- it is a way of caring for people who are at the verge of death and to make sure that they are enjoying their last quality hours.

People on the verge of dying- patients who are diagnosed with chronic and terminal illness and who are told by physicians that they are left with 12 months or less.

Religious Value- the value people hold as resulting from the religion they follow and the lenses how they view world

Social support—Support family Caregivers gain from their families, friends and the community

Chapter Two

Literature Review

This chapter provides a review of relevant literatures which particularly talk about palliative care and end of life care with cultural, religious and ethical components. The chapter tries to cover the definition and context of end of life care. The chapter incorporated death, loss and grief. As the care of end of life is undertaken as palliative care centers, the chapter also shows the different experience of countries towards palliative care, role of caregivers at end of life care. Communication and telling the truth has been discussed from different views. It also presents the ethical issues and challenges that caregivers face at end of life care. Lastly it shows the cultural and religious values towards end of life care from different contexts. Looking through the cultural value it shows about social support as one component of cultural values manifestation. The chapter gives slight insight for others to know in which contexts the area is addressed or previously studied by different scholars. The sources for the reviewed literatures were books, book chapters, journal articles and few thesis works from both national and international.

2.1 What is End of life care?

When we think of end of life care, it is the care provided before death. On this regard it contains planning the death of the individual as well as caring for the person’s cultural and spiritual care. It also includes the need for discussion on organ donation, place to be cared at and ways to manage preventive symptoms (Bennett, 2012). The National Council for Palliative Care (NCPC) (2012) also indicated that carers (explained as family caregivers who are unpaid) should be supported, not just because it is the right thing to do, but in order to enable them to care, in the way that they want to. The physical demands of caring may become more exhausting as the person's condition progresses and their physical, social, emotional and spiritual needs become heightened or more complicated, making it harder to cope. As more professionals become involved in the person's care, the carer often takes a lead role in coordinating, chasing and communicating with them. This can be time consuming and frustrating if there is not a single point of contact to help.

Mental and emotional needs are the one area of care to provide. This means helping the dying person to manage mental and emotional distress. It is quite obvious to find dying people feeling anxious and depressed. Thus having encouraging conversations, contacting counselor, talking about fears and concerns of the person will help patients to get calm. There are ways to make a person who is dying more comfortable. Our clients might be uncomfortable because of pain, breathing problem, digestive problems and temperature sensitivity. Thus we provide care as to relieve the physical discomfort they are dealing with. This implies that caring for the physical being of the person takes the highest value (National Institute on Aging, 2012). Whereas Chaturvedi (2007) stated that spiritual care is an essential component of palliative care. It comprises relief from pain and other distressing symptoms; psychological and spiritual care of the patient with the aim of improving morale and emotional status despite poor physical prognosis. It will also benefit to work with family, friends and caregivers to establish a support system to help patients to cope, to remain self-determining and to live as joyfully and actively as possible until death.

2.2 Breaking bad news

It is important to define the central element of bad news. Basically, the impact of bad news is proportional to its effect in changing the patient's expectations. In fact, one practical definition of bad news is "any news that adversely and seriously affects an individual's view of his or her future." All bad news, therefore, has serious adverse consequences for patients and families (Fallowfield, Lipkin & Hall, 1998). There are two principles that explain the bad news. First, the "badness" of the news is the impact on the patient and family. This is the thought as the gap between the patient's expectations of the situation and the medical reality of it. Second, it follows that, as a practitioner, you cannot know how patients will react to bad news until you ascertain their perceptions of their clinical situations (Ptacek & Eberhardt, 1996).

The SPIKE strategy is the best one to be used at end of life care as it is always important to care about the Setting while revealing bad news. The place should be private as to make clients comfortable. Perception is the other one that practitioners need to assess what client feel can understand about their condition. As the other component is invitation that practitioners need to invite their clients to know and to question about. Before breaking bad news, patients need to get warning that bad news is coming. There is no need to drop a bombshell. This makes clients prepare psychologically for the bad news. This explains the Knowledge aspect of the strategy. As caring for clients, Empathy is the key aspect to take while breaking bad news. Lastly it is important to summarize the points for the clients so that they get the opportunity to voice any major concerns or questions (Buckman, 2005).

2.3 Truth telling

Truth-telling is a complicated business. From a health care perspective, it may be defined as total openness about the diagnosis and prognosis. For health care professionals the difficulty and the dilemma of whether to tell the truth or not, becomes obvious when having to break bad news, especially if it involves cancer. It has been described that bad news as any information likely to alter drastically and negatively the patient's view of his or her own future (Buckman, 2005).

A successful relationship between patients and health care providers depends on the establishment of trust, which is strongly connected with truthful communication. On that basis, truth-telling is considered to be an ethical issue as well as a moral obligation by a large number of health care professionals. Similarly, patients expect that their health care providers will tell them the truth, just as health care providers expect that their patients will tell them the truth. It has also been suggested that disclosure of truth fosters trust and is an essential element of the respect owed to the patient as a person. Therefore, the disclosure of truth aids the whole process of establishing an optimum patient–carer relationship. Awareness of incurable status among terminal cancer patients allows them to have adequate preparation for end-of-life planning. Without a clear disclosure of disease status and limited life expectancy, patients would have inappropriate anticipation for continued anti-tumor treatment. As the result, patients were referred to palliative care only after disease-directed treatments were exhausted; the opportunity for adequate evaluation of comprehensive and appropriate end of life care is missed (Kazdaglis, Arnaoutoglou, Karypidis, Memekidou, Spanos & Papadopoulos, 2010).

On the other hand, when disclosing the truth, there is always the risk of shattering a patient's hopes and dreams. Hope seems to an essential mechanism for coping with cancer and it can be jeopardized by excessive knowledge and detail (Schattner, 2002). Some cultures consider delivering bad news to those with cancer or other life-threatening illnesses as unacceptable as this could lead to loss of hope. Healthcare practitioners' may withhold information about serious diagnoses and prognoses, and decisions may be made about treatment with family members in the absence of the patient (Broom & Doron, 2009).

2.4 Death, Loss and Grief

As humans we are challenged to think of getting ready for death. But it is stated that we can think of death as we are still young and healthy in which we are not making it hard on ourselves as predicting or attracting negative things. We will not fear death when we consider it as part of life, normal, natural and expected part of life. Death can be taken as a life's "change agent" in whom we would be able to think as part of process. It is important to reject the superstitious belief, common in American culture, that thinking or talking about death makes it happen (Ruff, 2014).

At some point the numbness people feel as a result of loss wears off, and the reality of the loss starts to sink in. This part of the grief process, sometimes called confrontation, is when the feelings of loss are most intense and painful. This is the time the person starts to face the loss and cope with the changes the loss causes in their lives. Usually, the person comes to accept the loss slowly over the months that follow. This acceptance includes adjusting to daily life without the deceased. Like the earlier parts of the grieving process, acceptance does not happen overnight. It is common for it to take a year or longer to resolve the emotional and life changes that come with the death of a loved one. (American Cancer Society, 2016)

One of the original and best-known theories of grief is presented by Elisabeth (2005). She identified five stages: denial, anger, bargaining, depression, and acceptance. This theory is applicable to both the patient who has been diagnosed with terminal illness as well as his or her family members. Following her, many writers have presented their grief models with different numbers of stages or phases. A more simplified and inclusive view based on these models is that generally people tend to pass through three broad phases or stages of bereavement. First is acceptance of the reality of loss, second working through the pain of grief, then adjustment to the environment in which the deceased is missing, and the last stage or phase is emotional relocation of the deceased and moving on with life. These stages overlap and do not necessarily occur in a sequence. In fact, the bereaved individuals move back and forth between these stages as they work through them. And not everyone goes through these stages at the same rate and with same intensity (Singg, 2009).

2.5 What is palliative care?

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process; intends neither to hasten or postpone death, integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death, offers a support system to help the family cope during the patients illness and in their own bereavement and uses a team approach to address the needs of patients and their families, including bereavement counseling (WHO, 1998).

Palliative care is an approach which improves the quality of life of patients and families facing the problem of life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems physical, psychosocial and spiritual. It will enhance quality of life, and may also positively influence the course of illness (African Palliative Care Association, 2010).

It aims in providing relief from pain and other distressing symptoms, affirming life and regarding dying as a normal process, intending neither to hasten nor to postpone death, integrating the psychological and spiritual aspects of patient care, offering a support system to help patients live as actively as possible until death, offering a support system to help the family cope during a patient’s illness and in their own bereavement, using a team approach to address the needs of patients and their families, including bereavement counselling if indicated, enhancing quality of life, and sometimes also positively influencing the course of an illness and responding to people’s beliefs and practices as well as their social and cultural values (National Association of Social Workers (NASW), 2004, pp. 11-12).

Palliative care is a patient-centered approach that improves the quality of life of adults and children living with life-limiting conditions, including cancer. It addresses their physical, psychological, social and economic, legal and spiritual problems from the point of diagnosis throughout the life course. Palliative care is not just about the treatment of physical pain but this is a core element of it and access to the medication needed to treat moderate to severe pain, particularly opioid analgesics, is one of the major practical barriers to delivering quality palliative care worldwide (Morris, 2013).

Care for those who are dying is also referred to as Palliative Care. It encompasses care of patients with advanced, progressive illness, including end of life care, and bereavement support for their family and carers. It focuses on relief of pain and other symptoms, emotional, spiritual and practical support for patients and those close to them (Walsh, 2003).

2.6 Role of Caregivers in Palliative Care

A caregiver can be a family member or friend who is available to care for the dying person. The care may also be provided by a group of people. The choice to provide palliative care can be difficult to make. The person who is thinking to become caregiver needs to consider many factors including health and ability both physically and emotionally to provide the care. The relationship between the caregiver and the recipient need to be considered as well. Providing the care may mean that the care giver needs to take time off work and this may be a major decision for the individual and the family as well (Macmillan, Peden, Hopkinson & Hycha, 2004).

Palliative care social workers specialize in working with adults and children who are at the end of their life, their families, those they are close to and their communities. They use their particular skills and knowledge to help people to deal with the impact of what is happening to them, including loss and bereavement, and to have a good life and a good death. They work in partnership with people they offer support to. They work alongside other professions, agencies, organizations and as part of the wider community in which they are based. They bring social care expertise and perspective to situations in order to ensure that people get the support they need (Chaddock, 2014).

According to Stajduhar (2013) fulfillment of the wish of many patients to remain at home towards the end of life is heavily dependent on the caregiving efforts of family members. Palliative caregiving entails considerable health risks for the family caregiver. Provision of appropriate support for family caregivers can ameliorate these risks and enhance family members' quality of life. In the other line study conducted by Doris (2007) showed that family caregivers in Taiwan and Caucasian are considered as barriers. This is a result of age and less education that they impacted on drug administration on the client.

Providing care at home can itself be a source of stress, which in palliative situations is compounded by awareness of a terminal diagnosis. Home-based caregiving can be physically demanding and this, alongside emotional experiences, can negatively impact physical health. Sleep disturbances are documented, as are self-care difficulties. Family caregiving at end of life as involving intense, conflicting, negative and/or difficult emotions, such as fear and dread, anger and disillusionment, guilt and regret, anxiety, grief, helplessness and hopelessness (Funk, Stajduhar, Toye, Aoun, Grande & Todd, 2010).

2.7 Spirituality and Religious Views at End of Life Care

Spirituality definitions were divided between seven major thematic categories, including: a relationship to God, a spiritual being, a higher power, or a reality greater than the self; not of the self; transcendence or connectedness unrelated to a belief in a higher being; existential, not of the material world; meaning and purpose in life; life force of the person, integrating aspect of the person; and summative definitions that combined multiple themes. Spirituality embodies a sense of connectedness to a personal god or higher force or power, and is considered a broader construct than religion (Chochinov, 2006). This is not to suggest that those requiring more formal religious care do not need or want to address the wider questions of meaning. Conversely, at such times many people who might not describe themselves as ‘religious’ might wish to return to a faith they were brought up with, finding in that hope and comfort (Catholic Bishops’ Conference of England& Wales, 2010).

Bishops’ Committee on Bioethics (2002) showed thatthe ultimate meaning of personal existence is to be found in relationship with God. All the key moments of life, including the times of sickness and death, have the capacity to bring this relationship into sharper focus. In this regard, family caregivers always feel that they believe in God that He is able to do as He planned. They keep their relationship with God believing in Him.

As Searight&Gafford (2005) indicated many African cultures, spiritual and end-of-life experiences are often associated with meeting ‘your creator’ or ‘going to God’. When people are dealing with pain they believe that the creator is testing their faith upon him. Therefore, when they are able to understand pain and death, it would benefit them to have strength in their faith to cope with pain and dying. Spirituality and religion influence the decision of patients in the last days. The last days are important days for the dying. Thus, how and with whom these last days are spent and who provides spiritual care are all important decisions that need to be considered in providing end-of-life care to these populations.

For the Christians death is not taken as an end but as a beginning for the other life which is eternal. Death is described in the Bible as “falling asleep” (John 11:11, 1 Corinthians 15:6). Jesus has taken away its sting and victory in His resurrection (1 Corinthians 15:55). Protestant Christians will differ in their understanding of the cause of illness, some seeing it as a consequence of personal behavior and expressing guilt or shame. Others may view their illness as coming from causes over which they have no control and may see themselves as victims. Some may interpret illness as punishment or as a personal test from God. Some will view illness as a part of the natural course of events and will take responsibility for doing what is necessary to overcome a temporary inconvenience and return to their normal routine of life (Metropolitan Chicago Healthcare Council, 2012).

According to Dinef (1999) the Christian Orthodox religion is practiced today much as it was practiced hundreds of years ago, and is highly ritualistic and symbolic. After death, the priest says the first prayer and a candle are lit. This is repeated for 40 days, because it is believed that the soul roams on earth for 40 days. The lighting of the candle is symbolic in asking God for forgiveness on behalf of the deceased. Similarly, Taylor & Box (1999) said that there is a high emotional reaction to death and dying. The body is considered to be highly sacred. Practices include clothing the body in a white sheet under other attire. A vigil may be held in the funeral parlor. Traditionally the body is placed facing in an eastward direction, representative of Christ's resurrection.

It is only human to fear death and, even more, to fear dying. In order to be able to deal with these fears, Catholics gain the benefit as to understand and re-claim a rich tradition regarding health care decision making in the face of life-limiting illness. In this way they are usually able to think of death as beyond human ability and given to God and can reflect on the meaning of a good death as believed by followers that it is according to God's plan. While death is our common human fate, how, when, and where we die has changed profoundly in the past fifty years. Unlike our grandparents' deaths, our own deaths will more likely than not follow an explicit decision to set aside or to stop on-going use of life sustaining therapies (Kenny, 2014).

Muslims believe in divine predestination and attribute the occurrence of pleasure and suffering to the will of Allah. They generally perceive suffering as a way of atonement for one's sins. This is indicated in their Quran that no fatigue, no disease, nor sorrow, nor sadness, nor hurt, nor distress befalls a Muslim, even if it were the prick he/she receives from a thorn, but Allah expiates some of his/her sins for that. This helps patients and families to cope with serious and life-limiting illnesses as they believe their lives are in the hand of Allah. When inquiring about the life expectancy of a loved one, Muslim families are usually skeptical about definitive responses from healthcare professionals. They are likely to be more comfortable with less definitive answers and even with responses like “this is in Allah’s (God’s) hands, and we can never predict. It is advisable for healthcare professionals to continually keep the patient and family informed about progression of the patient’s condition and whether death is becoming imminent. Families often appreciate being aware of this information, as they may want to be around the patient during this period and be prepared for funeral rites (Al-Shahri& Al-Khenaizan, 2005).

2.8 Culture and Medical Care

Culture is an important part of the context within which people (including health care professionals) understand their world and make decisions about how to act. Although each individual has a perspective that is influenced by many factors such as personal psychology, gender, and life experiences, culture fundamentally shapes the way people make meaning out of illness, suffering, and dying, and therefore also influences how they make use of medical services at the end of life. However, culture is not an independent, homogeneous, dichotomous variable (Crawley, Marshall & Koeing, 2001). According to Lederach (1995) culture is the shared knowledge and schemes created by a set of people for perceiving, interpreting, expressing, and responding to the social realities around them.

The thought of death is determined by ethnicity and cultural factors. Culture is a group’s worldview and values. Ethnicity is one’s self-identified group and may include subgroups that share common values. The culture value a certain group has affects the people in their choices for life and preferences to be told about the terminal diagnosis, to die at home or in hospitals or at hospice centers and to promote quality during the last days. In some cultures, talking of death is taboo because it might bring sadness or hasten the demise (Barry & Henderson, 1996). Whether people die according to particular religious or cultural prescriptions will shape the grieving process (Anderson, 2010). In many cultures death is not viewed as the end of life, but as one of many steps or transitions throughout life. A key component of this belief is that the next step after death is not nothingness, but some other plane of existence (Parkes, Laungani& Young 1997).

Death to the Igbo people from South Eastern Nigeria is distinguished in three types, the first one is natural death which to mean death occurring in prepared as taken to be the conclusion or end for life. It is believed to be a reward and blessing from God. The second one is bad or shameful death which is particularly resulting from sickness. It is clearly associated with maternal and child death. Unlike the first type of death, this one is taken as a punishment from God. The third one human brought death which is technically taken as human agent. The death is believed to happen due to poisoning, deliberate murder or abortion (Okafor, 1996). Similarly Healthcare Chaplaincy (2013) showed that Kenyans Onset of sickness is caused by witchery imposed by someone else. They believe that someone who is sick has violated a social norm. Thus they may want to utilize traditional cures, which includes plants, bark, etc and diviners who can expel evil spirits.

2.9 Culture as a Social Support

Social support is defined as the perception or experience that one is loved and cared for, esteemed and valued, and part of a social network of mutual assistance and obligations. Information support occurs when one individual helps another to understand a stressful event better and to ascertain what resources and coping strategies may be needed to deal with it. Instrumental support involves the provision of tangible assistance such as services, financial assistance, and other specific aid or goods. Emotional support involves providing warmth and nurturance to another individual and reassuring the person that he or she is a valuable person who is cared about. Social support has long been known to mute the experience of stress, enhance well-being, reduce the severity of illness, and speed recovery from health disorders when they do occur (Taylor, Sherman, Kim, Jarcho, Takagi & Dunagan, 2004).

It has suggested that at least under some circumstances, the perception of social support that remains unutilized is more beneficial than social support that is actually mobilized. It is found that perceived social support was a stronger predictor of adjustment to stressful life events than received support. There are several possible reasons for this finding. These include the fact that overly intrusive social support may exacerbate stress (Shumaker & Hill, 1991).

2.10 Communication in End of Life Care

According to Bennett (2012) one of the crucial points to be considered in end of life care is the skill of communication. This is mainly because it gives insights and empowerment for the families to make informed decisions about the way of care. This is to bridge the gap between families and professionals which would help them to arrive at common understanding. When families do not understand what has been said or done and when they fail to receive it, it is possible to say communication does not exist. This idea is also supported by Dunne (2005) that the great stress, emotional tension and fatigue that attend a life-threatening illness often make it necessary for patients and families to hear information several times so that they can absorb it and feel reassured. It is stated that the fear of dying is not a single emotion hut rather it is composed of many different fears. Thus effective communication includes the emotional communication as well.

When patients and families are expected to make decision in end of life care it is important to be honest about the situation as it is a non-technical language. Patients and their families should be engaged in open communication about possible outcomes early in treatment, especially where the patient is seriously or critically ill, in order to prevent unrealistic expectations about what can be achieved with treatment. Early, honest and regular communication can also help create the trust needed for shared decision-making and to defuse tension (National Social Work (NSW) Department of Health, 2005). In the contrary it is indicated by Chew (2012) while discussion of death may be uncomfortable in many cultures, traditional Chinese beliefs take this attitude to more of an extreme, viewing death and ill health as taboo topics. Death is considered mysterious and frightening. It is considered impolite and bad luck to discuss. Thus it is not appropriate to communicate about death with family members.

Canadian Nurses Association (2015) showed that nurses should support the person, the family, the group and the population or community receiving care in maintaining their dignity and integrity. One major issue affecting our ability to provide palliative and end-of-life care is communication. A failure to understand or appreciate the cultural practices leads to inappropriate and inadequate health care. Both staff and patients need to recognize that their understandings come from their own backgrounds, and are therefore saturated in their own histories, languages and culture (Cass, Lowell,Christie, Snelling, Flack,Marrnganyin& Brown, 2002).

2.11 Ethical Issue and End of Life Care

Providing care for those at the end of life requires health care providers to competently address and manage the broad array of clinical, emotional, social, and spiritual issues that frequently arise in the dying process. It also requires providers to address many potential ethics issues in the end-of-life decision-making process. Despite the intensity of such challenges, providing competent, quality care at the end of life can be professionally fulfilling and reflects the health care professional's respect for their patient's life and values (Niemira&Townsend, 2009).

As a major issue for decision making ethical issues are highly considered. In this regard, surrogate decision making is one of the challenges caregivers face as it is believed that the patients are not making the decisions for themselves. This type of decision making has two approaches one is, substituted judgment based on the patient's clear and specific previous expressed values, desires, actions, or beliefs. The second one is best interest based on a comparative assessment of the burdens and benefits of the current treatment options in relationship to the patient's condition (Truog, Campbell, Curtis, Haas, Luce, Rubenfeld, Rushton, & Kaufman, 2008).

The key challenge in enhancing quality of life for older people at end-of-life is the preservation of the person's surviving autonomy and dignity balanced against inevitable paternalism. Respect for the person's dignity and autonomy are at the core of their human rights and the law on consent upholds these rights. The current Irish law on decision-making at the end-of-life is based on the principles of autonomy and self-determination. This means more information and enhanced communication between providers of care, families and patients (O'Shea, Murphy, Larkin, Payne, Froggatt, Casey, NíLéime& Keys, 2008). But this concept will not be accomplished as of the "good death" differ from the physicians' and patients' perspective. Yeolekar, Mehta &Yeolekar (2008) indicated that patients' way of thinking "good death" as death with dignity as of no pain and harm on the body, physicians consider it as overtaking by psychological and spiritual goals. It also creates controversial issue as of self-determination might be threatened as what family members wanting patients to stay at home performing rituals as to achieve salvation after death. In the same research, it is noted that physicians might want a closer supervision on their patients.

Murray & Jennings (2005) suggested that our approach to death and dying in health care has been excessively rationalistic and that end-of-life decision-making has been excessively individualistic, with too much emphasis on autonomy instead of caring, family solidarity, love, mutual respect and attentiveness.

2.12 Summary

Through the reviewed literatures it is possible to indicate that cultural and religious values have an important place for end of life care. As the literatures mostly cover the international context it is visible to indicate that caregivers have the role to incorporate patients' cultural and religious needs. In this regard it is observable that ethical issues arise as part of the issue of culture and religion in many places. When we think of end of life care and its service one aspect is indicating that death is approach for the person. Incidentally, caregivers are mentioning that the person whom is valuable for the family and even mentioning that for the individual him/herself brought an issue of moral. When we see this, in many places talking about death is taken as wrong and for one religion how followers think of death preparation and for others differ as they perceive life after death. The literatures also serve as a baseline for caregivers to understand about communication and the challenges they face. It is notable that caregivers sometimes fail to communicate about end of life with patients and also with that of decision making. With the available three theses studied the area in our country showed end of life care from nurses' perspective. Although no studied found to provide the knowledge about end of life care from bio-psychosocial and spiritual perspective. This implies that there is a gap to study the area in relation with religious and cultural values. Thus with the method section presented in the next chapter, exploratory case study with the data source from Hospice Ethiopia professional caregivers and family caregivers who will provide an insight for the current practice of end of life care in Ethiopia.

Chapter Three

Method

3.1 Research Methods

This chapter presents the method used to conduct the study. It presents the researcher's perspective which explains the ways the research was conducted. The research design, selection of site to access participants of the study, and sample size are also presented here. It also shows the sampling method, methods of data collection, method of data analysis. Finally, it presents the data quality assurance and ethical consideration.

3.2 Researcher's Perspective

Different people held different ideas towards how they view reality. For those who are positivists reality is taken as objectivity. They consider it as it really exists as it is and not actually possible to be understood or open for change. A theoretical perspective closely linked to objectivism is positivism which argues that reality exists external to the researcher and must be investigated through the rigorous process of scientific inquiry (Gray, 2004). For these people, reality is value free and they focus on observable facts. Positivist researchers believe that they can reach a full understanding based on experiment and observation. Concepts and knowledge are held to be the product of straightforward experience, interpreted through rational deduction (Ryan, 2006).

On the contrary there are people who are constructivists, who perceive reality driven by people's unlimited perception. Yes, the world exists but how people give meaning to it differ from one another. Constructivism rejects this view of human knowledge. Truth and meaning do not exist in some external world, but are created by the subject's interactions with the world. Meaning is constructed not discovered, so subjects construct their own meaning in different ways, even in relation to the same phenomenon. Hence, multiple, contradictory but equally valid accounts of the world can exist (Gray, 2004). For constructivism expresses the idea that mental structures and operations are actively constructed by one's mind rather than passively acquired. "Constructing" means that there is a developmental path from some initial state, rather than a teleological progress some final state (Riegler, &Bunnell, 2011).

For both perspectives the role of the researcher is different. For the positivist, researcher is mere observer of the process but for the constructivists he/she is part of the research process in which he/she gives value for people's interaction and how they produce meaning. As a researcher, I take myself on the position of constructivist as well as my professional self. As the study is about exploring the value of caregivers at end of life care, having the constructivists view benefit for valuing what people give meaning to, their interaction and way of perceiving different aspects of life. This would enhance my professional self to search the uniqueness of people and the multiple way of explanation they have towards reality.

3.3 Research Design

This research is qualitative research. Qualitative research strives to collect, integrate, and present data from a variety of sources of evidence as part of any given study. The variety will likely follow from your having to study a real-world setting and its participants. The complexity of the field setting and the diversity of its participants are likely to warrant the use of interviews and observations and even the inspection of documents and artifacts (Yin, 2011).

This research employed exploratory research with case study design. It aimed to give new knowledge about caregivers views from cultural and religious values and wants to make in-depth study of a small number of cases. According to Yin (2003) case study is used to describe an intervention or phenomenon and the real life context in which it occurred. It also stated that exploratory case studies set to explore any phenomenon in the data which serves as a point of interest to the researcher. As the researcher was interested to study people's cultural and religious value, the cases the researcher studied was in their real-life context. Here also understanding how the case influences and is influenced by its context is often of central interest to case researchers. Using case study, data was collected and analyzed about a large number of features of each case (Gomm, Hammersley & Foster, 2000). Case studies are tailor-made for exploring new processes or behaviors or ones that are little understood (Hartley, 1994).

It was cross sectional as it was employed at a single point in time. This is because the researcher did not get back to the setting and collect data further. Cross-sectional research study, either the entire population or a subset thereof is selected, and from these individuals, data are collected to help answer research questions of interest (Olsen & St. George, 2004).

3.4 Selection of Site to Access Research Participants

As the study focused on the religious and cultural values of caregivers at end of life care, the study area is Hospice Ethiopia located in Addis Ababa. Hospice Ethiopia is a non-governmental organization which was initiated and established on 2003. As it is a pioneer organization it is dedicated to palliative care that aspires to support patients who have suffering from pain in Ethiopia. It provides palliative care for clients while they are staying at their home and they provide home to home visitation. As nurses and health officers are dominating the service, it is quite obvious to find that the treatment is limited as being clinical and little emphasis is given to the psychosocial aspect of the patient. Hence, as for the rationale for selecting this center was because of the fact that there are only two centers (Hospice Ethiopia and Strong Heart) and as for selecting this, it is because of the possibility to contact clients and their families.

3.5 Sampling and Sample Size

Non probability sampling method was used to select participants for this study. The researcher chose purposive sampling technique to decide on which center to use in order to access the family caregivers. Also in choosing the specific center the researcher used personal judgment and prior knowledge. According to Palys (2008) one engage in purposive sampling signifies that one sees sampling as a sense of strategic choice about with whom, where and how does one's research tied with his/her objective. Here also the researcher chose among the clients' family caregivers based on their availability and possibility to be part of the research.

The sampling size for this study was three participants particularly the professional caregivers and eight family caregivers. The reason to use both caregivers for data collection is to get detailed information. The aim was not to make a comparison between the two caregivers. Both participant groups are different in their caregiving as the family members spend most of their times together with the patient, the professionals visit in two or three weeks; and they are also different in the care giving as the families are not supporting the patients professionally for being more dominated by the cultural and religious values. The professionals tend to use the professional experiences and ethics while providing care. The communication pattern between family members and clients is different from that of the clients and professional caregivers. Thus, the study did not aim to explore more differences and produce a comparative study. Whereas the family caregivers are also part of the service provision that made the researcher aimed to incorporate them to see the service provision at end of life care as one researchobjective.

Throughout the data collection, the researcher decided based on data saturation as to limit the number of family caregivers. Data saturation is reached when there is enough information to replicate the study (O'Reilly & Parker, 2012). Since the study was sensitive for data collection, it also depended upon the availability of family caregivers.

3.6 Method of Data Collection

For the purpose of this study, the researcher used both primarily and secondary data collection. As primary the researcher used observation and in-depth interview with family caregivers and with professional caregivers. These interviews involve semi structured and generally open-ended questions that are few in number and intended to elicit views and opinions from the participants (Creswell, 2003). As secondary source of data, the researcher reviewed different books, articles, journals and researches on the study area.

3.6. 1 In-depth Interview

For collecting data, the researcher had in depth interview with eight family caregivers as to deeply understand their values and understanding of cultural and religious view at end of life care. There were semi-structured questions which the conversations led to other questions through time. It was to help participants to freely speak about the issue. Probing questions were used as much as possible so that detailed information could be gained from the participants. (see appendices B and C). With the professional caregivers as well, there was an in depth interview, similar to the family caregivers which were semi structured and open ended questions. The interview for both participants was used in Amharic. The researcher could not use tape record as both groups of caregivers were not comfortable in being recorded. The place of data collection was limited as per the preferences of the participants. (See appendices E). As Boyce & Neale (2006) stated in-depth interviewing is a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, program, or situation. In-depth interviews are useful when you want detailed information about a person's thoughts and behaviors or want to explore new issues in depth.

3.6.2 Observation

For data collection purpose and to triangulate the data, observation was also used. It was done based on the checklist formulated ahead of the observation (see appendices D). When we are using observation as a way of data collection, it will be undertaken where and when an event or activity is occurring. It does not rely on people's willingness to provide information and it helps researcher to directly see what they do than relying on what they say they do. (Finn & Jacobson, 2008). Using observation as data collection helped the researcher to understand and grasp the real experience of professional caregivers working with clients and family members. The researcher was able to understand their communication pattern and challenges between caregivers and care recipients. The researcher has observed the care giving for about four hours in three visits for one client; I made a total of 40 hours of observation both in first, second and third rounds. This also helped the researcher to triangulate the data and came across with different findings and to choose which client to incorporate in the data.

3.6. 3 Document review

Along with the other data collection tools, the researcher also used document review as to know and understand what other researchers said about end of life care, religious and cultural components, the communication and ethical issues. Document review serves to supply pieces of information that are helpful in explaining social practices (Yin, 2003). Accordingly, the researcher reviewed documents on palliative care, journals on end of life care, association's report and testimonies at end of life care. It was also possible to see how other countries in Africa and other continents view palliative care, death and dying issues, cultural and religious implications. Such ideas helped the researcher to make the discussion against with the finding of the current study.

3.7 Data Collection Process

After gaining the approval from Hospice Ethiopia to collect the data, the researcher first interviewed the professional caregivers as to deeply understand their service provision and level of intervention with people at the verge of death. With the three professional caregivers who are available and currently working at the center, the researcher has made in-depth interview and gained detailed information. Before going through the family caregivers, the researcher had to make herself available for the clients and family members. Thus the researcher made two weeks visit for the selected clients and families. On the 3rd visit, the researcher made a schedule with the willing family caregivers who can provide the information and be part of the interview.

After agreeing for being part of the research each participant mainly the family caregivers made consent for showing their willingness to participate. For each interview 45 minutes was used and the researcher was writing down for each responses as I was not recording their voices. The researcher was intensively taking note without disturbing the participants. It was also important as a researcher to make sure that the participants did not feel neglected while keeping head down and writing. Specific issues, quotes, emotions and facial expressions were noted as it enriched the qualitative data. For observation, with the checklist prepared by the researcher, specific information were perceived as what the researcher planned to observe.

3.8 Method of Data Analysis

This qualitative exploratory study aimed to gain deep and detailed information on caregivers' cultural and religious views at end of life care using a case study design. As the nature of the qualitative data collection tool used, the information gathered from the participants were detailed as it reported in the finding. Qualitative data are in the form of text written words, phrases or symbols representing people, actions and events in social life (Krueger & Nueman, 2006). While the data were gathered the data analysis of this research started right away.

The first thing the researcher did in order to analyze the data was to get to know what have collected. This means to take time and to read through what have been jotted down from the observation and what have written from the interview. This helped the researcher to grasp the idea of what have been collected and the result intended to get. The written data were translated in to English as the interview was done in Amharic. The coding started from giving false names for each participant. This was to ensure the ethical issue to protect confidentiality.

Doing that right away helped the researcher to minimize bias. After the code formulated from the data, similar data was organized and categorized under each formulated sub themes . Rubin & Rubin (1995) stated in order to find a meaningful way of analyzing data it is important to use coding techniques for finding and marking the underlying ideas in the data, grouping similar kinds of information together in categories and relating different ideas and themes to one another. Coding helped me to make the data accordingly and to put it thematically. Similar categories came under one code and a different one stood apart under the major theme. This helped to produce and present a meaningful presentation.

A theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set (Braun & Clarke, 2006). Consequently, the researcher found the central point or analyzes it according to the research questions and put it under similar ideas. This meant as a way to categorize under a general idea. It is necessary to make sure that the theme emerged from the data. DeSantis &Ugarriza (2000) defined a theme as an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. In the process, the researcher used data reduction so that to remove duplicated data.

3.9 Quality Assurance

Honesty is essential, not only to enable straightforward, above-board communication, but to engender a level of trust and credibility in the outcomes of the research (Walliman, 2011). It is important to produce a research which is valid and trustworthy. Patton (2002) states that validity and reliability are two factors which any qualitative researcher should be concerned about while designing a study, analyzing results and judging the quality of the study. Seale (1999), while establishing good quality studies through reliability and validity in qualitative research, states that the trustworthiness of a research report lies at the heart of issues conventionally discussed as validity and reliability.

Similarly, in undertaking this study the researcher made sure the data trustworthiness as make the study valid and reliable. This also means that the researcher avoided personal bias as the researcher had strictly stated the attitude and stance before undertaking this study. In a qualitative study the data-gathering instrument is frequently the researcher himself/herself. Thus questions of researcher bias and researcher competency, if unchecked, may influence the trustworthiness of data considerably. Researcher bias may also be introduced by the tendency of the researchers to observe subjects and interpret findings in the light of their own values, the tendency to selectively observe and record certain data at the expense of other data (Brink 1993).

As the researcher has been thinking about undertaking this study, already knew the stance towards death will or will not be different from others particularly the study participants. As the researcher has experienced loss and grief one at end of life care and other as sudden death, how to see and interpret death did not affect the research finding and interpretation. A researcher should examine and declare his underlying values and assumptions in light of the research situation so that they can be considered when reading the research (Field & Morse, 1985).

One of the ways to say the researcher is honest throughout the study is when he/she employs triangulation. Rahman &Yeasmin (2012) explained triangulation as a process of verification that increases validity by incorporating several viewpoints and methods. In the social sciences, it refers to the combination of two or more theories, data sources and methods.

Data triangulation involves using different sources of information in order to increase the validity of a study. This type of triangulation was used as a researcher used different sources. For making sure that the data obtained were true, I have cross-checked from the two groups of participants and used observation. (Guion, Diehl & McDonald, 2013). It was also important to engage for a longer period so that the researcher can get acceptance and gather detailed information. Thus as a researcher I have exhausted myself to get responses which are representative from the participants.

3.10 Ethical consideration

As a social work professional great care was given for ethical consideration that guarantees confidentiality and rights of all participants. Before going through data collection, the researcher made a rapport so that to get acceptance for gathering information on the most sensitive issues caregivers were dealing with. At the beginning of data collection, written consent was given to caregivers as to inform them about their participation in the study. Informed consent is a voluntary agreement to participate in research. This implies a responsibility to explain fully and meaningfully what the research is about and how it will be disseminated. Participants should be aware of their right to refuse to participate; understand the extent to which confidentiality will be maintained; be aware of the potential uses to which the data might be put; and in some cases be reminded of their right to re-negotiate consent (Corti, Day & Backhouse, 2000).

Simply agreeing to take part in a study with no idea of what it entails is not informed consent. The researcher also explained the purpose and the possible outcome of the study as to know how far their contribution would be significant to the researcher, to themselves and to the society at large. Participants in research must be aware that they can withdraw from the research at any stage. Researchers should protect the dignity of participants in their research. Research participants should not be subjected to procedures involving tangible physical risks (Howitt & Cramer, 2000).

As it is explained by Scott (2005), anonymity is the degree to which the identity of a message source is unknown and unspecified. This made the finding and interpretation free from bias and exhibiting the data source as the researcher can make it harder to specify which data source among all participants. After obtaining the consent and their willingness to participate on the study, the researcher used pseudo names for each participant so as to avoid personal identifiers. Confidentiality means as protecting information about individuals is protected from inadvertent disclosure to others by physical means, such as a locked cabinet, legal means, such as signed confidentiality statements, or methodological means, such as the use of coded files (Easter, Davis & Henderson, 2004). Thus as a researcher it was important to keep all the data written papers and typed documents safe. This ensured their confidentiality is secured.

3.11 Summary

As qualitative exploratory research method with a cross-sectional case study strategy used, it was possible to explore the cultural and religious values of caregivers at end of life care in Hospice Ethiopia Palliative Center. The methods were used to gather information about the service provision at end of life care, to explore caregivers cultural and religious values at end of life care, to see how such values affects the actions of caregivers, the communication pattern between clients and caregivers and the experiences of caregivers at end of life care. Through the research methods used for this study, it helped the researcher gain detailed information on the issues which are mentioned above. The data were gathered from both family and professional caregivers through in depth interview, observation and document review and they are presented in the following chapter.

Chapter Four

Data presentation

This chapter outlines the findings from all sources of data. The data was gathered from in-depth interviews with professional and family caregivers, observations on the actual service provision, communication and the general palliative care conditions and document reviews. It shows the services at end of life care, the explanation of professional and family caregivers about death and dying through their views of culture and religion, the impact of the cultural and religious values on the actions of caregivers. It also presents the communication between professional caregivers and clients as well as the family members at end of life and breaking the bad news and lastly it looks to the belief and experiences of these caregivers at end of life care.

Description of the study participants

Table 4.1 Family caregivers

Pseudonym participants	Religion	Place of Origin	Relationship with the Client	Duration of Caregiving	Diagnosis
Abonesh	Protestant	Holeta	Daughter & Mother	3 Years	Cervical Cancer
Almaz	Protestant	Addis Ababa	Daughter & Mother	2 Years	Breast cancer
Beza	Orthodox	Deberziet	Blood Relative	6 months	Prostate cancer

Dagim	Orthodox	Addis Ababa	Daughter & Mother	6 years	Breast cancer Had surgery
Desta	Orthodox	Addis Ababa	Wife & Husband	4 years	Colon Cancer Had surgery
Tigist	Protestant	Addis Ababa	Wife & Husband	5 years	Prostate cancer Had surgery
Yared	Orthodox	Southern Part of Ethiopia	Son & Father	2 years	Prostate cancer
Yirga	Orthodox	Dessie	Husband & Wife	3 years	Cervical cancer

Table 4.2 professional caregivers

Pseudonym participants	Religion	Profession	Years of Experience
Kidane	Orthodox	Health officer	7 years
Mekdes	Orthodox	Palliative Nurse	16 years
Paulos	Protestant	Health officer	8 years

The aforementioned participants are from two groups who are family members and professional caregivers. For the family caregivers they are unpaid and who stay with them day and night. The client is under the supervision of these family members. As mentioned in the table except one participant all is in nuclear family. The clients reside in the same house with the family caregivers. The information of religion and place of origin is included in the demographic information as the researcher could be able to discuss the data. The professional caregivers' religious value also included for the discussion of the finding.

4. 1 Understanding the Service Provision at End of Life Care

From the information gathered from the professional caregivers, the service given for clients at end of life care is pure palliative care services. It means that the service provided for clients incorporates the biological, social, psychological and spiritual needs of people at the verge of death. Their service provision also includes family members as such people require attention and care as well.

4.1.1 Holistic service provision for patients

As it is mentioned on the previous paragraph, the professional caregivers do not only focus on the biological aspect of their clients. Unlike the medical profession, the person's totality is given attention. Even of the service providers are medical professionals, the social and psychological needs of the client and the family members are addressed through other links or by themselves.

"The palliative care should be holistic. When we care for clients we need to make sure that we are addressing the four components of human equally" (Paulos).

For alleviating the physical pain, caregivers are required to provide medication and follow-up. As he said it is the aim of palliative care. Reducing pain is the heart and they focus to minimize the suffering. When professional caregivers approach their clients at end of life, priority is given for minimizing pain and quality life than the other aspects of the person. For the social component, caregivers emphasize in making linkage for the socio-economic support their clients can get. "It is very important to pay attention for this component of our client because it contributes for the betterment of the physical health for our clients" (Kidane)

They work to find like-minded organizations who can address the needs of their clients such as food, shelter, financial support and other necessities. Professional caregivers also train community workers so that they can support clients with no family caregivers. Their services also stretch to educating the community to fight stigma and discrimination so as clients will be able to participate as their need in their community. It is to empower the clients to take part in decisions that affect their lives. Such as in idir, ikub and other social institutions.

For the psychological support, professional caregivers provide counseling and give advice for clients as they might be suffering from anxiety and depression. Family members are also part of these services as they need counseling and support. Regarding to the psychological support, family members are also part of the service provision as they are needed to be aware about breaking the bad news. They also get the counseling support on grief management.

> There might be few family caregivers who are not willing to talk about death and dying of their significant other. Thus we will not be able to discuss such issues with such people. The reason for such discussion is for letting the family members to be aware of the prognosis and minimize their cost as much as possible" (Paulos)

The spiritual domain is the most sensitive one that needs special attention. "If a person is spiritually strong, you do not need to exert much effort" (Mekdes).

She noted that when the person is able to figure out the purpose in life and its value, he/she is possible to understand their situation to accept it. According to her, the religious support is linked with the spiritual strength the client has. "When a client is ready to face anything and clearly communicates with his/her God/Allah or super natural power, can accept such incidents in life", she explained. For such people, professional caregivers assist them to communicate with spiritual fathers by consulting with family caregivers. "There are clients who want prayer every time after a visit. As their request we would give such services as per their religion" Paulos said about the wishes of their clients. Kidane made a point that there is also training given for spiritual fathers from Muslim, Orthodox and Protestant religion to support people at end of life care.

As part of my observation, the spiritual support is not always given. The support is given if and only if the client or family caregiver asked for it. The conversation of client and professional caregiver is limited to the point they make clients to understand that God or Allah has the power over their lives. “God knows the best” is the frequent phrase used by the caregivers. Further explanation is not given as to the point where clients can feel more comfortable and accepting God’s timing.

4.1.2 Service given to the family caregivers or members

As part of end of life care service provision, family members are also part of the care plan. Professional caregivers also work with them. This is to make sure that the necessary service is given to the patient. “We include the family in the care” Paulos said. This is because of the time the patient spends with the family. It is important to aware them what is happening in due time or soon.

4.1.2.1 Decision Making

One of the biggest plans for including the family is because of the power to make decision. Families are expected to make decision on the behalf of the patient due to the situation he/she is in. Decisions are usually left for the family as the professional caregivers cannot make that on behalf of the patient. On such conditions, family caregivers will be aware of treatment plan and the end of life care as they can make the decision in which it is best for their family member. This means that the service provision is usually taken care of as the family caregiver’s wants and needs. This includes the communication and the level of sharing information to the client. Professional caregivers do not go beyond the limit that the family members set to interact and communicate. This is usually limited to the level of cultural preferences of family caregivers.

"There are family members who want their families to be away from others thinking that there is cultural explanation for the why they are diagnosed with terminal and life ending illness" Kidane said. It is also quite obvious to find family members requesting for their loved ones to be with the families or in their land of origin as to make them happy in their last days of life. "I had one client who came all the way to Ethiopia from America wanting to spend her last moment with her families. It is the cultural value they have that made her to be here in her land of birth" Mekdes said. Thus the communication and the decision making is left for the family member.

4.1.2.2 Loss, Grief management and Death Preparation

As end of life care given for the patients who are on the verge of death, family members need to be ready about the death of their family member. Making them ready definitely requires the potential to assert that their significant other is about to die the sooner or later. "Unless and otherwise family members are ready to be told, we do not tell them" Paulos said. It is always important to see the needs of family members before telling them anything. If family members are not ready to discuss such issue, professional caregivers are not required to pressure them to hear about loss and grief management. Such refusal for not wanting to discuss about death is a result of cultural and religious views towards death. "We might be taken as cursing and saying bad things about the patient if we talk about death" Kidane said. For a religious person who believes that God has the power of the lives of His creatures such explanation as preparing for death might not be suitable. Mekdes added that "A person who is spiritually strong can listen and do whatever we say about the disease and the treatment. Because he/she knows how to deal with such incidents in life, they are ready to take part. Such people are always known for their positive spirit and saying God knows better."

4.2: Explanation of Caregivers about Cultural Values at End of Life Care

4.2.1 Views from the Professional Caregivers

4.2.1.1 Reservation for discussion

From my interview with the professional caregivers, I was able to understand that people hold different values that guide their day to day life. The cultural values count most as our actions are driven from them. When practitioners serve their clients, their professional ethics and actions must be aligned with the culture they are working in. Despite what their profession tells them, it is important for professional caregivers to give attention for their clients' religion and the value they hold. For practitioners at end of life care, the cultural values matter for the service provision. When they are caring for people at the verge of death, it is important to understand and value their needs.

> It is very important to consider their cultural views because we are working with people with different cultures and explanation for life. Especially in dealing with treatment plan and breaking the bad news (explaining about death) it is important to see how far are clients ready and comfortable to accept and discuss about the issue. (Paulos).

Similar idea is also shared by Kidane as "While we consider the communication about death and dying, it is always important for me as a professional to see clients' preferences in their cultural views. This is because communicating about this issue has cultural implication that clients might fear to listen about.

The willingness of clients to hear about their condition and to discuss about their lives is what makes the professionals work hard as they always need to assess the level of their clients' need and interest. Mekdes said, "I cannot simply tell my client about her condition just because she needs to be aware of it. This might cause unexpected problems like she might lose hope in her life. Patients especially cancer and HIV patients tend to reserve themselves from discussion fearing about their life in the future and what others would say about them".

The finding from the professional caregivers shows that people who are at end of life care treatment, there are points to be discussed from their time of admission to palliative care. Clients need to be aware of their prognosis, treatment, medication, expectation and even about the question of death timing.

> When we deal with people from different cultural background, it is important to understand their views. This is mainly because of their miscommunication that arises resulting from their cultural values that sometimes make them to deny scientific facts. Our clients who are mostly HIV/AIDS and/or cancer patients usually misconceive the fact we tell them about their health condition. This usually depends on their cultural views that shape their understanding and willingness to talk about the issue without fear. (Paulos)

> When we are dealing with cancer patients it is important to pay attention when we talk about the treatment that is the chemotherapy. As most patients lose their hair, lose weight, change the color of their skin and experience weakness, it is very important to discuss about the issue in a way they are comfortable to listen. They might fear or feel ashamed to express themselves in one of these ways as they fear what would people say or react in their socio-cultural way. (Mekdes)

This explains that from their previous knowledge or awareness about the disease, most of them do not feel comfortable to openly discuss about the issue, thinking how a society responds to such conditions. Thus it is important to pay great attention even when discussing what is coming sooner.

"This is mainly to protect the clients and families from false expectations and extra expenses" Pauols said about the reason why they need to discuss about death and dying with clients and family caregivers. The false expectations are the ones that patients and family caregivers might assume that the client might get healed or will be cured from their disease. When family members or clients do not accept the health condition of the patient, they always want to try more for curing the person even sometimes going to aboard seeing for a better medical health services. This is explained by the professional caregivers that they push clients and family members to be aware of their condition.

4.2.1.2 Breaking Bad News from the Cultural Aspect

Professional caregivers explained that following their ethical value alone cannot be always appropriate in dealing with family members and clients who are on the verge of death. They are expected to talk about death and dying as their profession requires them for breaking the bad news, in a way which is culturally accepted. The family members and clients might view breaking the bad news in their own cultural way.

> There are clients and family members who think that such things happen as a result of bad actions in life and for HIV patients especially family members do not want to talk about their issues and they fear to allow them to keep their contact and activities in their society. This is mainly because of the demeaning comments

> and actions the society exhibits and sometimes talks bad things about such patients in their presence. (Kidane)

As it is mentioned by the professional caregivers, at end of life care they do not only treat clients but also their families. Families are also part of the treatment plan that they need support and guidance. For that matter, professional caregivers communicate families to understand their level of awareness about their clients' condition. Families with great social support do not fear the 'would be'. "When we deal with family caregivers we try to advise them to keep their social commitments and to value the support that can be earned from such participation. This is mainly because of the fact that family members themselves need to think of themselves as they are caring for others" Paulos said. This is to encourage family members to keep their contact and participation in the community so that they can escape from stressful situations. Regarding to the cultural issues there are families that do not feel comfortable to disclose their families' situation fearing the response of their extended families and community members.

This would help the family caregivers even to get comfort in the death wait of their significant other. For most families the issue of death is not as comforting that they would likely to accept and be open for discussion. "I sometimes fear to talk about it because there might be families who thinks that I am cursing or saying bad things on their loved ones" Kidane said. The ethical principles make it easier for professionals to discuss about death when and only when patients and families are ready to talk about it. As for the culture that death issue is feared most families will not open a space for such discussions.

4.2.2 Views from Family caregivers

4.2.2.1 The different views on the availability and use of Social support

As a result of their culture, people hold different values that could offer them different explanations on a phenomenon. In this regard social support is one of the values people have. Social support is what matters in clients and family’s lives. The value people give for social support explains the situation they are in. From the family caregivers there are two categories of people those who value the social support and those who do not due to their cultural background. As the professional caregivers believe that the patients’ social being matters the same as their physical being, family caregivers tend to accept this as well and support their patients in a similar way.

The caregiving for family members is not as easy as for that of the professionals. With the limited resources, families are facing difficulties more than the stressing situation they deal with every member of the family. For family caregivers who are unpaid and spending most of their times caring for caner or HIV patients takes understanding and accepting their situation. Yirga said about the challenge that he is facing in social life.

“I have lost all my social life even my brothers and sisters are not contacting me due to my current situation with my wife. She is now disabled due to her illness and I am the only one who can assist her.” He explained how cultural value such as the expectation of a married couple to have children affected his relationship with families. For the fact that his wife is a dying, they forced him to have other relationship as he can lead his own life. The value they gave for having children instead of being alone made him to choose his wife over them and ignored their request. The value he has towards caring for his dying wife as being a lawfully wedded husband and wife affected by the value his siblings have towards life as they are more concerned about having children and not spending more time with a dying person. “I have been told to divorce her because my families think that I am only living for her with no children at home. But I am still living with her despite the illness and the fate we are in. she was not like this when I brought her home, she was beautiful and I cannot let that what happens to her” Yirga said with emotion showing to me their wedding picture that both looked beautiful and healthy.

As for Yirga, he gave the greatest value to social support. This is because of the need he has in taking care of his wife and making a good life. In the presence of no one who can stretch hand for help, Yirga is having a difficulty in being both the breadwinner and the only support in the house for his wife. He is the breadwinner in the house that he left his wife home alone. He feels that there should be someone to come and visit her. “Even her father did not show up when he heard that she was sick. But in the times of her good fitness, she has built a house for him thinking that he would rest in a good home during his old ages. He did not even bring butter and milk when he was told about her diagnosis” the husband said desperately with tearful eyes and vibrating tone. He values social support and believed that the Ethiopian culture favors caring for one another despite the situation of a person and this applies not only for family member but also for a neighbor. He always was wishing to get a support from anyone because he feels that it would make her feel better. He always feels that she might die soon but he is not sure who would go first thus he is committed to his vow to love each other in sickness and in health.

“I refuse for anyone to see her” Almaz said strictly about her caring for her mother. “I know she is ill and she will be infected more from the visit” said more about her reasons why. For Almaz social life and cultural values are not taken into account. The priority is best given to mother’s health condition. She said “my mother is above her 70s with cancer, what good would do for her people coming and saying sadder words even sometimes commenting that it is better to die than being bed-ridden". She was very angry even when she was recalling about the words of people that they use when they come for visit. In our society where words are not chosen to be said in front of the patient, it is hard to care for their psychology. "I do not want anyone to speak of her badly when she is in her last days" Almaz said about her firm stance neglecting and even avoiding such cultures of visiting patients and even refused for family members to enter to her room. She does not see the value of the cultures comparing to the damage it is causing for the patients' feeling. "Have you not been ill and people started telling you how complicated and worse it would get and the challenges that you would face? I cannot let that happen to my mother" Almaz said with passion on her caregiving.

"What made my husband live longer is the support he got from his friend" Desta said. Her husband is both cancer and HIV patient. It is a colon problem that made his situation sophisticated as Desta reported. She always feels better when she thinks of the cultural value that helped her to overcome those stressful days of her life during critical time (when her husband was in chemotherapy) she needed support. Those times were very hard for her as her husband was staying at hospital for chemotherapy and surgeries for the infection. Desta argued that the good communication her husband had and the value he used to hold in reaching to people during their problem has helped now him to survive. "When his friends receive their salaries they always come asking for the things we demand. They have never been away when we need their hand" Desta said with a thankful heart. She felt that she would not pass through those dark hours of her day if it was not for them. "Even when he was in chemotherapy it was their support that made us here. When I was not able to stay in the day time, his friends or relatives assisted me to cover my shift. They were so understanding and comforting" Desta said remembering those hard times. When Desta was first introduced about her husband's situation, she was forced to discuss the issue with other family members so as to gain help in taking care of him.

Beza shared a different experience caring for a relative.

> I do not know where we are heading. I used to think that we are Ethiopian with great values and norms for caring for people who are seeking our help. What I am facing right now is different from what I have imagined. A wife giving up on her husband just because he is about to die is unthinkable. I used to believe the culture we are in would help us to act in a certain way but not. (Beza)

She said with a frustrated sound that she is in a conflicting situation dealing with the patient who is relative by blood. It is challenging for her as the wife and daughter are not in contact to provide him the support he needs. He is more challenged economically and psychologically than his physical health. For that matter, she does not know how to help him as both wife and daughter refused to help him.

4.3 Religious Components at End of Life Care Treatment

4.3.1. Views from the Professional Caregivers

4.3.1.1 Level of Spiritual Strength

When people are spiritually strong, they are able to face any situation in their life. The professional caregiver further explained that it is related to the purpose they give in life and to their communication with their God/ Allah. Especially when the issue of death is discussed there are divergent views being raised even if people have same religion. People's spiritual strength and the value they give to life also matters on how people understand and react to death and related issues.

> There are clients who already gave up in life who do not expect things to be in a better way. For such people it is hard to manage their physical pain since they have already lost hope in taking their medication. It is from God that they are waiting their death time and due to their inability to be part of their social life, they take themselves as people who gave up in life and as dead person. (Kidane)

Paulos shared the above idea and said what people at end of life would say about death and dying as they are waiting for miracle to happen. They are patients and families who are waiting for a brighter day to come so that their old times would arrive and they will not face death at a time they are not expecting it. Discussing about death issue Paulos said "we always go around the bush." He reported that they do not actually dare to talk about death for patients and families who are waiting on a miracle. It is actually happened for clients that they feel better in their inside but their medical condition says it differently. It is impossible to argue with these people saying 'no you are going to die'. The power over death is usually tend to lean on who created us that every patient expects God's or Allah's timing than the medically estimated period to live. In a cultural way, the death issue is usually taken from what people dealt in life with. There are people who think that they are dying young as on the cultural value they hold and most importantly related with religion and righteous way of living. "Being sick does not mean you are going to die" Kidane uses this phrase to discuss about death issue with clients who are ready to hear about their condition. This implies to the patients that there are people who die without being sick. "We all are humans and our destiny is death" he further uses comforting words that they are not alone on their journey.

4.3.2 Views from family caregivers

4.3.2.1 God is in action

Similar to the professional caregivers, family caregivers sometimes entertain their religious values in caring for their significant others. The action of family caregivers tends to depend on their level of spirituality and understanding of their religious values. “I do not say no for my husband to take his medication knowing that the holy water and prayer heals him. I believe that God has a plan for him and I hope He also works through the medications and the hands of the doctors” (Desta). She believes that God can make a difference that He has the power to make him better or to take him. Similar thought is shared by Yirga as well that he does not take only the one way but incorporates both the scientific and the religious ways for caring for his wife. He prays for his wife to get better but he knows that the issue of death is only left for the one who he believes in, God.

Abonesh takes a different view in caring for her mother that she felt she should focus in one of the treatment and she should not fight with her faith. It is her belief that God can do it but has a plan for her mother if she has to pass through this hard time in dealing with cancer. There is different value that the mother and the daughter caregiver holds but Abonesh tries to make the mother feel comfortable that the one and only God has the full power in what she has to become. But for her mother having a different religion could not take action as the request of Abonesh.

“I have never made my husband to feel and to question God” Tigist said. She always made him sure that God would make something in his life and would do a miracle through the therapy or tablets he is taking. She always has the heart to believe that God would make a miracle and would see the husband in good position. As young and adventurous he is, Yared did not pay attention for the value his father needs. “I have never thought about it differently, he takes the medication, he always gets up early and goes to church; I believe he is feeling the change in himself than what I would say to you as he is always sick and tired.” And yet he is thinking that the religious aspect that the father is taking makes a difference in the life of the father.

The issue of religious aspect usually tends to give strength and aspire a hope for the families and patients that believing God is at work. They believe that God made them in this situation for the sake of His plan in their life. But as another caregiver Beza who always complains thinking of what bad her relative had done making to suffer not only with his (the relative’s) illness but also being left home alone with no wife and a child. “I sometimes think that he is reaping what he had harvest but I ask for forgiveness as I fear that I made wrong conclusions” Beza shared her part. From what she believed there would be no other reason for being left at home alone than being a bad person for his wife and child. Even if she was not sure what he exactly did to them, she is feeling that it is eye for an eye.

4.4 Impact of cultural and religious views on the action of caregivers

4.4.1 On the professional caregivers

4.4.1.1 Patient autonomy

“No matter how well you know your profession and value it, it is not always possible to go through that, especially for caring for people like Ethiopians with different types of cultural and religious views.” Mekdes said. From what she said that there are times where the day-to-day activity would be affected by the way people especially family caregivers see things. As professionals they are expected to function as one but in order to have a smooth communication especially on their first contact, they need to understand and accept family members' preference and values. Even if it is important to follow the professional ethics, there are times that do not allow them to do so. "We cannot discuss about illness and treatment plans with our patients if family members do not want them to be aware of it" (Kidane)

As professionals there are priorities that they give for their patients while they are on the verge of death. But there are times that stop them from being guided by their professional ethics. "Patient's autonomy is the most important value that we need to give for our patients. But due to the pressure coming from family members we are not able to explain the exact condition of patients for themselves." Paulos said. Kidane further discussed this issue that patients get hopes up and feel that they have a future even if the truth is far from being fine that they are at the last stage of their diagnosis as they are on the last stage of their life span. "Family members do not want to tell their condition for their significant other fear what they would do or react to it. They care and wants to protect them from depression but it causes other problems on the patients' side that they feel as if family members do not pay attention to" (Kidane)

On such cases patients feel neglected and feel like a burden to the family. This is because of the miscommunication that arises between them. When family members request the professional caregivers not to tell, professional caregivers make the condition secrete from everyone. This makes the patients' need any family's response unmatched. "They keep on asking us about their illness but we are not able to tell them as it is said boldly by the family members" (Kidane). This causes more pain and frustration to the patients. They are aware of their situation as they are not doing their best as their earlier time in life, but not getting the appropriate responses from their loved ones affected how they perceive about their situation and their communication with their family member.

4.5.1 Communication Between family members and professional caregivers

4.5.1.1 Ethical Issue

This issue has never been easy when dealing with different clients and families. There are families who do not want to let their dying family member or others to be aware of his/her situation. Especially the issue of death cannot be dealt with clients as a request of families.

> The first contact with family member is filled with dealing with different issues and reaching to agreement. The families who do not want to let their dying person to be discussed about death. These is usually challenging for us as we are battling between the cultural value they hold and the ethical issue that we need to be guided by. We cannot deny the interest of the families yet we cannot let the patient not to know about his condition. (Kidane)

Even if their professional ethics says that they should inform their clients about their diagnosis and prognosis family members might resist that and kept it secret. “We have a client who does not know that she is diagnosed with cancer because her daughter as a caregiver did not want her to know” Paulos said. The communication they have with families really matters because as professionals they make priority for the wellbeing of their patients and with having bad communication with family members they do not want to lose the contact they can have with patients.

When dealing with family caregivers the professionals also go through the path that needs to be discussed for breaking the bad news. But there are families who do not want to discuss this issue. Family members are not only resisting listening about prognosis but also refuse to talk about death and dying. “It has a cultural implication” Paulos said about the reasons why they do not want to talk. Culturally, death is something we fear for many reasons that we might not be raised in a family where discussing such issues as normal. “Family members might consider us professionals that we could not value the life of our patients just because we are in the medical field that we might witness so many deaths in a day” Paulos said about what families think about their value.

Kidane said about the importance of communicating with families about the condition of their loved ones. “I make them to explain by themselves so that they can understand and to give them the chance to raise questions that they are confused with.” In this regard, family members tend to accept the condition the dying person is in and limit themselves from running to hospitals and other medications. Families fear for themselves as they do not want to explain to the dying person or being asked by them about the imminent death. For the fact we are living in different situation, how we respond to this issue is also different. For families who think that talking about death does not bring the actual death, they are more open to discuss about the death of their significant other.

4.5.1.2 Talking about death and dying

Kidane shared how he deals with family caregivers in making them aware about death and dying after knowing their acceptance to discuss the issue. “I sometimes fabricate stories to tell them about loss and grief and management so that they can relate themselves to the story as they can get prepared and be ready.” He would explain the prognosis and how the client can lead him/herself during the last stage of life. He explains how families’ can cope up with the loss of their loved ones comparing to the best situation it would be for them instead of feeling the pain and suffer. “Yes they would fear when they talk about the death of their loved ones even if they are aware of the incident that will happen soon” Paulos made the comment about the feeling of family members.

4.5.2 Communication between clients and professional caregivers

4.5.2.1 Professional value Versus Cultural Value

When they are older patients, family members prefer to tell them that they are diagnosed with age related health problems than exactly telling them about it. For such cases professional caregivers cannot talk about diagnosis and prognosis. They do not tell them about the treatment because they are refused to make clients aware of their situation. “I know as my professional ethics that it is the right of clients to know about their health condition because they have the autonomy but due to the cultural barrier and the family’s request they are denied from their rights.” Paulos said. There are also patients who are diagnosed with cancer but they are only informed about it as if it is lump or simpler diagnosis. “I feel that their guts tell them even if we hide from them that they are suffering from something bigger than what they hear” Kidane expressed his view. The patient’s autonomy is highly disgraced that they are not able to know about their condition and even being lied about their diagnosis because of the choices family members made.

4.5.2.2 Clients who are not willing to hear

There are also patients who do not want to be communicated about their diagnosis and death issue. For such clients, professional caregivers understood how far they need to go with them. Regarding to the cultural value they have patients who do not want to know how and when they die. This is the cultural implication that client fear to talk about death as they feel it is attracting it and taken as bad to predict such kinds of energies. “If your client is not willing to listen about his/her condition for many reasons, you cannot force them to know” Mekdes said about the communication between caregiver and clients. Kidane said about the type of client he used to have who refuses to die because he was 36 years old and he used to say that he has a purpose in life that he did not accomplish yet. He was so challenged to accept his death even he was at the critical stage of cancer. Kidane said from his way of not even being sure to tell for his clients about their dying and death because he said “I cannot be sure about where they are going after death, even if I know they are orthodox [Christian] and I can assist from the same religion. So it is difficult to tell them forcing their interest.”

4.5.2.3 Client who are ready to hear

When there are clients who are ready to know about their situation, the prognosis and that death is approaching it is important to make it in way that does not threaten their dignity. “When we explain about Cancer for instance …” Kidane said about the communication they have with clients who are ready to be told “…it is important to declare everything that is not disgraceful. We need to make sure that the person does not lose the interest to live and wishing to die in fear of what is going on” he added to his point.

There are clients who strongly ask about the time of their death so that he/she can prepare to write will and to spend their last time at their favorite place and with the people they want. “Especially elders and mostly men expect to be told about their condition as they feel they need to prepare everything for the family. For most men taking care of such issues is important as to make sure that the family would not struggle because of the loss” Paulos said about the special requests from his clients. When such requests come from clients, professional caregivers make sure to involve family members as to pay great attention for the last wishes of dying the persons.

> We encourage family members to involve because they need to be part of the request as they can pay attention to their significant others. It is hard to listen and attend a family member that you love states that he/she is going to die and asks to do whatever he/she asks before he/she dies. It might be hard to discuss such issues but it is important to make sure that family members take part. (Mekdes)

The purpose is to make the dying person happy even if it might be difficult for family members to be in such position.

Through the observation, I have found that these issues especially mentioning about the timing of death is so difficult for professional caregivers. One of the cancer patient was talking about her medicines and the feeling she had due to the medication, when she was asked about the feeling she had about her situation she said “my friend who had the same diagnosis like me and who had surgery on the same date as of mine has passed away few weeks ago, ever since I am having a hard time pondering that I might die soon” it was with a broken heart and tearful eyes. It was challenging for Kidane to tell her anything differently. This is what happened that he neglected the issue and talked only about the medication and the side effects. Different from other observation I had with other professional caregiver at different patient’s house, the man was instantly talking about God’s plan in human life. The family caregiver was way far from listening to the man’s word because that is not the issue he wants to hear at the time of care for his mother in law. He was not comfortable to hear about what God would do even he knows in his religious practice that God has a plan for him and his family. The issue of religious value is not as comforting as it should be for clients and families. “If clients and families are weak in their spirituality level, their questions, doubts and fears due to the existing situation puts them in the worst condition” Mekdes said about the different types of clients.

4.6 Experiences of caregivers at end of life care

4.6.1 Professional caregivers

4.6.1.2 Professional-self Versus Personal values

As professional caregivers know the medical world where such patients at end of life care are suffering from, how they deal with patients and families is different from one another and they might face difficulties. The cultural and religious values caregivers have in relation to the value patients had can affect the communication and service provision. For the Muslim client all the professionals had, they could not understand and deal with his needs at end of life care as per his religious requests especially on issues of death and dying. For the fact that religion is something that all people take as a right and only way to live and to communicate with their creator, people reacts differently as their religious values. It is difficult to explain differently than what the patient is expecting.

For the protestant client Paulos had for a longer time, he was challenged for her and family's belief that God would do miracle on her that she will be healed. It was difficult for him afterwards to communicate about death and dying with her and the family caregivers who were waiting for miracles in their lives. "I know God has a plan in our life. I am sure that her faith can heal her but with the same religion I am following I tried to tell her that God has a purpose in our lives. I even tried to tell her life testimonies and stories from the Bible" Paulos explained his situation. He said he was fighting with his professional self and with his personal life that he could not make sure that his patient is free from pain and at least leading a peaceful life. As the purpose of palliative care lays on pain management, it could not be made an assertion to keep taking her medicine and fight the pain without losing faith in her God. It was a challenging situation for Paulos to prioritize between the two values he has. To explain loss and grief management with her family's due to their firm stance not to talk about that.

On a different story Paulos shared a successful one that a man who was happy with the religious support he gained. He reminded the word of the man "I am going to wear white clothes when my wife dies because she got everything she wanted when she was alive and she was happy with the treatment she gets" Paulos was saying the man's word in confidence knowing the goal of palliative care has been done successfully. The woman never felt bad about the situation she was in as great care and support has been provided by professional and family caregivers. When Paulos was dealing with the man in death preparation, he knew it was going smoothly as the man accepted the wife's situation.

Kidane explained about his experience he had with a client who refused to take medication because she wanted to be in church and use prayer and holy water instead of the medicines she is taking. "She was HIV/AIDS patient that she refused taking her ART and made her physical condition even worse" Kidane said. He also faced challenge with a patient in different religion from him and the man refused for his wife to take chemotherapy as he believed that God had healed her and she would be fine sooner where the medical explanation says differently. As he could not argue on such cases due to the difference already being made, the client's condition was getting worse and worse from time to time. Kidane remembered the physical pain the woman was going through and said "I know God does not want us to suffer, I do not mind about the difference we have but as believing in God I know He does not want us in worst condition."

4.6.2 Experiences of Family caregivers

With the day to day life family caregivers are leading while caring for patients as their loved ones, family caregivers' experiences different issues as per their religious and cultural views. Not only that but also the social support they have affected caregivers differently.

4.6.2.1 Fear to Let Go

When family caregivers were asked about how they handled the discussion of death and dying with their significant other and with the health professionals they differently explained their situation. In a cultural explanation where death issue is left untouched Dagim said she will never be ready to say anything about the death of her mother. Her mother who is aged in their late 60s and fighting cancer always looked up praying for Dagim to get married and for the mother to see the grandchildren of the only daughter Dagim. "My mother always says 'let me live for you' so how I can talk about death with her. I cannot shade her hope" she said with a desperate voice. She thinks that if the cancer keeps spreading this fast that it will be a different story for her but she is not morally ready and cannot accept the death of her mother whom she sacrificed everything for. "I am a high school dropout. When my mother was diagnosed with cancer three years ago I stopped my education so that I can work and assist her" she remembered those times and she became tearful. Even if it was medically estimated for her mother to be part of end of life care but she feels she survived. "For a person to die, I believe the purpose in life should be completed but my mother's is not, she still wants to see the best in me" she noted with firm stance expressed that the time period estimated by doctors will not always be right.

As a human life with limited but unknown journey Almaz feels the same way for a mother diagnosed with cancer. For anyone who would give to answer if it is ok to die in their late

70s or 80s it is predictable what the answer would be. But not for a daughter who wants to see her mother longer in life. Almaz never spoke about death not only with her mother but with anyone else as well. She feels it is irritating. It is attracting negative energy in life. She wants her mother to live and die peacefully without making her being concerned about death. “She should enjoy her last moment without fearing death and being stressed” she said with a smile in her face that she wants all the best for her mother.

4.6.2.2 God has a plan

“Would you want your loved one to die? Of course not” Tigist said about the situation she is in. “But I cannot let him [her husband] suffer more than this. I know he wishes the same because the chemotherapy is killing him in the inside. I can say all his childhood dream came true and nothing he would want more” a tearful eye filled with courage being ready to say good bye to her husband. She was saying this because she believed there is no better tomorrow for him and has faith that God made the choice in their life. ‘Before your bones came together’, God said this so he already knew that my husband would go through this” Tigist said feeling that it is in God’s hand. “I cannot fight for another journey” Tigist made her last remark.

4.6.2.3 Challenging Situations

Abonesh who is challenged to care for her dying mother due to religious difference said, “God created her and definitely knows her last moment in life” with a desperate voice. She is not having smooth communication with her dying mother because of what other relatives are saying about Abonesh and her families.

> They tell her not to pray, not to dine with us, not to talk about God with us just because I am a different religion family member. I know God would do anything, a miracle as well

> but I do not want her to suffer because I am in worse situation taking care of her that I cannot work to support my family. But no one understands that and just tells her wrong things to make our relationship rough. When I ask for religious fathers to pray for her she refuses. We are just creatures of God, what is the problem asking for mercy? Dying in peace with no pain is also a mercy from God. Abonesh was fighting her tears back feeling the pain she is going through.

For a relative caregiver who feels she is suffering for the situation she is in “I always pray for him to die in peace. The situation he is in is worse than what he is suffering from” Beza said. For the fact that the man has a rough relationship with his wife who filed divorce and a daughter backing up her mother, a cancer patient already lost hope and faith in God. “He is already dead” Beza said about the situation he is in. she is challenged because the man became depressed and the wife usually comes to make feel worse. As a caregiver, Beza is challenged to give the care the man wants because he is in dilemma. With a good economic condition, he is now, wants to go aboard and get medication to treat his cancer but the dark side he is having with his divorce remains to be a challenge for him.

> I have never heard such a thing in our culture. I am so ashamed knowing them. I have never experienced a wife betraying her vowed husband when he needs her most. Not only that the cruel daughter is the one who is pushing the mother to make her against her husband. They are not Ethiopians. I know we care for people even for those who are not related with us by blood but also for the ones we have never seen. Simply by listening to their touching stories we provide help. They are not humans at all (Beza) explained her challenge as a caregiver.

For Yirga who is highly stigmatized by his families for being with his wife all over these years, life is getting harder and harder every time. He said “She is not my burden as everyone thinks, she is my wife and I am committed to her.” He explained about his situation with a determined heart to care for his wife. He was forced to leave his family’s house where he used to live in due to the fact that he refused to abandon his wife. “Expecting the thin legged to die the bigger one left instead” (እግረ ቀጭን ይሞታል ሲባል እግረ ደንዳና ሞተ） Yirga expressed the unknown fate that everyone would face. For the fact they do not have children and she is diagnosed with cervical cancer, Yirga’s families did not want to see his life ending with her as they think it is getting darker because of her. He said he does not know God’s plan in his life but he knew not to betray his wedded wife. “She was not like this (looking at her with smile). Feeling that she might die soon I cannot betray her” Yirga confirmed. For him and his wife, death issues are not discussed openly because they left it for God as He knows better. He is hoping for her to better from time to time believe that she will be healthy again.

“I do not see the point” Yared said about his father’s last moment request to visit his childhood place. The father is both HIV and cancer patient with no wife and 24 years old young boy caring for him. The father wanted to be at his birth place wanting to be with his families and relatives. For the young boy who has never heard about them in his early years could not see the purpose in going all the way to country side. “Yes he asked me to do it for him before he dies but I cannot agree with his request because if they were alive and wanted to come to visit, they would have done it already” Yared said that he is not convinced by the request of his father even if it a dying wish at the verge of death.

4.6.2.4 Availability of social support

For a wife who is filled with joy for having the largest support system. Desta said

> I would not fear what would happen tomorrow. Our families and friends are doing the best they can to make my husband happy at his last stage. The illness he is dealing with made some much complication to our life especially in raising the two little children. The support made him to feel better and gave me the courage to deal with all the pain he is suffering from. In our society yes, when a person is diagnosed with cancer everyone says that the person is going to die soon. But I believe if we are doing everything in possible right way, we can make sure that he has more time to live

The support she gets gave her the strength to care for her husband every day. She also gets a good support and understanding from her office that she can get to office late and leaves early especially at those times when the husband is in chemotherapy.

4.7 Summary

Culture and religious values are the most important aspects at end of life care. The service provision at Hospice Ethiopia incorporates the biological, social, psychological and spiritual being of the person. Aspects as social support and the communication clients and family caregivers have with their God affects how they accept and respond to end of life care. Use of social support is seen different as the finding indicated. Gaining a lot support from friends and families, there are family members who value the availability of social support. Fearing how they would respond to the clients’ situation and using negative words impede family caregivers from allowing other people to come and visit them.

Due to the cultural implication as fearing the response from the society, family caregivers do not feel comfortable to expose information to others and clients themselves. Not to worry clients as well, family members’ challenges professional caregivers from giving full information about their health condition. The communication between client and family caregivers is designed to how far family members want to let them about their condition. For those clients who are ready to make be aware of their situation, professional caregivers tell them about it in a respectful and dignified way. Family caregivers have different experiences as they face while caregiving. Religious differences, giving different value to life and availability of social support are the major ones that challenge them while providing care.

Chapter Five

Discussion

This study aimed to explore cultural and religious values caregivers has at end of life care service provision. Using the qualitative method, six major themes are presented in the previous chapter. Accordingly, this chapter presents the discussion part to situate the findings of this study within the existing literatures. The different religious values and cultural values in Ethiopian, African and other countries ‘ cultures are discussed in this chapter. It also shows how professional caregivers address the needs of clients and family caregivers incorporating the religious and cultural needs of these people.

5. 1 Understanding the Service Provision at End of Life Care

As the finding indicated the service provision at end of life care is holistic as to the level to address the biological, social, psychological and spiritual needs of the client. The service provision is supported by the studies conducted by Morris (2013) and NASW (2004). Both talked about that the service provision at palliative care is holistic as it gives attention for each component of the patient. According to professional caregivers, great attention is given for the biological component believing that the aim of palliative care is to minimize pain.This finding is also supported and refuted by the previous research findings. National Institute on Aging (2012), showed that the physical being of the person takes the highest value in which the most care is needed to be given for that. Whereas Chaturvedi (2007) showed that the spiritual care is essential component of palliative care. The finding of this study gained similarity as the Hospice Ethiopia center’s caregivers give priority for alleviating the physical pain.

As part of the social component of the clients, Hospice Ethiopia Palliative center works in training and awareness creation programs to avoid stigma and discrimination. It also has been found that they give training for community members to help patient who are diagnosed with life threatening illness. They also work with like-minded organizations to make sure that patients get the necessary services. From the study conducted by Chaddock (2014) it is possible to link the finding of the study. The previous study indicated that it is important to bring the wider community as part of the care as they bring social care expertise and perspectives to the situation ensuring that patients get the support they need.

The service provision also includes the family. The Hospice Ethiopia center includes the family members as part of the care and treatment plan. The National Council for Palliative Care (2012) also indicated that it is important to support family members. This is basically to enable them to cope up with life stressing situations as they (Family Caregivers) would be all day and night long available for caring for their significant other. According to the finding, the family caregivers can get advice and counseling from the professional caregivers.

Involving family members in decision making is the way to show that they are empowered and have the power on their significant other. As Bennett (2012) indicated the importance of smooth communication between family members and professional caregiver, the center's professional caregivers do the same. The requests of family caregivers are highly accepted as the professional caregivers do not want to have tough communication.

Having the power to decide makes family members to take actions that are preferable for them. According to the information obtained, it is quite possible to find family caregivers not allowing patients to interact and to exercise their wishes. This is known that clients feel that they are neglected and burden on the family. This is because of the lack of communication that professional caregivers are requested not to tell about the condition to their clients. This is supported by the idea Dunne (2005) raised that in such cases patients feel great stress, emotional tension and fatigue. Such denial of their interest which is basically taken as protecting the patient from listening to bad things explains that best interest of the patient. This is actually being able to make a comparative assessment by the family caregivers who can tell about the burdens and benefits of exposing them to the information (Truog, Campbell, Curtis, Haas, Luce, Rubenfeld, Rushton & Kaufman, 2008).

Discussing about death and loss does not take place just because it is important to tell clients and family members. If family members are not ready to be told, professional caregivers do not have the power to state the condition of their family member. Speaking of grief, the professional caregivers take the action to help family members to manage it. As it is indicated in the previous researches like Elisabeth (2005), they do not go through the stages of grief management. They might not work with family members to accept the loss, to work through pain management, adjusting the environment and emotional relocation of the deceased and to move on. Sometimes the professional caregivers tell family caregivers a fabricated story so that family members can understand and accept their loss.

5. 2. Explanation of Caregivers about Cultural Values at End of Life Care

This study shows that professional caregivers do not give full information about clients' condition for themselves. Their main reason is that clients and their families might not be willing for discussion. This stance is accepted in a previous study conducted in Israel by Schattner (2002) which explains that it is quite good to do so as it is always a potential risk of shattering a patient's hopes and dreams. Having hope for such people is one of their coping mechanism; but not telling the truth, despite the needs and interest of family caregivers, impacts the client as well. This is because of their limited knowledge that they might not even get the necessary medical treatment if they are not aware of their situation. This is stated by Kazdaglis, Arnaoutoglou, Karypidis, Memekidou, Spanos & Papadopoulos (2010) and Buckman (1992) that information giving is to reduce uncertainty for clients and they can make informed choices about their own health care and plan for their future. This study also pointed out that, telling the truth for patients helps them to accept the effects of the disease. They can also cope-up with the change in physical situation especially for cancer patients who are on chemotherapy.

The benefit of open discussion is also for preventing families and clients from false expectations. The present study showed that professional caregivers try as much as possible to expose clients at end of life care and their families with their exact health condition. On a similar condition, National (Australian) Social Work Department of Health (2005) showed that, open discussion when it is early and honest helps both the client and the family member. It prevents them from unrealistic expectations about what can be achieved with the treatment. Whereas, for clients who are denied to know the truth about their situation; they are in a situation wishing and aspiring for something better in their lives.

Similarly, when professional caregivers are ready for breaking the bad news certain cultural values affect them. As Chew (2012) showed in his study China, talking about death is a taboo that Chinese feel uncomfortable to discuss such issues. This is also similar in the African culture; specific to Nigerians death issue has three different connotations. When death is a result of sickness, it is taken to be shameful, bad death unlike the natural death that people die in their old age and the other one which is human brought (Okafor, 1996). The Kenyans believe as well onset sickness is resulting from witchery imposed by someone else or if the person violated a social norm (Healthcare Chaplaincy, 2013). For such cultural implications, this current study found that families do not feel comfortable to discuss such issues. They do not even disclose the information of their significant others to others fearing the response they would get. With similar fear, professional caregivers as well do not feel comfortable to talk about death and dying thinking what families would say to them. Barry & Henderson (1996) share this because, it brings sadness or rush feeling to die and usually taken as cursing or saying bad thing about the person who is about to die.

Family caregivers have their own explanation about cultural values as related to availability of social support. Family caregivers who are going through on the same situation feel differently about social support. From the finding, it was possible to see that there were family caregivers who felt blessed and great about the existing social support as it helped them to share burden. As Taylor, Sherman, Kim, Jarcho, Takagi & Dunagan (2004) mentioned the availability of social support as informational, instrumental and emotional that family caregivers are benefited. They are supported as there are available people who can understand their stressful situation and avail themselves for coping strategies; tangible assistance as financial support and the warmth and nurturance support respectively changes the family caregivers' situation at end of life care.

This study's finding showed that there are family caregivers who are not willing to accept any social support that comes from extended families and the community fearing the way they respond to the situation. It has been noted as well that there are family caregivers who have lost their social support as a result of the care they provide for their significant other. This finding is supported by the research by Shumaker & Hill (1991), which explained that perceived social support was a stronger predictor of adjustment to stressful life events than received support. This explains that overly intrusive social support may exacerbate stress. As it is indicated in the finding, this is usually resulting from the way others react for such conditions.

5.3 Religious Components at End of Life Care Treatment

For the religious aspect, the finding showed that the level of clients' spiritual strength affects their level of understanding and accepting their condition. Chochinov (2006) showed that the relationship one has with God or the higher power, the purpose he/she has in life and the meaning they give to it shows their level of spirituality strength. For the patients who are not able to understand and give justification why they are going through this stressful situation, they usually have a hard time to maintain their relationship with their God. They usually question their faith in God as what they have been through challenges their faith. People who are able to accept their situation, as believing there is a higher power for them, can deal with such situation easily.

Discussing death and related issues is quite challenging for professional caregivers as it is indicated in the previous chapter. They do not dare to talk about it directly; rather 'they go around the bush'. They do speak openly about it showing that for the creations of God, He has the power to take their lives away. But it is not always possible to talk about it as easily as the other issues for discussion. This idea has been argued by Jeffrey, Peter & Peter (1997) that palliative care avoids extremes in that it both upholds absolute respect for human life and acknowledges human mortality and the limited dominion we have over life. This shows that professional caregivers do not need to avoid such conversation as it is important yet the finding shows that due to the religious barriers, it turned out to be very difficult.

The finding of this study is supported by the previous study conducted by Searight & Gafford (2005) as in many African cultures, spiritual and end of life experiences are often associated with meeting with God. They accept the pain as they feel it is the test from God. As the family caregiver said as well, they do not test their faith on their God and they accept everything that is happening to them.

For family caregivers, the religious component seems as valuable as they are more attached in their value and relationship with God compared with the professional caregivers as the finding showed. This is mainly because of the value family caregivers have in their religious practice. They tend to accept that God is in action that He would do whatever He plans in the life of His children. This belief is mainly to save the lives of their significant other from death. They tend to take both the religious cures such as taking holy water and prayer and the medical ones adhering to the medicines. The study by Bishops' Committee on Bioethics (2002) showed that the ultimate meaning of personal existence is to be found in relationship with God. This explains that when humans face such kinds of negative situations in life like sickness they tend to come closer to their God. In this regard, family caregivers always feel that they believe in God that He is able to do as He planned. They keep their relationship with God believing in Him.

On a different way, such illness and being on death-bed has been also taken by the research participants as an action of God as paying of the bad deeds that people had in life. The finding stated a caregiver feeling that a patient is reaping his own harvest believes that he has been doing something terrible for his wife and child. The study conducted by Metropolitan Chicago Healthcare Council (2012) supported this finding that people see patients as victims of their actions and consequence of their personal behavior and expressing guilt and shame.

5.4 Impact of cultural and religious views on the action of professional caregivers

Professional caregivers face the challenge of respecting patients' autonomy that making clients aware of their situation as they are obliged by the family members not to share any information. The studies O'Shea, Murphy, Larkin, Payne, Froggatt, Casey, NíLéime& Keys (2008) and Murray & Jennings (2005) conducted showed that it is always important to respect the person's dignity and autonomy than the family solidarity, care and mutual respect. But as working with family members requesting not to share information about their diagnosis and life span stage, professional caregivers are not able to respect the rights of their clients to know the truth. The finding of this study on the other hand is related to what Yeolekar, Mehta & Yeolekar (2008) conducted which showed that performing the wishes of family members threatens the self-determination of their clients.

5.5 Understand the communication among professional caregivers, clients and family members

The communication professional caregivers have is always limited to how far the family members want their involvement and exposing information. The finding of this study showed that the first contact between family caregivers and professional caregivers is limited in making things clear for the client about his/her condition and reaching to agreement whether to state that for clients or not. This is also supported by Bennett (2012) that showed that it is always important to reach to understanding. If families do not understand what has been said or done, it explains that there is miscommunication. For that matter, this finding also shows that professional caregivers always try to make sure that families understood the service as end of life care treatment requires communication with clients. This shows that the professional caregivers prioritize positive communication as they care more to continue caregiving to their clients without making disagreement with family members.

This current study shows that when professional caregivers expect family members to understand about death and dying, they fabricate stories so that family members can accept loss and grief. As the study from the American Cancer Society (2016) showed it always takes time for a person to accept the loss of the significant other and to adjust his/her life without the presence of the deceased person. Thus the story that is provided by the professional caregivers helps them to learn to accept and resolve the emotional disturbances and life changes. As to the finding of this study, they help them cope up with their lives after the deceased person. They engage with the family to make them able to get better and they also visit them in mourning. As part of the bereavement, professional caregivers visit the family so that they can get comfort.

Some cultures consider delivering bad news to such clients at end of life care as unacceptable as this could lead to loss of hope. Healthcare practitioners may withhold information about serious diagnoses and prognoses, and decisions may be made about treatment with family members in the absence of the patient (Broom & Doron 2009). This is also what the finding of this/my study shows. Accordingly, professional caregivers do not share all the information with their clients as it is requested by the family members.

When clients are ready to be told it is always important to tell them in ways that is graceful and accepting their dignity. The finding showed that professional explains about clients' health condition in a way that is appropriate and in a way that they do not make them lose interest in living.The study from the Canadian Nurses Association (2015) supported the idea of telling information gracefully and with dignity. It is important to remember that there are many ways to die with dignity. These include living out the slow decline of a progressive illness, as long as a person's symptoms are managed so that he or she has a chance for quality of life within the context of dying with supportive care.

5.6 Experiences of caregivers at end of life care

As to the findings of this research, the professional caregivers have the experience that they battle between their personal value and professional value. As their personal value, they give the highest value for their religious values that sometimes contradicts with the wish and interest of their clients. As there are no Muslim caregivers, it is always challenging for them how to deal with client with different religion. Even if they have similar religion they are also unable to discuss about death and dying issues as clients and family members could have different value and explanation for these issues. It has been showed in other study conducted in Philadelphia that patients and their families may insist on interventions that physicians consider futile. Such insistence may result from disagreements over prognosis, rejection of physician authority, distrust of the medical system, or a religious belief in miracles (Lo, 2000).

Family caregivers as well had their own experience in dealing with their family member at end of life care. It is quite obvious to find them fear to let go their significant other. There has been other study that showed that home-based family care-giving at end of life as involving intense, conflicting, negative and/or difficult emotions, such as fear and dread, anger and disillusionment, guilt and regret, anxiety, grief, helplessness and hopelessness (Funk, Stajduhar, Toye, Aoun, Grande & Todd, 2010).

They also face challenging situation as they have different religion with their significant other. It has been also presented in the previous chapter that family caregivers face difficulties as a result of loss of social support and being isolated from their family. According other study in Toronto, Canada there is a strong religious belief that there is value in suffering and patients refuse pain and other symptom control. Their wishes need to be respected because suffering for them may be restorative and offer personal reintegration (Downie, 2004).

As it has been noted in the finding section, wish fulfillment is taken as one part of the challenge between clients and family members. A family caregiver did not feel that it is possible to fulfill the wish of the dying client. This is also indicated in the literature section that Stajduhar (2013) showed that the wish fulfillment always depends on the family's effort that they value their family member's wish. It is indicated that it is always good to fulfill the wish of family members as it helps them to give value for the few days left. But the finding of this study showed that is has not been as easy task for the family caregiver to fulfill the wish. This is mainly because of the different value between the child and a father. As a child he did not give much attention for bringing his father back to his place of origin where the father wants to be at the last moment of his life.

5.7 Discussion Summary

According to the systems perspective, for understanding a person's situation it is always important to look through the environment it is functioning in (Anderson, Carter & Lowe, 1999). The mutual influence from one system on another shows the interdependence. As to the finding, the people at end of life care need the intervention of the community as a larger system to make them empowered and to enhance the goal of goodness of fit as it will be suited for the lives of people at the verge of death. Such patients in the community can be treated and get the necessary care and support they require in their community. As reported, the training professional caregivers provide for the community and for religious fathers explains these interdependence as to enable the one system which is the patient to function well in the community.

Boss (2002) explained the family stressor theory that families face impact for any event that happens in the family. As family caregivers are challenged at the care-giving at end of life care, it shows that the illness as an event made a huge impact in their personal life and need. The social support availability and absence shows that the resources such caregivers have while they are caring for their significant other at end of life care. Family caregivers have their own interpretation and views about the illness and dying of the patient in their religious and cultural explanations (Wilmoth, 2009).

The service provision of the professional caregivers is holistic it has the explanation of the bio-psychological and spiritual model. According to Frankel, Quill & McDaniel (2003) there is complex interaction of these four components in understanding health, illness and health care delivery. The finding of this study showed that the other three components are given the huge attention as much the biological one is given. Even if the professional caregivers are not able to provide the service, they use linkage and training for the community to provide services at the end of life care.

Chapter Six

Conclusion and Implication for Social work

6.1-Conclusion

This chapter provides the conclusion from the study and states the implications for the social work education, practice, research and policy. This study wanted to explore caregivers' religious and cultural values held by caregiversat end of life care. Using qualitative research method, it showed major findings on the service provision at end of life care, the religious and cultural values caregivers have at end of life care, the communication pattern, and the impact of such values on the actions of caregivers and explored the experiences of caregivers.

The finding showed that end of life care treatment has a holistic approach while the care is provided for patients on the verge of death. As much as pain relief is given the attention, the social, psychological and spiritual being of the person is also given attention by the professional caregivers. For providing holistic services, the professional caregivers from Hospice Ethiopia palliative center, use their linkage and referral services as to incorporate the community members and religious leaders as they are influential actors in the community. The service at end of life care does not stop at caring for the individual client. The family members are also part of the service provision targets. This is to make them aware in the care giving as caring for the caregiver is so important. This is actually very important to care for carers because family members are stressed and in burden while caring for their significant other. It is always important to guide and support them through the care giving. By doing so, family members can feel that they have a value and being cared of. This can help them to do more in their caregiving as they would not feel as if they gave up in their own life. Family caregivers would also discuss on the issue of death awaiting loss and grief with the professional caregivers. Professional caregivers provide them information on how they can lead their life after the deceased one. As being early attached and having a good communication, family members are able to trust and accept them. This is actually to help them get ready and to be prepared for the death of their family member.

Cultural value has been taken by the professionals as a way to hinder professional caregivers to discuss about end of life care treatment with clients and family members. This is to mean that family caregivers are usually reserved to talk about such issue fearing the society's response to the condition of their significant other. Thus it is always important to see the cultural implication while discussing such issues as diagnosis, death and dying. When breaking the bad news takes place, it is always important to give value for the clients' and family members' acceptance and willingness for discussing the issue. As death is feared in the Ethiopian society to freely discuss, professional caregivers need to give attention not to upset their clients and family members.

Availability of social support has been the important issue family caregivers had in relation to culture. The finding showed that family caregivers valued social support in their own preferences. This explains that the social support always gives a huge relief for family caregivers who are burdened in caregiving. For such reason, there are family members who are also in need of such support so that they can share their experience of care giving. With the societal implication and negative comments people uses when someone is sick brings more challenge both for the patient and the caregivers. Thus it is possible to say that social supports need to be used wisely.

The religious component was one major area to be explored. The finding showed that the level of spiritual strength that clients and family members has an impact in the treatment. For family members and clients who have good communication with their God has shown that they do not give up in life. The meaning they give to life and their justification for their current situation also has an impact on their condition. The finding from the family caregivers showed that they believe that God is in action that they do not feel stressed over the condition of their significant other. Believing that God has a power over their lives, they do not give up in life and they still pray, use holy water and religious rituals while using their medication.

The cultural and religious value has impacted the roles and actions of professional caregivers. The finding stated that, professional caregivers are not always exercising their professional ethics as they need to work accordingly to the requests of family members. One impact is that they do not always give the client his/her right to known about his/her situation. This explains that patient autonomy is not fulfilled as family caregivers usually request them not to expose the information to the patient. This shows that professional caregivers are not following their professional ethics. They are more concerned about the positive communication they can have with the family caregivers. The societal response that family members fear and the feeling they have towards the client not to hurt their feeling as telling them about the truth makes professional caregivers away from walking their professional line.

The communication pattern between professional caregivers and family caregivers is that, they always tend to work according to their professional ethics despite the problem they face with respecting patients’ autonomy. They allow family caregivers to participate in the decision making as they need to involve. Professional caregivers have always needed to accept their requests as family caregivers are the decisive actors on the client. While communicating about death and dying, professional caregivers go around the bush and usually make family members to raise questions by themselves so that they can have open communication. Discussing death and dying issue has never been easy for professional caregivers.

The communication professional caregivers have with client is usually limited to the personal value the client holds. There have been times that the professional and the personal values coming against especially when the religious values of the client differs from the professional caregivers.

The experiences of family caregivers have been pointed out as those who are not ready to let go of their family members. These family members are always concerned about a better life for their significant others believing that their purpose in life did not end. There are family members who believe that God has a plan for the life of their significant others. This is how they perceive their condition and they have had hope that God will heal him/her not but as God planned. There are also other groups of family caregivers who are in challenging situation while care giving. This is a result of different perception towards life and responses both caregiver and family member has. Having different religion with the client also made the communication harder and challenging for the family caregiver.

In conclusion, end of life care treatment has to be shaped through the cultural and religious values family members and clients have. In order to give a holistic service for both service recipients, it is important to address their needs in their won preferences. There have no right and wrong deeds in care giving especially from the point of family caregivers. Besides, the availability and the use of social support have to be managed as it gives a burden or release burden from family caregivers and clients. Furthermore, the wishes of clients need to be seen as it has been denied as shown in the patient autonomy.

6.2. Implications to Social Work

Implication for social work education

As the study indicated that end of life care treatment is holistic, the social work education should incorporate training in palliative social worker. As the existing service provision showed the service is limited by the health professionals, though the role of palliative social workers is very important. As the health care social work concentration has been introduced to MSW program of the School of Social Work at Addis Ababa University, there should be courses that incorporate palliative and hospice care issues and approaches that also encourage the creation of programs and services fitting in to the Ethiopian context. In this regard, the role of social workers and advocating for their profession in different workforce would be possible. As the profession has to advocate for itself as being in the multidisciplinary team especially in health care services, the School of Social Work at Addis Ababa University and other similar schools at different public institutions should work hard to produce more qualified and equipped health care practitioners by infusing palliative and end of life care issues in the respective curricula.

It is also important to give short term trainings and experience sharing programs with the hospital social workers as they can get the awareness and advance their skills in palliative care. This would make the service provision better for the client as it would be from multidisciplinary team as to provide holistic service. With the help of Schools of Social Work and Ethiopian Sociologists, Social Workers and Anthropologists Association (ESSSWA), students and practitioners can upgrade their knowledge and skills in the palliative care through trainings and seminars.

Implication for social work practice

The finding stated that, family members and clients are facing challenges in the issue of social support. As one part of intervention area, social workers need to practice advocacy and awareness creation regarding supporting such patients in the community and help them to maintain their social commitment in the community. It is also not to stigmatize and discriminate because of the physical and social situation. It is also important for social workers to intervene in caring for family members, give social work support for those who are experiencing problems with family relationships and conflict, support those who struggling with the challenges of growing old and for people who are facing difficulties as a result of disability, including feeling isolated within the community and experiencing practical problems with money or housing. Social workers need to involve in the area of palliative care stretching their support from the individual to the family and community level. As the study area (Hospice Ethiopia) work in the community, it would give a great chance for social workers to give trainings for community members, elders and religious leaders so that the society can support the patients and families. This would help both patient and families as addressing wish fulfillment and care respectively.

Involving in the multidisciplinary team of health care service provision, social workers can address the need of clients in social and psychological support. As the finding showed the professionals from Hospice Ethiopia give counseling for clients and family members, social workers as counselors can provide education and emotional support. It is showed in the finding that professionals are unable to expose information to clients, social workers can intervene between clients and professional workers as clients feel burdened on the family. They can also advocate for the clients' as their right can be respected at end of life care.

Regarding to loss, grief management and bereavement, social workers act in assessing and delivering the necessary support as it can alleviate intense emotion and stress. Working in the community, social workers can make them available for the loss and grief period of family members. This role is actually being played by the professionals from Hospice Ethiopia as they avail themselves in mourning with the family members, social workers can also practice such community work in grief and bereavement with the family members. Not only this, social worker can also function as carer for family caregivers as these people need attention and care while they care serving for their family members.

Implication for social work research

It is quite possible to say that there have been limited researches in the area of palliative care in Ethiopia. This study shows a way for future researches. In the existing researches, it is impossible to find them in relation to social work and its intervention. As the service is given in the hospital settings and dominated by medical professionals it is unlikely to find the role of social workers in the area. With the unavailability of social workers in this research's study area, the role of social workers in palliative care is not incorporated. Previous studies being done on palliative care in public hospitals as well did not show the involvement of social workers. This study also limited itself to explore the values of professional and family caregivers without assessing the clients' side. Thus future researchers can study about the role of social workers in palliative care, to assess the clients' view of culture and religion at end of life care, clients' wish fulfillment and respecting rights and community's involvement and responses at end of life care

Implication for policy and program

Having a unit of palliative care at Ministry of Health at national level gave the chance for palliative care professionals to intervene in the area. With the high need of patients at end of life care treatment, the national health policy should work in formulating independent policy that addressed the needs of people at the verge of death. Such as in training hospital social workers in palliative care, incorporating hospital social workers in the practice of palliative care in public hospitals and training health professionals about the totality of pain and holistic service provision. The public hospitals themselves has to avail the service for people at the verge of death as most clients do not have the financial and social supports to get end of life care treatment.

With the new initiative being given by Ministry of Health, the palliative unit should get its funding and budget like the other units under the umbrella of the Ministry of Health. The unit could stretch its hand in providing training, awareness creation programs and other activities while incorporating social workers who can intervene in the community. Having this unit in the MOH should bring a chance to social workers especially the ones working in public hospitals to be part of the multidisciplinary healthcare team.

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Appendices A

Informed Consent

My name is Mahlet Endalku, and I am a graduate student at Addis Ababa University, School of Social Work for the purpose of partial fulfillment for my master's degree. I am conducting a qualitative study on exploring the cultural and religious values of caregivers at end of life care. The purpose of this study is to gain the knowledge on how family and professional caregivers responds to death and dying at end of life care through the cultural and religious value they hold. This is to show your willingness to take part in this study. I would like to inform you that you as participating in this study will benefit the service provision and the family members getting your care. While you are reading this, it is important to make you aware that it is voluntary and you are free to withdraw at any time and can skip any questions that you are feeling uncomfortable. While being part of the study, your identity will not be revealed and no identifier will be attached with your responses. I as professional will promise you not to use your information rather than for the use of this study. There will be no incentive I will provide for being part of the study and there will be no risk for you and your profession and your families. With your willingness to be tape recorded I will use that as a help for data collection and make sure no identifiers will be given. The data collected will be kept confidential.

Following what have been written and your agreed to take part in the study please sign and write your name as you feel comfortable to be part of the participants.

Participant's name

Name:_________________________
Signature _________________________
Date ____________________________

Appendices B

In depth interview guide with family caregivers

Socio Demographic data

Age: _____ Sex: _____ Religion: __________ Place of Origin: ________________

Relationship with the Patient: _______________ Diagnosis period of the patient: _________

1. What services do you get from Hospice Ethiopia?
   - How do you see the service provision?
   - Have you ever get any counseling on care giving?
2. Have you ever get any training on caregiving?
   - From Hospice Ethiopia or from any volunteers?
3. How do you see life threatening illness from your cultural values?
   - How does society responds to it?
   - How do other family members react on such cases?
   - Feeling comfortable to talk and discuss about death and loss
   - Ethically and morally viewing topics of death preparation and loss
4. How do you explain religious values you have while caring for people at the verge of death?
   - How do you explain about the use of religious rituals and medication?
   - How do you see about God's response for such cases?

Cultural and Religious Values…

- How Christianity/Islamic view responds to end of life
- How is religious groups reacting when they think of death and dying
- Feeling comfortable to talk and discuss about death and loss

5. Have you ever faced any encounter while caring for people at the verge of death?
    - How did you respond to such cases?
    - How do you explain yourself as a caregiver while facing such challenges?
6. How do you see the communication between professional caregivers and patients?
    - When they are providing information about prognosis and treatment
    - How they respond to clients' needs and interest
    - How is the communication pattern?
7. What about the communication between professional caregivers and family caregivers?
    - Do they incorporate the family caregivers as part of decision making and treatment plan?
8. How do you support family members to get prepared for terminal illness prognosis?
    - Understanding their reactions or emotions
    - Responding to their emotions and experiences of pain
9. How is your experience in caring for people at end of life care?
    - How was your reaction or feeling when you first aware that the family member is diagnosed with terminal illness?
    - How is your contact with the person before and after diagnosis?

Additional point?

Appendices C

Interview Guide with the professional caregivers

Socio Demographic data

Age: _____ Sex: _____ Religion: __________ Place of Origin: ________________

1. What type of services do you provide for clients at end of life care?
    - Do you incorporate the family?
    - Do you see other systems of the client?
2. If family members are part of the service provision, how do you provide the service?
    - Do you have a different model of care giving for family members who are different in their nature of caregiving and different values at end of life care?
3. How do you explain cultural value while caring for people on the verge of death?
    - Making clients and families aware of their cultural values?
    - How do you respond to clients' and family members' cultural value at end of life care?
    - How do you incorporate in the caregiving?
4. How do you explain religious values while caring for people on the verge of death?
    - How do you manage your personal religious values with the clients'?
    - How do you incorporate religious values at end of life care?
5. What type of communication patter do you use while caring for people on the verge of death?
    - How far do you tell the truth?
    - How do you communicate breaking bad news?
    - What type of communication pattern do you use while exposing clients and family members about the health condition?
6. While communicating with family members and clients how do you manage ethical issue?
    - How far are you able to manage professional ethics?

Cultural and Religious Values…

    - Have you ever failed to comply to religious and cultural values while communicating with clients and families?

7. Can you share your experience of caregiving for people at the verge of death and their families?
    - Any challenging situations?
    - Any success story you had?

Additional point?

Appendences D

Observational checklist

- ✓ To observe the communication pattern between professional caregivers and patients
- ✓ To observe the communication pattern between family caregivers and professional caregivers?
- ✓ The available support system and the level of communication with other system
- ✓ The type of service provisions given by Hospice Ethiopia
- ✓ To observe the treatment given at end of life care

Appendences E

Place of interview with the participants

Participants Pseudonym	Caregiving	Place of Interview
Paulos	Professional	At Hospice Ethiopia Center
Kidane	Professional	At Hospice Ethiopia Center
Mekdes	Professional	Home
Dagim	Family	Café
Abonesh	Family	The community recreation
Yirga	Family	Home
Almaz	Family	Home
Desta	Family	Office
Yared	Family	The community recreation
Beza	Family	Café
Tigist	Family	Home

Appendices F

አዲስ አበባ ዩኒቨርሲቲ

ሶሻል ወርክ ትምህርት ቤት

ለመጠይቅ ፈቃደኝነት መጠየቂያ ቅጽ

እኔ ማህሌት እንዳልኩ በአዲስ አበባ ዩኒቨርስቲ በማህበረሰብ አገልግሎት (Social Work) የትምህርት ዘርፍ የሁለተኛ ዲግሪ ተመራቂ ተማሪ ነኝ። በዚህ አመት መጨረሻ የምመረቅ ሲሆን ለዚህም ማሟያ የሚሆን የጥናት ፅሁፍ በመስራት ላይ እገኛለሁ። የጥናት ፅሁፍ የሚያተኩረው በቤተሰብ አስታማሚዎችና በባለሞያ አስታማሚዎች ዙሪያ ሲሆን ለዚህም የእምነትና የባህል አመለካከተታቸውን የሚዳስስ ነው። እርስዎም የዚህ ጥናት አካል መሆን ትልቅ ጠቀሜታ ሲኖረው በቅድሚያ ከልብ ላመሰግኖት እፈልጋለሁኝ። ከእርስዎ ጋር የምናደርገው ቆይታ ቃለ መጠይቅ ከሰላሳ ደቂቃ እስከ አርባ የሚፈጅ ሲሆን ድምፅ መቅረጫ ወይንም ሌሎች ነገሮችን እንደ እርሶ ፈቃድ የምጠቀም ይሆናል። ቃለ መጠይቁን ወይንም ውይይቱን የምናደርገው ከኔ ውጭ ከጥናቱ አላማ በስተቀር ለሶስተኛ ወገን እንደማይደርስ ቃል እገባለሁ። የሚነሱ ጉዳዮች በሙሉ በኛ መሀል የሚቀሩ ሲሆን ሚስጥሩ ተጠባቂነትነትና አደጋ ላይ የማይጥሎት መሆኑን ልገልፅ እወዳለሁ። ቃለ መጠይቁ የሚካሄደው በእርሶ ሙሉ ፍላጐት ላይ ብቻ ተመሥርቶ ሲሆን መመለስ የማይፈልጉአቸው ጥያቄዎች ካሉ ማለፍ ይችላሉ።

የተሳታፊ ስም

የአጥኚው ስም

ቀን

ፊርማ

Appendices G

ቃለ መጠይቅ ከቤተሰብ አስታማሚዎች ጋር

የኋላ መረጃ

እድሜ: _____ ጾታ: _____ ሀይማኖት: __________ የትውልድ ስፍራ: ________________

ከታማሚው ጋር ያለ ግንኙነት ወይም ዝምድና _______________

በህመም ቆይታ: _________

1. ምን አይነት አገልግሎትን ከሆስፒስ ኢትዮጵያ?
    - እንዴት ይመለከቱታል?
    - በማስታመም ዙሪያ ላይ ምክር አግኝተው ያውቃሉ ወይ?
2. ስልጠና አግኝተው ያውቃሉ ወይ?
    - ከማዕከሉ ሰራተኞች ወይም አብረዋቸው ከሚሰሩ በጎ ፈቃደኞች?
3. ከሚኖሩበት ባህልና አኗኗር ጋር እንዲህ ያለ ለሞት የሚያደርስ በሽታን እንዴት ይመለከቱታል?
    - ማሕበረሰቡስ እንዴት ነው ምላሽ የሚሰጠው?
    - ሌሎች የቤተሰብ አባላትስ እንዴት ምላሽ ይሰጣሉ?
    - ታማሚውን ቤተሰብ በሞት ስለማጣት የሚነሳ አርዕስት ላይ መነጋገር ላይ ምን ይሰማኦታል
    -
4. በሚከተሉት እምነት አኳያ በሞት አፋፍ ላይ ስለደረሰ ቤተሰብ ማታመም ምን ኤኔት አመለካከት አሎት?
    - የእምነትና የሳይንሳዊ የመዳኛ መንገዶችን እንዴት ይመለከታሉ?
    - የፈጣሪንስ ምላሽ እንዴት ይመለከቱታል?
    - በሚከተሉት እምነት እንዲህ ላለ ሁኔታ ምን አይነት ምላሽ ይሰጣል
    - የሀይማኖት አባቶች ምን አይነት ምላሽ ይሰጣሉ
    - ታማሚውን ቤተሰብ በሞት ስለማጣት የሚነሳ አርዕስት ላይ መነጋገር ላይ ምን ይሰማኦታል
5. ምን አይነት ሁቤታ አጋጥሞዎታል በሞት አፋፍ ላይ ላለ ቤተሰብ በሚደረግ እንክብካቤ ዙሪያ?
    - ምን አይነት ምላሽ ሰጡ?
    - እርሶ እንደቤተሰብ አስታማሚ ምን አይነት ተግዳሮቶች አጋጥሞታል?
6. በባላለ ሞያ አስታማሚዎችና በህመምኛው መካከል ያለ መግባባት፡ ንግግርና ግንኙነት እንዴት መለከቱታል?
    - መረጃ በመስጠት አኳያ
    - የህመምተኛውን ፍላጎት በመረዳትና ምላሽ በመስጠት ረገድ

7. ከቤተሰብ አስታማሚ ጋርስ ያላቸውን ግንኙነትና መግባባት?
    - ውሳኔ አመስጠትና መረጃና በአጋባቡ በመስጠት ዙሪያ?
8. ታማሚ ቤተሰብን ላለበት በሽታ መዘጋጀት ምን አይነት እርዳታ ያደርጋሉ?
    - የሚሰጡትን ምላሽና ስሜት በመረዳት ረገድ
    - ህመምን በመረዳት አኳያ
9. በማስታመም ዙሪያ ያሎት ልምድ ምንድነው?
    - ለመጀመሪያ ግዜ ምን አይነት ስሜትና ምላሽ ሰጡ?
    - ከታማሚ ቤተሰብ ጋር ከህመም በፊትና በኋላ ያለ ግንኙነት ምን ይመስላል?

ተጨማሪ ሀሳብ

Appendices H

ቃለ መጠይቅ ከባለሞያ አስታማሚዎች ጋር

የኋላ መረጃ

እድሜ: _____ ጾታ: _____ ሀይማኖት: __________ የትውልድ ስፍራ: ________________

1. ማዕከሉ ምን አይነት አገልግሎት ይሰጣል?
    - ቤተሰብን ያማከለ ነው?
    - የደንበኞችሁን ሌላ የግንኙነት መስመሮችና ሰዎች ትመለከታላችሁ ወይ?
2. ቤተሰብ የአገላግሎቱ ክፍል ከሆኑ ምን አይነት አገልግሎት ለነሱ ትሰጣላችሁ?
    - አገልግሎቱን ለመስጠጥ ለየት ያለ መንገድ ለተለያ ቤተሰቦች ትጠቀማላችሁ?
3. ያለንበትን የባህልና የአኗኗር ሁኔታ በተለያ በሞት አፋፍ ላይ ላሉ ሰዎች እንዴት ትመለከታሉ?
    - ግንዛቤ እንዲኖራቸው ያደርጋሉ?
    - ላላቸው ልማድና አኗኗር ምን አይነት ምላሽ ይሰጣሉ?
    - በማስታመምና እርዳ በመስጠት ረገድ እንዴት ያቀናጁታል?
4. በእምነት ዙሪያ ላሉ አመለካከቶች ምን አይነት ምላሽ ይሰጣሉ?
    - የእርሶን አይማኖት አቋም ከታማሚ ደንበኞት ጋ እንዴት ያጣጥሙታል?
    - በእምነት ዙሪያ የሚነሱ ሀሳቦችን እንዴት ከአገልግሎቱ ጋር ያቀናጁታል?
5. ምን አይነት የመነጋገር የመግባባትና የግንኙነት መንገድ ይጠቀማሉ ከታማሚው ጋር?
    - እውነታውን ምን ያህል ይገልጻሉ?
    - ስለሞት እንዴት ይገልጻሉ?
6. ያሎትን የሞያ ምግባርን ከሚሰጡት አገለክግሎትና መረጃ ከመስጠት ጋር እንዴት ያዩታል?
    - የሞያ ምግባሮን ምን ያህል ይተገብራሉ?
    - በሰጡት አገልግሎት ውስጥ ለእነትና ለሰዎች አኗኗር ምላሽ መስጠት ላይ ምን አይነት ልምድ አሎት?
7. ልምዶን ሊያጋሩን ይችላ በአጠቃላይ በሞት አፋፍ ላይ ለደረሰ ሰው የሚሰጡትን እንክብካኤ?

- **ያጋጠሞት ተግዳሮች**?
- **ስኬታማ የሆነ ልምድ**?

ተጨማሪ ሀሳብ