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Bahir Dar University

Faculty of Social Sciences

Department of Social Work

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A Thesis Submitted to the Faculty of Social Sciences, Department of Social Work in Partial Fulfilment of the Requirement to the Degree of Master of Social Work (MSW)

By Alebachew Fentaw

Advisor: Kerebih Asrese (PhD)

September, 2019

Bahir Dar, Ethiopia

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This is to certify that the thesis titled *Palliative Care Service for Chronic Disease Patients at Felege Hiwot Hospital* is the work of Alebachew Fentaw. It has been submitted in Partial Fulfilment of the Requirements for the Degree of Master of Social Work (MSW). It Complies with the Regulations of the University and Meets the Accepted Standards with Respect Originality.

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Advisor : Kerebih Asrese (PhD) __________________

Declaration

I, Alebachew Fentaw, declare that this thesis titled *Palliative Care Service for Chronic Disease Patients at Felege Hiwot Hospital* is my original work and has not been presented for a degree in any other university, and all sources of materials used for the thesis have been duly acknowledged.

Name: Alebachew Fentaw Beyene

Signature: ____________________

Place: Department of Social Work, Bahir Dar University

Date: September, 2019

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Abstract

Since the number of chronic disease patients and the demand for palliative care service augmented, this sequential-exploratory inquiry, aiming at exploring and determining the quality of palliative care service for chronic disease patients, was conducted at Felege Hiwot Hospital. The study population was 576 chronic disease patients. Nine chronic disease patients and four key informants were selected through purposive sampling technique. Proportionate sampling formula was used to determine the number of respondents from each stratum of disease; then, two hundred thirty-six respondents were selected with stratified random sampling method. Interview guidelines and an observation check-list were used to gather the qualitative data and a structured questionnaire was used to gather the quantitative data. Thematic analysis in the qualitative phase and one sample *t-test,* and a one way *ANOVA* in the quantitative phase were applied to analyse the data. The type of palliative care service provided was primary palliative care. Dysfunctional infrastructure and interaction, incapacity, scarcity of drugs and supplies, lack of manpower, long waiting time, medical error, and poor complaint system were the hurdles decelerating the quality of the palliative care service. The test results of one sample *t- test* of quality ([t (235) = -10, $p < 0.05$] and satisfaction [t (235) = -11, $p < 0.05$] proved that the quality of the ppc and the level of satisfaction of the chronic disease patients with the primary palliative care were low. The results of the one way ANOVA analysis concerning quality ([F ((3) (236)) = 89.9, $p < 0.05$] and satisfaction [F ((3) (236)) = 122, $p < 0.05$] attest that there were statistically significant differences among the groups of patients with regard to the quality the ppc and their satisfaction with it. The palliative care service didn't comprise structure, process and outcome in such a way that it could manage the symptom and the pain of the diseases, and promote the quality of life of patients.

Key words: primary palliative care, renal failure, breast cancer, cervical cancer, diabetes, Felege Hiwot Hospital, Bahir Dar.

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CHAPTER ONE: INTRODUCTION

Background and Justification

According to Ewertowski *et al.* (2018), Matzo & Witt (2015) and Mosadeghrad (2013), the word palliative was derived from the Latin *Pallium*, a cloak. Palliation means cloaking over. To palliate is to cloak or shield the symptoms of an illness. According to Mithrason and Thomas (2015), palliative care aims at improving the quality of life of patients with chronic disease. Palliative care can be initiated while curative or disease modifying treatments are still being utilized.

It is a specialized medical care to get relief from the symptoms, pain, and stress of serious illness. It affirms life, promotes quality of life, treats the person and supports the family. It directs patients toward social functioning. Through the focused holistic, individualized, family and team view of care, palliative care incorporates principles of person-centered care (Institute of Medicine, 2013; Kvale & Bondevik, 2008). As Blank, O'Mahony and Selwyn (2015) affirmed, palliative care takes what might be called a developmental approach to medical conditions. As people reach a certain stage in the development of their illnesses, the trajectory of their lives enters the palliative phase. Consequently, palliative care is appropriate for people of all ages and most diseases.

To achieve the quality of palliative care, As Nadin *et al.* (2017) attested, the focus should be symptom management and pain relief with care plans evolving based on need rather than diagnosis or prognosis. It should also focus on quality of life. According to Seow, and Bainbridge (2017), palliative care comprises integrated teamwork, management of pain and physical symptoms, holistic care, caring, compassionate, and skilled providers, timely and responsive care, and patient and family preparedness.

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Punnakitikashem, et al.(2012) and Naik *et al*. (2010) affirmed that the quality of palliative care service comprises tangibles [appearance of physical facilities, equipment, personnel and written materials], reliability [ability doctors and nurses to perform the promised service dependably and accurately], responsiveness [willingness of doctors and nurses to help customers and provide prompt service], assurance [doctors' and nurses' knowledge and courtesy and their ability to inspire trust and confidence], and empathy [caring, easy access, good /communication, customer understanding and individualized attention given to customers. In other words, the quality of palliative care comprises structure, process and outcome. As Ewertowski *et al.* (2018) confirmed, in a number of countries, the fundamental right for patients of all diagnoses to receive palliative care from an early point in the course of a life-limiting condition is now anchored in policy and legislation, involving an increased emphasis upon the role of primary palliative care. Donabedian (2005) defined health care quality as the application of medical science and technology in a manner that maximizes its benefit to health without correspondingly increasing the risk. The quality of health care, including palliative care service, is a degree of performance in relation to a defined standard of interventions known to be safe and have the capacity to improve health. Quality of palliative care service is a question of degree of satisfaction.

Non-communicable diseases, such as renal failure, cancers, diabetes, and chronic respiratory diseases have become causes of death in most regions of the world. Africa is believed to have the world's largest increase in non-communicable disease deaths. "In sub-Saharan Africa, non-communicable diseases are projected to be the leading cause of death by 2030" (Naik & Kaneda, 2015, p.1). Non-communicable diseases, in Ethiopia, have become social problems, too, as it assaults a significant number of people. In Bahir Dar, the number of patients of renal failure, breast and cervical cancer, and diabetes patients increased greater than the number of other chronic disease patients. As a result, this study was conducted on the aforementioned patients.

Statement of the Problem

The number of chronic disease patients increased at an alarming rate and they suffered from the deadly diseases and associated problems. They faced hundreds of little deaths before dying due to the deadly sickness and the poor palliative care service. The quality of palliative care service was under question for it was not paid attention.

As Al-Damen (2017) revealed, the interest in the health service is increasing. Health professionals strongly believe that patients' satisfaction or positive perception is a prominent signal of health care quality and many hospitals are searching for ways to change the delivery of patient care through quality improvement initiatives. According to Sandsdalen et al. (2016), patients' perceptions of important aspects of palliative care have been found to be a focus on living a meaningful life, experiencing trust, compassionate and respectful care; participating in effective communication and shared decision-making and receiving help to minimize the burden. It also involves being cared for in a safe, comfortable environment and having organization of care that ensures access whenever needed and an experience of care that has continuity, and is well coordinated and planned.

What has been explained so far affirms that the quality of palliative care is based on the patients' norms, expectations, and experience, and by the encounter with a care structure. It is, therefore, important, when measuring quality of care, to include both patients' perspectives of the actual care received and how important the various care aspects are to them. The advantage of including both these angles is that areas for improvement may appear to be in line with what patients perceive as most important aspects.

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As Donabedian (2005) claimed, to deliver quality service, the service should include structure (the tangible aspects of the characteristics of a care setting, including facilities, personnel and drugs, and supplies), process (determines if the services provided to patients are consistent, responsive, reliable, credible, safe, effective) and outcome (evaluates patients' improved health as a result of the care received; wellbeing and resilience of patients and satisfaction). As stated so far, all health systems should ensure that all people with chronic disease are enabled to minimize its impact on the quality of their lives; build resilience to enable prevention, detection, and response to health security threats through focused attention on quality.

Palliative care service is increasingly being regarded as a human right and incorporated in the United Nations' Commission on Human Rights. It is obligatory to instigate and make them resilience, optimist and decisive (WHO, 2016). However, it is not developed to its full extent everywhere in the world; in Ethiopia, it seems to be ignored although the number of chronic disease patients and the demand for palliative care increased.

Palliative care had been provided in Felege Hiwot Hospital, but its nature [type], content and quality had never been studied. Few researches were conducted on palliative care from nurses' perspectives. The first one was conducted on knowledge, attitude and practice and associated factors towards palliative care among nurses working in selected hospitals, in Addis Ababa, Ethiopia by Hiwot, Murugan, Fissiha, Mignote and Desalegn (2014) and they found out that many of the respondents (nurses) have "favourable attitude" but poor knowledge and practice towards palliative care.

The second study was carried out on Nurses' knowledge, attitude, practice and associated factors towards palliative care*:* in the case of Amhara Region Public Hospitals, including Felge Hiwot Hospital, by Samuel, Hiwot, Tesfaye and Tadesse (2016) and they affirmed that "… majority of the nurses have a favourable attitude" and "good knowledge" on palliative care; in contrast, they had poor practice towards PC" (p.121). The third one had been conducted in Jimma University by Temamen, Yeamanuelwork, and Admasu (2018). They found out that "Almost two-thirds of the nurses had poor palliative care practices" (p.1).

The three studies claimed that palliative care was poorly practiced at the hospitals, but they did not assess why the practice of palliative care was poor and nor did they recommend how it could be improved; never did they reveal what the consequence of the poor practice of palliative care could be.

The gap studied in this study was palliative care for chronic disease patients from the patients' perspectives. This study is different from the previous studies in that it focused on hurdles decelerating the quality of palliative care service, the status of quality of palliative care service and the patients' satisfaction with it. In addition, this study applied a mixed-method design and model was used as a theoretical framework. So is this study different from previous studies methodologically. This study applied thematic analysis and one sample *t-test,* independent samples *t-test,* and one way *ANOVA* as techniques of data analysis.

The number of chronic disease patients increased; so did the demand for palliative care service. Unless the hurdles and the quality of the palliative care service were studied and intervention was proposed, there would be bio-psychosocial chaos of the patients and their families would be in a state of shattering; it would also be a problem of the society at large. The prevalence of the chronic diseases and the demand of quality palliative care service were high in Bahir Dar, but palliative care was not paid attention and had not been investigated from the patients' perspectives. Patients of chronic diseases had been between that day's dim light and the next day's complete darkeners; they lived rolling naked on a cold wave and of a vast indifferent ocean. Life was non-sense for the patients as their hope and the meaning of life vanished. They dwelt with a strangely aching heart and tried if they couldn’t feel forsaken. From these problems, the researcher believes that quality of palliative care service is mandatory and obligatory to restore the hope, well-being, meaning of life and social functioning of chronic disease patients. It, therefore, needed to be studied.

The study comprises a general objective and four specific objectives: the first two objectives were achieved qualitatively and the third and fourth ones were met quantitatively.

Objectives of the Study

General Objective

To explore and determine the quality of palliative care for chronic disease patients

Specific Objectives

To explore the hurdles decelerating the quality of palliative care service,

To explain the quality of palliative care service for chronic disease patients,

To determine the status of the quality of palliative care service and

To examine the levels of satisfaction of patients with the palliative care service

Research Questions

What are the hurdles decelerating the quality of the palliative care service?

What does the quality of the palliative care service look like?

What is the status of the quality of the palliative care service?

What is the level of patients’ satisfaction with the palliative care service?

Significance of the Study

The findings of this study may be significant for chronic disease patients. It voices their problems. It reveals the lacks of quality of palliative care service. The patients faced problems for the palliative care service lacked structure [infrastructure, manpower and drugs], process [communication and timeliness of service] and outcome [improved health status and satisfaction]. The study, therefore, publicises the problems stated so far.

Furthermore, the findings of this study affirm what health institutions should fulfil for chronic disease patients from the patients' perspectives. The patients affirmed that they faced a number of problems. Medical error can be a case in point. The study, therefore, identified the problems that the health institutions should intervene in and solve. As the problems have already been identified, the institutions can easily intervene and alleviate and/ or resolve the hurdles that the patients are suffering from.

Moreover, the findings of this study will be important for social care practitioners. As the study identified and explained the problems, the social care practitioners won't waste time in exploring the problem; they rather should protect the rights and promote the interests and wellbeing of the chronic disease patients. They can promote the autonomy of service users while safeguarding them as far as possible from danger or harm [medical error].

Furthermore, this study will be helpful for researchers. It may inform them issues about palliative care which have not been studied so far. It may help them to be sane to conduct studies on the issues recommended at the end of the study.

Eventually, the findings of the study may be important for policy makers. It may instigate them to make a policy on how hospitals should serve chronic disease patients. It may also help them as a ground to formulate standards for hospitals for chronic disease patients. So will it help them develop quality standards for palliative care service.

Delimitation of the Study

The study is delimited to cases at Felege Hiwot Hospital. It focuses on palliative care service for renal failure, breast, and cervical cancers and diabetic patients. It explored the hurdles decelerating the quality of palliative care service, explained the quality of the palliative care service, examined the status of the quality of the palliative care service and the patients' satisfaction. The quality of the service was investigated basically based on Donabedian's (2005) model of study of health service—it focused on health service quality [including palliative care service] of any aspects [structure, process and outcome].The model encompasses palliative care service and it is used for investigating health service including palliative care service. In addition, it has not been refuted so far. Furthermore, it has been used by Ministry of Health of Ethiopia as framework to prepare the standards of hospitals. Above all, Donabedian's model is a seminal or a ground-breaking work; it was used as a mode in this study.

Operational Definitions of Key Terms

Chronic disease: life-threatening disease [cervical and breast cancers, renal failure and diabetes].

Palliative care service: service provided to the chronic disease patients at Felege Hiwot Hospital to shield their symptoms and pain, and to improve their quality of life.

Quality of life: achieving and maintaining maximum potential physical, psychological and social health aspects and hope of living with a meaningful stance of life.

Satisfaction: worthy sensation due to the alleviation of the disease by the primary palliative care service

CHAPTER TWO: REVIEW OF RELATED LITERATURE

Under this chapter, the basic concepts of palliative, focus and goals of palliative care, quality of palliative care service, factors affecting the quality of palliative care service, quality of palliative care service, composition of palliative care service, ethical issues in palliative care service, empirical studies and theoretical framework have been included.

Palliative Care Service

Any of us face disease and pain and suffering follows. When a person becomes sick of any disease, he/she needs care. When the disease is chronic one, care is an obligation for the disease is horrifying, devastating and deadly.

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 aspects.
It provides relief from pain and other distressing symptoms— Curtails, cloaks or shields pain and it affirms life by improving quality of life of patients and regards dying as a normal process (Matzo & Witt, 2015; Mosadeghrad, 2013; Murphy, 2014 and Saeed, Ghafoor, Sarwar, Lodhi , and Ahmad, 2013).

Palliative care is a holistic care of patients and their families by a multi-professional team (doctors, nurses, palliative care specialists or physicians, cancer specialist, heart specialist, renal specialist counsellor or psychologist, spiritual care practitioner, social worker, among other care and support givers) that acts when the patient’s disease is no longer responsive to curative treatment. So is it an evidence-based health care service that improves the quality of life for patients, including their families, who suffer from chronic life-threatening illnesses (Centre to Advance Palliative Care, 2014). According to the World

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Health Organization (2015), palliative care is a kind of method to improve the quality of life of patients who face chronic diseases and their families.

Palliative care is an evidence-based health care service that aims at improving quality of life for patients who have chronic life-threatening illnesses and their family (Centre to Advance Palliative Care, 2014). It is evicting or ameliorating suffering, hopelessness and gloom line of thinking. According to WHO (2011), palliative care is an approach that progresses the quality of life of patients and their families facing an incurable disease with limited prognosis, and/or a serious illness through prevention and relief of suffering by means of the early identification, proper evaluation and rigorous treatment of physical problems such as pain, and psychosocial and spiritual problems. It is an interdisciplinary approach to maintain holistic care and quality of life of patients. It makes meaning of life and hope for the patients.

As Dangal (2014) elucidates, care of the dying was attributed to a physician; palliative care worldwide is rapidly developing specialty. It was Dame Cisely Saunders who began the work in 1948 and kept on establishing the first modern hospice—St Christopher's Hospice—in 1967. Palliative care was introduced in Canada in 1976 marking the extension of hospice principles into hospital and community settings. Palliative care emerged in the 1960s as consequence of the hospice movement in the United Kingdom. It, in Portugal, is a relatively recent phenomenon. The first inpatient unit arose in 1992 in a hospital in the centre of the country. The world wide spread of palliative care in high and low income countries has been remarkable; with the first hospital-based palliative care program in the USA beginning in the 1980s. In India, palliative care has been developing in various places since the mid-1980s (Matzo & Witt, 2015; Dangal, 2014; Matzo & Witt, 2015).

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According to Grant *et al*. (2011), there has been rapid progress in palliative care in Africa since the assembly of World Health in 2005 which identified palliative care as an urgent humanitarian need. It is recognised as a basic human right, and African countries are attempting to put it into practice. The Cape Town Declaration (2002), cited in National Palliative Care Guidelines (2013), affirmed that pain relief is a human right, and it testifies that it is an obligation to incorporate palliative care into national health care strategies. This prompted the formation of the African Palliative Care Association which declares that everyone with a chronic disease should have access to affordable and culturally appropriate palliative care.

The crux of the above review includes that palliative care was accredited as a basic human right for it is pain relief and hope ignition. So is it improving quality of life patients and vanishing symptoms. In other words, pain relief is humanism. In addition, it is claimed that incorporating palliative care into national health care strategies is an obligation. Furthermore, it is declared, for it is easier said than done, that everyone with a chronic disease should have access to affordable and culturally appropriate palliative care, but palliative care has not been paid attention in Ethiopia.

The essence of palliative care is specialized medical care to get relief from the symptoms, pain, and stress of serious illness. It affirms life, promotes quality of life, treats the person and supports the family. It directs the patients toward social functioning. Through the focused holistic, individualized, family and team view of care. It incorporates principles of person-centered care that involves acknowledgement of the individual patient being at the center of care, being respectful and responsive to patient’s circumstances in life, life story, preferences, needs and values, and integrating knowledge of the patient and the competence of the health care personnel to give the best for the patient.

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Focuses and Goals of Palliative Care Service

Palliative care has its own focuses. It focuses on physical, psychological, social and spiritual aspects of life to manage symptoms, to achieve pain relief and to promote quality of life. As it is a specialized medical care, it provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten nor postpone death and integrates the psychological and spiritual aspects of patient care (Matzo & Witt, 2015; WHO, 2016). Also, it 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 patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (Matzo & Witt, 2015; Mosadeghrad, 2013; Murphy, 2014 ; Saeed, Ghafoor, Sarwar, Lodhi , and Ahmad, 2013 & WHO, 2015).

The scope of palliative care includes some basic issues so as to improve the quality of life of patients. It focuses on patients' families because patients are typically part of a family when care is provided; the patient and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the patients' and families' personal, cultural, and religious values, beliefs, and practices, their developmental state, and their preparedness to deal with the dying process. It also focuses on high quality of service (Matzo & Witt, 2015; Mosadeghrad, 2013).

Palliative care activities are guided by the ethical principles of autonomy, beneficence, non-maleficence, justice, truth telling and confidentiality; standards of practice

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that are based on nationally accepted principles and norms of practice and standards of professional conduct for each discipline; policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines; and data collection and documentation guidelines that are based on validated measurement tools. Safe and effective service is the other focus. Palliative care activities are conducted in a manner that is collaborative; ensures confidentiality and privacy; is without coercion, discrimination, harassment or prejudice: ensures safety and security for all participants; ensures continuity and accountability; aims to minimize unnecessary duplication and repetition; and complies with laws, regulations and policies in effect within the jurisdiction, host, and palliative care organizations (Mosadeghrad, 2013; Murphy, 2014 ; Saeed, Ghafoor, Sarwar, Lodhi , and Ahmad, 2013 & WHO, 2015)

Also the service focuses on accessibility. All patients and families should have equal access to palliative care services wherever they live at home, or within a reasonable distance from their home, in a timely manner. There should be adequately resource. The financial, human, information, physical, and community resources are sufficient to sustain the organization’s activities and its strategic and business plans. Sufficient resources should be allocated to each of the organization’s activities. Palliative care needs collaborative activities. Each community is needed for palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership (Murphy, 2014; WHO, 2016).

The palliative care service should be knowledge based. On-going education of all patients, families, caregivers, staff, and stakeholders is integral to the provision and advancement of high-quality hospice palliative care. It should also be advocacy based. Regular interaction with legislators, regulators, policy makers, health care funders, other palliative care providers, professional societies and associations, and the public is essential to

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increase awareness about, and to develop, palliative care activities and the resources that support them. All advocacies are based on nationally accepted norms of practice countries. The service should be research based. The development, dissemination, and integration of new knowledge are critical to the advancement of high-quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations in effect within the jurisdiction that govern research and the involvement of human subjects (Mosadeghrad, 2013; Murphy, 2014; WHO, 2016).

The goals of palliative care are to provide relief from pain and other physical symptoms, to maximise the quality of life of patients, to provide physical, psychosocial, social and spiritual care, to rehabilitate the patients, to support patients economically by finding fund, to access drugs for patients and to facilitate bereavement. It also has a goal of supporting in funeral activities. To achieve these goals, the structure, process and outcome of a hospital should be fulfilled (Loitman, Sinclair and Fisch, 2011, Murphy, 2014; WHO, 2016).

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The service environment in the hospital is very complex with multiple interactions occurring internally between service providers in the delivery of any service to a single external client. Service quality is a measure of how well the service matches the patients' expectation of treatment and zeal to recover. Delivering quality service means confirming to the patients' expectations or addressing what the patients are in need on a consistent basis. Hospitals, as it is apparent, are concerned with the provisions of services rather than physical goods. As Mosadeghrad (2013) claimed, quality of palliative care is pleasing the patients regularly through efficacious, effective and efficient services according to the "latest clinical guidelines and standards" that meet the patients' needs. As Donabedian (2005) affirmed, health care quality, including palliative care service, is applying “medical science and technology” to accelerate acquiring improved health status and without risk, as stated above.

In the health care field, measuring quality care depends mainly on structure, process and outcome developed by Donabedian (2005) model. Structure comprises the characteristics of the resources, manpower and drugs and supplies in the health care delivery system and process consists of what is done to and for the patients and includes practice guidelines and aspects how patients seek to obtain care; outcome is the end result of care. It comprises health status, social functioning, resilience and general well-being of patients. In other words, the outcomes reflect the changes in health status—relief from symptoms or cure of a disease—and so does it comprise reduced morbidity and/or mortality, prevention of disease or accidents and maintaining patients’ satisfaction.

According to Bainbridge and Seow (2016), Palliative care, and more specifically end-of-life care, serves to address the physical, practical, psychosocial, and spiritual needs of dying patients and their families. The quality of this care is critical to reduce the burden of illness and moderate escalating health-care costs. Quality of Palliative care service includes adequate pain and symptom management, psychosocial support, avoidance of inappropriate medical interventions, and maintenance of quality of life for the patient and family, as well as their satisfaction with care. What Donabedian (2005) delineated as quality of palliative care encompasses the qualities elucidated by Bainbridge and Seow (2016) above. Donabedian (2005) came up with structure [infrastructure of a hospital, manpower and drugs and supplies], process [meaningful communication and service provision] and outcome [improved health status, wellbeing, social functioning and satisfaction].What Donabedian (2005) postulated has not yet been refuted by any researcher and it was used by Ethiopian Ministry of Health to prepare the standards of service quality of hospitals, including the standards of quality of palliative care service.

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Factors Affecting Quality of Palliative Care Service

As stated elsewhere in this paper, palliative care service is measured through structure, process, and outcome to achieve pain relief, to manage symptoms and to promote quality of life of patients. When we talk about quality of palliative care service, we mean the result is found from the interweaving service of structure, process, and outcome. Though the three components of palliative care service are available, the patients may not be satisfied. In other words, even if there are structure, process, and outcome of the health service, there may not be a quality that brings about the health progress of the patients in view of factors that affect the quality of the service. The gap here is that the status of palliative care service and factors that affect it have not been studied from the patients perspectives. Nor have the burdens on the patients, due to the factors that affect the palliative care service, been studied.

Saeed, Ghafoor, Sarwar, Lodhi, and Ahmad (2013) confirmed that the inconsistent provision of primary palliative care service and access mechanisms, skills, physicians behaviour directly affect customers' satisfaction. Wanjau, Muiruri & Ayodo (2012) found out that low employees' capacity, low technology adoption, ineffective communication channels, and insufficient fund affect the delivery of quality service of the palliative care to patients. Widayati, Tamtomo, and Adriani (2017) asserted that the low income of patients and poor communication between patients and service providers affected the palliative care service (outcome) quality. Mosadeghrad (2014) argued that personal factors of the provider and the patient, and factors pertaining to the healthcare organization, healthcare system, and the broader environment affect the palliative care service quality. Mwonjoria (2014) found out that, regarding customer care factors, approachability of staff, caring, listening, friendliness, efficiency, knowledgeable staff, flexibility, staff initiative, empathy, attention, language used for communication, explanation of procedures and prompt passage of new information had a significant influence on the utilization of private health facilities and concerning price-related factors, equipment costs, cost of prescription drugs, laboratory test fees and doctor‘s fees significantly influenced the utilization of palliative care service. Nyambura (2016) asserted that employees’ capacities, physical environment (infrastructure, adequate hospital’s equipment and availability of drugs, the work environment was not safe and free from hazards, but instead dangerous, therefore, it hampered the provision of quality palliative care services at the hospital, beds, beddings, and amenities such as washrooms), staff development, staff work schedules and communication affect the quality of palliative care service.

The authors found out that the factors affecting health service in general and quality of palliative care service in particular. They should have analysed the impact of the factors via the health service on the patients’ physical, social, and psychological health aspects. In addition, they ought to have revealed what distortion the patients faced in view of the factors the authors found out. Identifying only the factor that affects the health service and the quality of the palliative care doesn’t reveal the burdens that the patients faced.

On the other hand, there was no an empirical study conducted on the hurdles decelerating the quality of the palliative care service, the status of quality of palliative care service and the patients’ satisfaction with the palliative care service. This study, therefore, was conducted to bridge the gaps stated so far.

Quality of Palliative Care

Report of Institute of Medicine (2013) specified aims of a high quality medical care system that are more specific: safe–avoiding injuries to patients from the care that is supposed to help them, effective–providing services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit (avoiding underuse and overuse), Patient-centred–providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions, timely–reducing waits and sometimes harmful delays for both those who receive and those who give care, efficient–avoiding waste, in particular waste of equipment, supplies, ideas, and energy, equitable–providing care that does not vary in quality because of personal characteristics, such as gender, ethnicity, geographic location, and socioeconomic status.

The quality of palliative care service includes the above contents. They describe two related, but distinct types of excellence; technical and interpersonal (Donabedian, 2005). Interpersonal excellence refers to care that meets the information, emotional, and physical needs of patients in a way that is consistent with their preferences and expectations. It is that kind of care which maximizes an inclusive measure of patient well-being. The technical aspect focuses on the clinical competence.

Quality is the measurement of actual level of service rendered and the efforts to modify when necessary the provision of these services in the light of the results of the measurement. It is the degree to which patient care services increase the expectation of patient and minimizes undesired outcomes. In other words, it is maintaining patients' expectations, health and satisfaction.

Donabedian (2005) abridged and explained his work about the components of quality. He suggested that one could assess whether high quality care is provided by examining the structure [infrastructure, manpower, equipment, drugs and supplies] of the setting in which care is provided, by measuring the actual process [interaction between nurses and doctors, and patients, the service delivery and involving patients in decisions in a way that is consistent with their preferences] of care, and by assessing what the outcomes [a patient's health status or change in health status e.g., an improvement in symptoms or mobility resulting from the medical care received. It also comprises intended outcomes, for instance, the relief of pain and unintended outcomes, such as complications] of care are.

The quality of palliative care service, therefore, comprises structure, process and outcome to achieve pain relief, to manage symptom, to improve the quality of patients and to help patients holistically.

Composition of Palliative Care Team

Effective palliative care comprises an experienced, multi-professional team. It is composed of a general practitioner or a doctor, nurse, palliative care specialist or physician, cancer specialist, heart specialist, spiritual care practitioner, social worker, nephrologist, oncologist, psychologist, diabetic specialist, massage therapists, Pharmacists, Volunteers, therapists, nutritionists and support givers (Mosadeghrad, 2013; Murphy, 2014; O’mahony *et al*., 2010); usually, the size and the complexity of a palliative care team depend on the needs of the patient.

The palliative care team provides any kind of assistance and care for those patients who have progressive, terminal and life-threatening diseases (Klarare *et al*., 2013). In normal circumstances, the palliative care team attends to the patients who are within a particular palliative care facility or based on special appointments. On the other hand, a palliative care team visits the patients in their respective homes. All the members of the palliative team liaise and coordinate with one another in the process of care to enhance maximum care and comfort for patients. Nurses and other health care professionals are concerned with ensuring that patients receive and access to medicines and other treatments for pain and symptom relief. In addition, the palliative care team is entitled to help patients recover from any fears, conflicting emotions, guilt, pain, hopelessness, negative attitude of life, anxiety, depression , panic disorder, threats, acute stress disorder, post-traumatic stress disorder, social phobia, obsessive compulsive disorder, sleeping disorder and worries (Matzo & Witt, 2015; Nakanishi, *et al.*, 2015).

This reveals that palliative care team members focus on deconstructing gloom line of thinking and deal with cognitive restructuring to improve the life skill of patients that lets them entertain meaningful and quality of life. In order for the patients to live meaningful life, the team members ought to incorporate the logic of rhetoric (ethos, pathos, and logos). Eventually, they should apply Socratic questioning method to make sure that the gloom line of thinking has been deconstructed and normal line of thinking has developed.

Ethical Issues in Palliative Care

The fact that we die is nothing new. What matters is not our death. Illness and death are part of human experience. In contrast, how we get sick, suffer from pain and how family and community members respond matter. The nature of illness has changed and so too has dying. Palliative care responds to these changes and uses the tools developed by modern medicine to meet the needs of the dying to relieve suffering and enhance quality of life. Dying is the most horrifying and devastating phase of life and people have the right to expect quality of life to ensure death with dignity occurs. Each activity of palliative care should be based on ethics to bring the desired results of a health care (Dangal, 2014; MacLeod, 2006; Murphy, 2014).

While carrying out palliative care service activities, nurses and other health care professionals are faced with lots of challenges as they endeavour to provide care to the elderly and other patients. Here, therefore, comes ethics. Ethics are the guidelines and codes that are provided for physicians as they carry out their daily duties and responsibilities. In palliative care, the palliative care team is normally faced with issues related to decision-making, autonomy, and all aspects of palliative care (De Caestecker, 2012; Matzo & Witt, 2015; Murphy, 2014; Nakanishi, *et al.*, 2015). During palliative care, various ethical issues are supposed to guide the palliative care team in supporting and caring for the terminally ill patients.

There are ethical guide lines for the palliative care team: clinical integrity where the palliative care team should and must care for the whole person, the palliative care team should respect the decisions of the terminally ill patients, the needs of the patient, his or her family, and friends should always come first and treated with urgency, the palliative care team should ensure that the treatment method and the care given to the patients achieve maximum benefit to the patient , the dignity of the patients should always be upheld, the palliative care team should be true and honest to the patients; a patient under palliative care has the right to choose or refuse the treatment given by the palliative care team. All the fundamental rights of terminally ill patients should be respected. The team members should keep confidential the personal issues of the patients. Whatsoever the service is, it should be done when the patient believes in it (Ko, *et al.* 2011; Matzo & Witt, 2015; Murphy, 2014; Nakanishi, *et al.*, 2015).

The palliative care team members should be abided by the ethical principles of palliative care: autonomy, making one's own decision; beneficence, intending to do well; non-maleficence, intending to do no harm and justice, providing equal access. Although the palliative care service is helpful for the patient, he/she has the right to refuse the service. The service is not provided without the informed consent of the patient. The medical obligation should be implemented. Generally, the health professionals must keep their sworn obligation for their patients.

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Empirical Studies on Palliative Care in Ethiopia

Few researches were conducted on palliative care from nurses' point of view: Hiwot, Murugan, Fissiha, Mignote and Desalegn (2014) claimed that the nurses had had poor knowledge and practice, but their attitude towards palliative care was constructive. Samuel, Hiwot, Tesfaye and Tadesse (2016) conducted a study on "Nurses' Knowledge, Attitude, Practice and Associated Factors towards Palliative Care: In the Case of Amhara Region Hospitals" and had found out that the majority of nurses had poor practice of palliative care. The third study, entitled Palliative Care Practice and Associated Factors among Nurses Working in Jimma University Medical Center South-West Ethiopia (2017), was conducted by Temamen , Yeamanuelwork and Admasu (2018) and they found out that nearly two third of the nurses had poor palliative care practices. The three studies are nearly the same. The first two studies are the same in title and focus area. One is the mirror image of the other or one seems to be the replication of the other without extension. The third one is nearly similar to the two studies. The studies are cliché as they exploited the same issue and were conducted with the same fashion of study. The gap here is that the status of palliative care was not investigated from the patients' point of view. The hurdles that decelerated the quality of the palliative care service, the status of quality of the palliative care service and the patients' satisfaction were not investigated. This study, therefore, focused on the aforementioned issues.

Promotion of hope and quality of life are essential component of Palliative care for patients experiencing chronic disease. Palliative care service for breast and cervical cancer, diabetes and renal failure patients is the centre of this study. Cancer-related pain is not adequately managed and a number of patients suffer from unrelieved pain (Thomason *et al*. 1998 and Sela *et al*. 2002, as cited in Bostrom *et al*., 2004). Cervical cancer occurs over 40, but it can occur at any age. About one in 200 women will develop cervical cancer before the age of 75 (Australian Institute of Health and Welfare, 2017). Patients with end stage renal and diabetes diseases do not cure and this disease affects the patients' and their families' lives with serious physiological, psychological and socioeconomic implications (Talas & Bayraktar, 2004).

The fight against cancer is multifaceted and the aggregating burden of the disease make it one of the most difficult social problem and serious health threats to the population in low and middle income countries (Gafer and Elhaj, 2014). As Palat and Biji (2005) state, overdue and poor treatment, lack of resources to carryout study, poverty and the poor status of women in society contribute to a high prevalence of unalleviated pain from cancer of the cervix. The disease process can be associated with several types of pains that are difficult to control. Psychosocial problems worsen the pain experience.

Theoretical Framework of the Study

Quality of palliative care comprises well-furnished setting, qualified manpower, drugs and supplies, guideline, well-structured interaction, pain relief, symptom management and quality of life. In other words, it includes tangibles, reliability, responsiveness, courtesy, empathy, assurance and Credibility (Beresford, Adshead and Croft, 2015; Foley and Gelband, 2014; Payne, Seymour, Ingleton, 2015). But, these components have been encompassed in Donabedian's (2005) model of health service in such a way that they can easily be measured.

The Donabedian's model for quality of care was used as a theoretical framework in this study to assess the quality of the primary palliative care service for chronic disease patients at Felege Hiwot Hospital. Donabedian model (2005) affirmed that there are three essential factors in investigating quality –structure, process, and outcome. Structure is defined as the places where medical care takes place and the instrumentalities of each product. In other words, it comprises infrastructure, manpower, drugs, and supplies. Process refers to the set of activities that take place, on the one hand, between professionals and, on the other, between professionals and patients. It includes technical and interpersonal aspects. Process reflects the way the system and processes work to deliver the desired outcomes. For example, the length of time a patient waits for a senior clinical review, if a patient receives certain standards of care or not, if the staffs wash their hands, recording of incidents and acting on the findings and whether patients are kept informed of the delays when waiting for an appointment.

Outcomes are the consequences for the health and well-being of individuals and society (Donabedian, 2005) and include clinical outcomes, quality of life and satisfaction with the care provided. Outcomes reflect the impact on the patient and demonstrate the end result of your improvement work and whether it has ultimately achieved the aim(s) set. Examples of outcome measures are reduced mortality; reduced length of stay, reduced hospital-acquired infections, adverse incidents or harm, reduced emergency admissions, and improved patient experience. Donabedian (2005) proposed that there are relationships between structure, process and outcome constructs based on the idea that good structure should promote good processes and the good process should, in turn, promote good outcomes. In other words, Donabedian believed that structure measures have an effect on process measures, which in turn affect outcome measures.

According to Donabedian's pioneering work (2005), it is inferred that structure and process have an impact on the outcome. The structure has impact on process and outcome and process has an impact on outcome. Hence, it would be possible to build a causal model where each factor is a necessary condition for the next factor.

This model implies that the structural characteristics of the places where care takes place may influence the process of care so that its quality decreases or increases. Changes in the process of care will, in turn, have an effect on patients' health. Donabedian recognizes the existence of causal links between factors but also recognizes the arbitrariness of his model. The Donabedian model suggests a relationship where each factor is affected by the previous factor. But he states that the model is a guide–not a straightjacket –and encourages researchers to develop a model from original thinking (Donabedian, 2005).

Donabedian defines Structure as the professional and organizational resources associated with the provision of health care (e.g. availability of medicines/equipment and staff training); process as the things done to and for the patient (e.g. defaulter tracing and hospital referrals) and Outcome as the desired result of care provided by the health practitioner (e.g. patient satisfaction with quality of care). Donabedian distinguished between two types of outcomes: i) technical outcomes, which are the physical and functional aspects of care, such as absence of complications and reduction in disease, disability and death; and ii) interpersonal outcomes which include patients' satisfaction with care and influence of care on patient's quality of life as perceived by the patient. Donabedian's (2005) framework was used investigate the quality of palliative care service at Felege Hiwot Hospital not only because it is the dominant framework for evaluating the quality of medical care, but also it is comprehensive in its nature. In addition, this model was used in this study because it had not been refuted so far and had been used by Ministry of Health of Ethiopia as a model to prepare standards of service quality for hospitals.

The conceptual framework of the study was developed from the literature reviewed. It indicates the relationship of the concepts studied. The hurdles were dealt with the first objective and the structure, process, outcome, symptom, pain and quality of patients' lives were about the quality of the primary palliative care service were explored based on the second objective; the status of the quality of the primary palliative care and the patients' satisfaction were dealt with the objectives three and four respectively.

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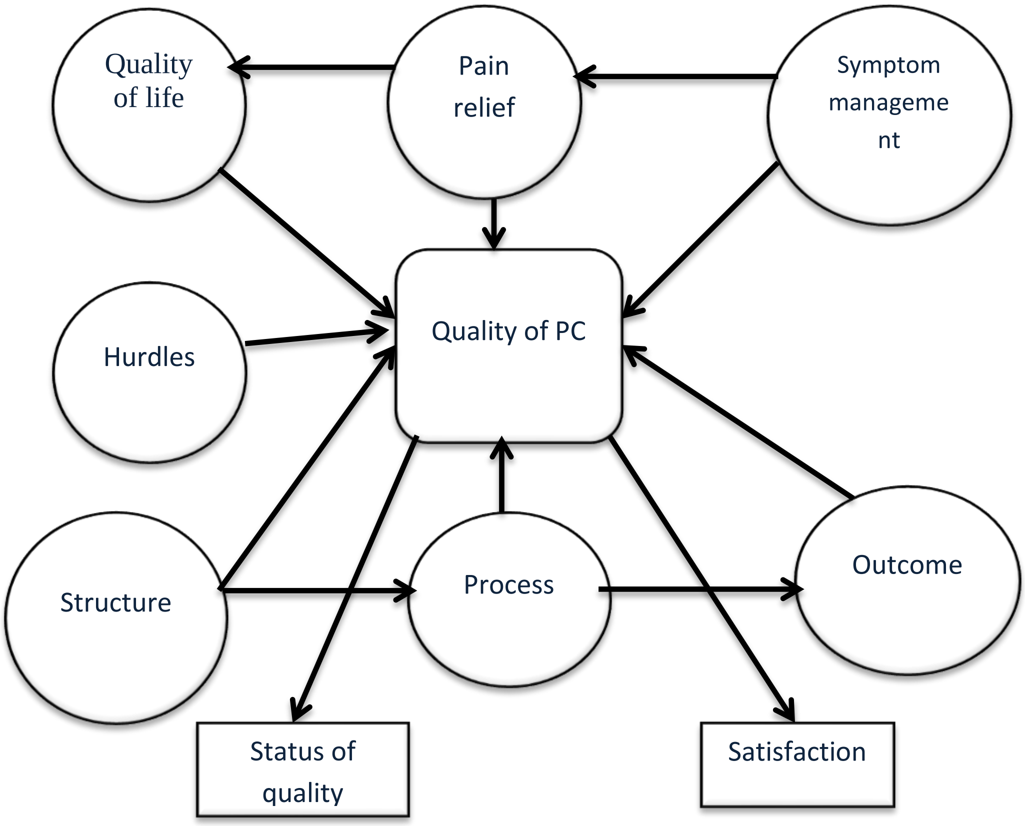
Figure 1Conceptual framework of the study developed from the literature review



CHAPTER THREE: RESEARCH METHODOLOGY

Description of the Study Area

The study was conducted at Felege Hiwot Referral Hospital found in Bahir Dar Town. According to the information found from plan, monitor, evaluation and health office of Felege Hiwot Hospital, the hospital was built from 1953-1955 Ethiopian calendar by the help of the government of Germany and began its service as soon as its construction was finalized. The hospital had been constructed to serve about 25,000 people; however, it served about five million people. Since the hospital served for about 56 years, the internal facilities including the water lines and tanker, electric and sewage disposal tubes, the building and the medical equipment have become old and dismantled. In addition, the hospital lacked modern medical equipment and ICT service. The structure, manpower, materials and supplies and the infrastructure were not up to their standards. The problems stated so far decelerated the provision of the primary palliative care service. According to the plan, monitor, evaluation and health office, the hospital had 6 wards with 263 standardized beds and more than 40 unstandardized beds (temporary beds rooms outside) and more than 20 different medical service rendering rooms. As the human resources centre attested, there were 353 male and 417 female medical employees and 58 male and 114 female administrative workers in the hospital. The number of chronic disease patients increased in this hospital from year to year.

Table 1 Rate of Chronic Disease Patients at Felege Hiwot Hospital [2008-2010]

Disease	Year								
	2008			2009			2010		
	M	F	T	M	F	T	M	F	T
Diabetes	80	105	195	894	717	1611	805	443	1248
Cervical cancer	-	1	1	-	8	8	-	149	149
Breast cancer	-	36	36	6	66	72	7	271	278
Renal failure	18	23	41	19	25	44	40	26	66

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The setting was chosen for it was the only referral hospital where a number of chronic disease patients were treated in Bahir Dar; it was also the only hospital primary palliative care service was provided.

Research Approach

To achieve the objectives of this study, a sequential exploratory mixed methods research design was used. The mixed method was used for some reasons. First, mixed method design was conducted to make solid arguments—either quantitative or qualitative could be insufficient because the issue under investigation had not been studied from the patients' perspectives. In addition, mixed method was used to make persuading conclusion from multiple perspectives. It provided different pictures about the palliative care service. Above all, the mixed design mirrored the real circumstances of the service in the hospital with regard to the chronic disease patients.

It has two phases. In the first phase, the qualitative research had been conducted and the instrument was developed from the findings. In sequential exploratory mixed methods, the emphasis is on the qualitative phase whose findings are tested in the second phase (Hesse-Biber, 2010); this process can be iterative. Hanson *et al*. (2005) avowed that qualitative data proceeds quantitative and the qualitative data are given greater priority. "The researcher first begins with a qualitative research phase and explores the views of participants. The data are then analysed, and the information used to build into a second, quantitative phase. The qualitative phase may be used to build an instrument that best fits the sample under study" (Creswel1, 2014, p.44). As there were no previously conducted studies on the quality and the status of palliative care for chronic disease patients, sequential exploratory mixed method design was the appropriate design to study the issue. Data analysis is connected, and integration occurs at the data interpretation stage and in the discussion (Hanson, Creswell, Clark, Petska, & Creswell, 2005). The findings of this study were integrated in the discussion section.

According to Creswell (2014), "… .The qualitative phase may be used to build an instrument that best fits the sample under study, to identify appropriate instruments to use in the follow-up quantitative phase or to specify variables that need to go into a follow-up quantitative study" (p.44). As elucidated in Creswell (2012), "The mixed methods researcher emphasizes the qualitative data more than the quantitative data. This emphasis may occur through presenting the overarching question as an open-ended question or discussing the qualitative results in more detail than the quantitative results" (p.543). The mixed method design, therefore, was used to gain multiple perspectives, to enhance the meaning of the results, to contextualize information, to gain a more understanding of the problem, to compare, validate or triangulate results and examine processes and experiences with the outcome of the study.

Qualitative Phase

Designed as a case study, the qualitative phase had been conducted first for the study was mainly a case inquiry. A case study was used to explore, understand, and explore the hurdles that were decelerating the quality of the primary palliative care service and to explain the quality itself. As a case study, according to Simons (2009), is an in-depth exploration from multiple perspectives of the complexity and uniqueness of a particular phenomenon in a 'real life, it was used to explore the hurdles and to explain the quality of the primary palliative care service in depth at Felege Hiwot Hospital.

Study Participants

The population of this study included patients of chronic diseases at Felege Hiwot Hospital: renal failure, cervical and breast cancers and diabetes patients who have been treated at the hospital; these patients were selected because the diseases were the most prevalent ones. To select the participants, purposive sampling technique was applied. In this sampling technique, participants were intentionally selected by the researcher based on the assumption that they could be information rich .Of the different types of this sampling technique, intensity sampling technique was applied. It looks for information-rich cases, and the ones that are more typical than those at the extremes (Gray, 2004).

Based on common threats (being chronic disease patients and whose pain reached the highest chronicity) and characteristics (taking lifelong medicine and who have been treated regularly for longest period) (Creswell, 2012) was employed. The inclusion criteria were being chronic disease patients (renal failure, diabetic mellitus, breast and cervical cancers), the degree of chronicity (attested by the doctors/ nurses), being treated at this hospital at least for six months regularly (those who had treatment for longest period were prioritized) and being willing to be interviewed and tape recorded and; based on this, 3 patients of diabetes, 2 patients of renal failure who were under dialysis, 2 patients of breast cancer and 2 patient of cervical cancer were selected. The exclusion criteria included patients with less than six months of service, less severity of pain and irregular service and medicine intake. Four key informants were selected, too. The coordinators of the dialysis and cancer treatment units, senior nurse from diabetes mellitus patients' treatment centre and a nurse and coordinator from physiotherapy unit were selected respectively. As coordinators, the three nurses were supposed to be information rich and the same prediction was associated to the fourth nurse who was selected from diabetes patients' treatment centre.

Methods of Data Collection

In this phase of the study, two data gathering instruments were used: in-depth interview, and participant observation.

In-depth Interview

It was conducted to have intensive individual interview with interviewee to explore their perspectives or attitudes about a particular issue, the quality of the primary palliative care service in this case. This data gathering instrument was helpful to gather detailed information about the patients' thoughts and to construe their perspectives about the issue studied. Therefore, nine participants were interviewed face to face and separately. In addition, the researcher kept accounts of field notes revealing the emotions, facial expressions and gesture of the participants and the condition of the compound, the waiting room and the examination rooms where the patients had been treated. Interview was held once at the participants' residences between March 3 and April 20/2019. The data gathered through interview was transcribed and translated into English, and including the key informants' interview, the translation data included 65 pages.

Key Informant Interview

Key informant interview was the other method used to gather data. The instrument used had been evaluated and verified by a health officer ahead of the interview. In this study, four participants who were likely to provide detailed information about the challenges that decelerate the quality of the palliative care service for the chronic disease patients were interviewed. The interview was held on April 10, 13 and 17/2019 in the examination rooms and a store; the interview data was used to strengthen the data gathered from the patients.

Participant Observation

The researcher prepared a structured observation checklist with a remark column for justification and nominated two simulated patients who were nurses working in one of the health centres in Bahir Dar Town to observe the diabetes and the cancer patients' health service procedures and the status of the examination rooms. This task was done to gather data which were used to triangulate the data gathered from the patients.

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The researcher informed the simulated patients the objectives of the research and what they had to do, but, at the very beginning, they refused what the researcher asked them to do. The researcher informed them that, though they acted as if they had been patients (one as cervical and the other as breast cancer patients), the treatment could be significant for them as a check-up for their own health status. They were even reluctant to act as though they had been patients. After meeting them four times and discussing the issue, the researcher persuaded the nurses. He also persuaded them to debrief for the deceptive observation to promote transparency by explaining the deception and its rationale. Taking the observation checklist and acting as though they had been patients, they joined and observed the aforementioned examination rooms and the procedures the doctors and the nurses followed while treating the patients [themselves]. When they finished being examined and the observation, they filled in the checklist, but eventually, they refused to make debriefing. On the other hand, it was difficult to get a simulated patient of renal failure because it could be impossible for a person who would be a simulated patient to have a dialysis service. In other words, it was difficult and impossible to be a simulated patient of renal failure as the person could not be under dialysis procedures. The researcher, therefore, had a medicine student of Bahir Dar University observe the status of the dialysis centre and he filled in the checklist. Also, the researcher let this student observe the laboratories and fillin the checklist.

Data Gathering Procedures

The first process of data gathering was selecting the participants of the study. Based on the inclusion criteria (severity of the pain, regular service, longest time service), the participants had been selected. The researcher asked the coordinators of the four units (dialysis, diabetic and cancer patients' treatment centres) to give him the list of the patients with the degree of chronicity of the diseases and their addresses. Based on the inclusion criteria set, the participants for in-depth interview were selected and the researcher met the participants, introduced himself and told them that he wanted them to take part in the course of the research. To build strong rapport, the researcher appointed the participants after three days. When he met them for the second time, he informed them about the research, especially about the objectives; he assured them that the interview would only be used for the research purpose and confidentiality would, for sure, be kept; he asked them for their consent. They agreed to take part in the course of the research. He again appointed them to meet after three days. When he had met them for the third time, he got them signed the informed consent agreement. Then, the researcher, going to the residences of each participant and asking for their willingness to be tape recorded, interviewed them. Tape recording was conducted and note was taken alongside. The interview was conducted on the basis of the appointment to make it comfortable with them.

Interview setting was arranged earlier according to their interests. The researcher engaged with the interviewee by posing questions, listening to their responses, and asking follow-up questions and probes based on their responses. In addition, the interview sessions were supported by an open-ended guide framed based on the specific research questions prepared in English and translated in to Amharic, the mother tongue of the interviewee. The focuses of the questions in the interview were snags decelerating the quality of the palliative care service and the standards of the quality of the palliative care service itself.

During the interview, the researcher listened to the interviewee attentively, focused on what the interviewee said, and showed proper acceptance of their ideas. He concluded the interview session with gratitude for their contributions they made to this study and for devoting their time.

Concerning the observation data gathering procedures, the researcher, as it was stated earlier, employed two simulated patients who were nurses working in one of the health centres in Bahir Dar Town. He gave them orientation about the data they would gather; so did he tell them the objectives of the study. According to the orientation, the two nurses (Alem and Soleme, pseudo names) took service identification card from the hospital. Alem acted as if she had been a patient of diabetic mellitus and Soleme acted as though she had faced breast problem. Both of them were admitted in the exam rooms, diabetic mellitus and breast cancer patients' examination rooms, respectively and were examined; thereby, they carefully examined the room, what the doctors and the nurses were doing and she also observed the equipment and the conditions in the rooms. Eventually, they filled in the observation checklist and submitted it to the researcher. Regarding the observation data gathering procedures in the dialysis centre, the researcher employed a medicine student who was there for an internship. Giving orientation, the researcher got the student fillin the checklist within a week's time while doing his internship activities and submitted it to the researcher. He also observed the laboratories and filled in what he had observed.

Data Analysis Techniques

In the qualitative part of the study, thematic analysis, analysis that gives an opportunity to understand the potential of any issue more widely (Marks and Yardley 2004), was applied. The data were gathered through interview and observation from the nine chronic disease patients; [interview quitted at the 9th interviewee for the data were saturated], and from the four key informants. The data was transcribed by an agent employed by the researcher and translated by the researcher himself. The data was dissected and was coded using by QDA Lite miner. The themes were identified based the emerging issues from the analysis.

The data was transcribed and translated. Using the Microsoft word, the emerging concepts were identified and highlighted by the new comment and track changes. In addition, the data were fed to the software and the concepts highlighted [dysfunctional infrastructure and interaction, incapacity, scarcity of drugs and supplies, lack of man power, long waiting time and medical errors] were coded under hurdles and [quality of life, symptom management, pain relief, not holistic, physical aspect, social aspect and satisfaction] were coded under primary palliative care. The coded issues had been categorized and the themes were made. Then, the themes were explained analytically and meaning was made.

Ensuring Data Trustworthiness

The researcher used a variety of techniques to establish credibility, and dependability of the study. The creditability of the study was ensured by adapting well-established methods, developing familiarity with the research work via preliminary visits to research participants, developing the scheme of encouraging informants to be free, honest and frank and questioning iteratively

In addition, the rsearher developed open-ended interview items from the available literature and his own experience that were used as a guide. This meets the assumption that when performing as a discovery-oriented research instrument, qualitative researchers tend to construct study-specific sets of questions that are open-ended in nature so the investigators provide openings through which interviewees can contribute their insiders' perspectives with little or no limitations (Chenail, 2011).The researcher, being free of bias, interviewed the participants in such a way that they could state their perspectives about the palliative care service. The various perspectives about the primary palliative care were taken because the consideration of multiple perspectives of using interview and participant observation for triangulation purpose is believed to increase the validity of the data Creswell (2007). Also, careful scrutiny of the methods and the data helped the researcher substantiate the trustworthiness of the interpretations. The researcher kept on taking field notes during the interview and observation of the hospital and he applied bracketing (i.e., putting his perceptions, personal beliefs and bias aside) past experiences (Saldana, 2011).

Moreover, the researcher had the study examined by his peers. He worked together with colleagues (PhD classmates) who held impartial views about the study. The impartial peers examined the final report and general methodology. Then, they gave him feedback to enhance credibility and ensure quality. He let his colleagues to detect overemphasized and underemphasized points and vague descriptions, general errors in the data and biases or assumptions made by the researcher. The researcher, then, applied rich and thick description. Furthermore, to ensure dependability, sections devoted to research design and its implementations were included.

The Quantitative Phase

Research Design

The researcher employed cross-sectional survey design; so he collected data at one point in time. “Cross-sectional designs evaluate a program, such as a survey that provides useful information to decision makers” Cresswell, 2012, p.379). The service (palliative care) is the health program that was run to improve the health status and the well-being of the patients. This study, therefore, was designed as cross-sectional survey.

Study Population and Sample Size Determination

Regarding the participants of the quantitative part of this study, the population included 576 patients, including the patients who had been selected as participants of the qualitative part of the study. There were 55 renal failure, 125 cervical cancer, 179 breast cancer and 217 diabetes patients who had dialysis, chemotherapy, treatment and follow up regularly at the hospital and the number of patients might have varied for patients who sought treatment increased every week, but this study focused on the aforementioned population (576 patients) because these patients took the palliative care service regularly. Sample was selected from each stratum of the patients. Yamane’s formula ($N=N/1+N (e^2)$) was used to decide the sample size from each stratum: diabetic, renal failure, breast and cervical cancers patients. Then, the individual participants were selected from each stratum in simple random sampling method.

The sample size of the study was 236. This sample was taken based on the formula $n = N/1+N(e)^2$ from each stratum. The sample included 23 renal, 73 breast cancer, 51 cervical cancer, and 89 diabetes patients.

Data Collection Instrument

The instruments used to gather patients' satisfaction of palliative care were developed from the findings of the qualitative data. The questionnaire included different sections. The questionnaire to gather data about the quality of the primary palliative care service included 10 items about structure, 15 items about process and 10 items about outcome. In sum, the questionnaire included 35 items. The questionnaire about the level of satisfaction of patients with the primary palliative care service included 17 questions.

Data Gathering Procedures

To gather the quantitative data, the researcher reviewed the admission and discharge record of each unit. He identified the number of patients from each type of disease; so did he identify the sample size using the sample determination formula. Based on the list, the researcher selected the participants in simple random sampling method from each stratum (diabetic, renal failure, breast and cervical cancer patients). Taking the address from the list, the researcher gave the list of the patients to the three medicine students who were employed as data gathering agents. The agents [medicine students] met the participants at the hospital based on their [participants'] appointment of health service and got the questionnaire filled in within two weeks' time. Some of the participants who were selected from renal failure (five) and cervical cancer (three) patients could not fillin the questionnaire that time due to the chronicity of their illness. The researcher went to those patients residences. Visiting them, the researcher got them fillin the questionnaire.

Data Analysis Techniques

In the quantitative part of the study, descriptive statistics were used to summarize the data. The findings of the descriptive statistics were not solid enough to answer the research questions clearly, to infer to the population and to make conclusions. Therefore, asserting that their assumptions had fulfilled, the researcher, to answer his research questions, used one sample t-test [for objectives 3 and 4], and one way ANOVA [for overall analysis in terms of the types of diseases].The statistical tests were set at 2-tailed and alpha level of 0.05. The questionnaire had five categories in length. As individual rating items with numerical response is treated as continuous data, and as the aggregated rating scales is treated as continuous data, too (Harpe, 2015), the data was transformed in to scale and the aggregated data was analysed.

Validity and Reliability of the Instruments

Concerning the validity of the instrument, the researcher got the instrument commented by his advisor and he admitted and considered the comment. In addition, he gave the instrument to a health officer [to get it commented its content validity], a psychologist [to get it commented its content of psychological aspects] and an English instructor who is his PhD classmate [to get it commented its face validity]. They commented the instruments; the researcher admitted and considered their comments.

The reliability of the instrument [30 questions for quality of palliative care service and 15 questions of satisfaction] was pilot tested at Gondar Referral Hospital. The reliability of the questioner was acceptable. The Cronbach's alpha value of structure, process, outcome and primary palliative care satisfaction were 0.747, 0.917, 0.907and 0.907, respectively. The values are in the acceptable range. Then, based on the pilot test and the comments he had got, the researcher refashioned the instruments—the questions for quality were 35 and the questions for satisfaction were 17.

Ethical Consideration

With regard to ethical consideration, the researcher took two broad ethical responsibilities when he conducted this research: scientific responsibility for following established guidelines and conducting research that would yield argument worth knowing and the researcher's engagement with the patients.

In addition, the researcher, taking the ethical clearance from the hospital medical director, approached the participants with a written letter approved by Social work Department of Bahir Dar University. The objectives of the study and their roles in the study were informed to them. They were also told that, to keep confidentiality, pseudo names would be used. Informed consent was taken in two ways: in a written form and verbally from key informant interviewee by asking them to take part in the research course work and to be tape-recorded while interviewed.

Moreover, he protected the rights of the study participants (the patients) such as refusing to respond some questions and to withdraw from the study endeavour any time they wanted; fortunately, they kept on participating in the research endeavour; they did not refuse responding any question and they did not withdraw from the research endeavour.

Limitation of the Study

The study achieved its intended objectives, but it should be considered with its limitations. Despite the presence of many chronic diseases, this study focused on four types of chronic disease patients. In addition, the study was conducted in a single setting: Felege Hiwot Hospital. Moreover, the study did not analyse the laboratory result of the patients. These limitations could decrease the provision of comprehensive findings and their explanations in the area. In addition, the researcher should have had the simulated patients make debriefing as soon as they had finished the observation. This could also be the limitation of the study. Finally, the researcher's lack of experience in conducting studies on health-related issues might impose its own limitation on the study.

CHAPTER FOUR: FINDINGS OF THE STUDY

Profile of the Participants

A total of 13 people took part in the qualitative part of this study, nine chronic diseases patients and four key informants. Four of the chronic disease patients are male and five of them are female. Hune and Mulu were renal failure patients; Birtukan, Mohammed and Ayele were diabetes patients; Sofia and Kal were breast cancer patients; Hilina and Lemlem were cervical cancer patients. The table below shows the detail demographic characteristics of the patients.

Table 2 Background Characteristics of the Participants

Participant	Sex	Age	Disease	Educ	Marsta	Service in year	Job
Hune	M	52	Renal failure	MA	Married	3	Clerk
Mulu	F	31	Renal failure	8th grade	Married	Six months	labourer
Birtukan	F	61	Diabetes	4the grade	a widow	15 years	a housewife
Mohammed	M	63	Diabetes	Diploma	Married	9 years	Judge, a sharia court
Ayele	M	61	Diabetes	Degree	Married	4 years	clerk
Sofia	F	41	Breast cancer	4th grade	a widow	3 years	Labourer
Kal	F	37	Breast cancer	Degree	Married	3 years	Eng teacher
Hilina	F	33	Cervical cancer	Degree	Married	2 years	Teacher c& eth educ
Lemlem	F	38	Cervical cancer	Degree	Married	2 years	Civil servant

With regard to the three key informants, the first one [named Hana] was a BSC nurse and coordinator of cancer patients' treatment center. The second one [named Yelibe] was also a BSC nurse and coordinator of the dialysis center. The third one [named Beza] was a BSC nurse who has a long period of work experience in the diabetic case treatment center. The fourth one [named Bekalu] was a BSc nurse and coordinator of a physiotherapy center.

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With regard to age and marital status and occupation of the key informants, Hana was 36. She was a BSC nurse and married and had a son and a daughter. Yelibe was 38 and she was a BSC nurse. She was married and had 2 sons and a daughter. Beza was 27; she was a BSC nurse. She was married and had a daughter. Bekalu was a BSc nurse, too. He was single.

The findings affirmed that the hospital lacked the basic components of quality of the primary palliative care service. They reveal that what Donabedian (2005) postulated as quality of health service [including the quality of the primary palliative care service] have not fulfilled in the hospital. The structure, process and outcome did not maintain the goals of the palliative care service. The symptom management, pain relief and quality of life were not achieved due to the lack of structure, efficient interaction and desired outcome.

Hurdles Decelerating the Quality of the Primary Palliative Care Service

The qualitative data were gathered through in-depth interviews and observation checklist. The interview was tape-recorded. The data on the tape was transcribed and translated in to English. The researcher read the data thoroughly and identified the segments based on the objectives of the study. Based on the concepts emerged, the researcher assigned code words by the help of QDA Lite software. In other words, the researcher organized the emerging problems thematically and the meanings of the themes were made. The findings are dysfunctional infrastructure and interaction, incapacity, scarcity of medicine and Supplies, lack of manpower, long waiting time, medical error and poor complaint system. As the study focuses on the hurdles decelerating the quality of palliative care service, it only focuses on the problems and their consequences.

Poor Infrastructure

The patients were at the death’s door; they looked seriously ailing. They, seeking relief, went to the hospital, but, due to the dysfunctional infrastructure of the hospital, things, for the patients, were at sea, they were disorganized and chaotic. Dysfunctional infrastructure was a shared stance of the patients, which was one of the threats that decelerated the quality of the primary palliative care service. All of the participants attested that the dysfunctional infrastructure was one of the challenges that affect the quality of the primary palliative care service. This threat was nearly the collective voice of the participants for they underlined that the infrastructure was not up to their expectation of this referral hospital. Adequate infrastructure is a crucial part of health service, but the participants attested that the physical infrastructure of the hospital seemed to be another pain for the patients. Being asked about the challenges that decelerated the quality of the primary palliative care service, Hune (renal failure patient) attested that the infrastructure was dysfunctional. He asserted that due to the dysfunctional nature of the infrastructure, patients died. His voice is read as follows:

> They [service providers] say that there is a problem of water treatment; there is an electric power break. There is a generator, but no one turns on the generator as soon as the electric power breaks. Blood clots [when an electric power quits during dialysis]. … . The service interrupts; blood clothing appears and then the patient dies. …We, for instance, told them [medical director and manager] that there is a problem of power and water supplies. They replied that they could solve the problems soon, but they didn't.

It was always giving hope, but never healing the scares; the unpractical response was all that fuelled the dysfunctional aspect of the infrastructure of the hospital. Hune compared his expectations of the service with the service he has received; his expectation of the infrastructure was not met and his evaluative, affective, or emotional response about the infrastructure was adverse. He faced the undesirable aspect of the infrastructure of the hospital. The second participant (Lemlem), when asked about the hurdles decelerating the quality of the primary palliative care service, affirmed that the dysfunctional infrastructure was one of the problems that distorted the quality of the primary palliative care service:

> … . It is difficult for patients to enter the hospital and get information because there is no direction indicator sign. Especially, ours [cancer patients' treatment center] is far, far away from the center of the hospital; so it is too difficult for a patient to find it. The ward, as it was exposed to sun radiation, is boiling hot.

Lemlem was at the end of her tether (at the limit of her patience or endurance) due to the dysfunctional infrastructure of the hospital. She, being angry, critiqued the lowness of the quality of the primary palliative care service through a rhetorical question: "Alas! Can we think of quality at this hospital?" In the same spirit, Mulu confirmed that the hospital was not comfortable. She affirmed that there was no service due to the dysfunctional infrastructure of the hospital. Birtukan confirmed that the waiting room was problematic for the diabetic and the old, like her. Hilina (the fifth participant) proved that the dysfunctional infrastructure was another disease in the hospital. As she stated, there was no waiting room; so they waited around the treatment center for turn. There was no bench to seat on; many of them sat on the floor. The ward was not wide, clean and enough. As there was a lack of beds, they slept in the corridor. … There was no direction indicator sign in the hospital. The hospital, instead of being a place where patients get aid, became pain accelerating center.

As Hilina asserted, the infrastructure of the hospital was a banana skin, an embarrassment or caused problems for the patients. She, being surprised, asked how the hospital had been leveled as a referral hospital. She asserted that the patients were puzzled due to the dysfunctional infrastructure of the hospital. Here comes what she stated:

> … . I don’t know how this hospital was leveled as a referral hospital. It doesn’t fulfill the materials needed in a hospital. It is a place where patients are puzzled; it is a place where human beings become cheap objects left on the floor, compound, stone and corridor of the hospital.

Due to the dysfunctional aspect of the hospital, the patients were suffering. They wasted time in searching for a service center and the chronicity of their diseases increased. The hospital, for the patients, was the center of soreness. Ayele asserted that the infrastructure, for instance, the laboratory, was not active regularly. Also, Mohammed confirmed that the infrastructure was not as comfortable as he had expected.

The implicit stance of the patients was that the infrastructure of the hospital was below par, it was not up to its standard. The voices of the participants, in what seemed to be their consensus stance, revealed that the dysfunctional infrastructure was one of the challenges that decelerated the quality of the primary palliative care service for chronic disease patients. They contended that the road, the buildings (waiting and examination rooms and the ward), the water and electric supplies decelerated the quality of the primary palliative care service as they didn’t meet the patients’ expectations. As there was no direction indicator sign in the compound of the hospital, the patients and their families became in a state of panic; they wasted time and were puzzled in searching for information, they hovered here and there to get to the service center.

On the contrary, Sofia witnessed that the infrastructure was good. Her voice read as:

> It [the infrastructure of the hospital] is good. … . It is good so far. … .The waiting room is good. I didn’t sleep on the floor of the ward while I had been admitted to the hospital. …. . Uh-Oh! It is partly good.

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Though Soia affirmed that the infrastructure was good, she, implicitly, asserted that there was a dysfunctional aspect of the infrastructure of the hospital. The last sentence of her word, in the above quoted idea, attested that the infrastructure was dysfunctional for chronic disease patients.

The key informants asserted that the infrastructure of the hospital was dysfunctional. Beza [a nurse from the diabetic treatment center] confirmed that there was no enough examination room. The second key informant [Hana- coordinator of cancer treatment center] asserted that the infrastructure of the hospital was dysfunctional. Her idea is read as:

> The center was first built for TB patients. It is not equipped for chemotherapy. It doesn't have water. When the solution is prepared for chemotherapy, it is spread towards us; we can't wash the contaminated part of our body immediately as there is no water in the ward. … .Their [patients'] families sleep with them [patients], but the patients under chemotherapy must not sleep with other persons for 24 hours after the chemotherapy because it is dangerous for the other person.

The third key informant [Yelibe- coordinator of the dialysis center] shared the patients' and her colleagues' ideas about the dysfunctional nature the infrastructure of the hospital. Her voice is read as:

> The ward is narrow. We use a narrow, as you observe, room as a store and as an office simultaneously. When they first come, it is not catheter insertion that we do for them, but it may be jugular. So, there is no room for this activity. We do it in the same ward dividing the room by screen as there is a lack of room and as the dialysis center itself is very narrow. … .The most difficult problem of this center includes a lack of power and water. … . The most difficult problem is water quits while the patients are under dialysis; as a result, the patient's blood clots.

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As triangulated so far, the infrastructure of the hospital was like a dead duck, it was a failure as it didn't maintain the patients' desired outcome. This in turn decelerated the critical aspect of the primary palliative care service delivery—quality. Availability, accessibility and affordability, equity and quality depend on the distribution, functionality and quality of infrastructure of the hospital, but Felege Hiwot Hospital did not fulfill one of the critical forms of quality—active infrastructure.

The patients, but one to some extent, proved explicitly that there were inadequacies in health infrastructure. The functionality and utilization of health infrastructure were poor. This poor infrastructure led to poor quality of the primary palliative care service. In addition, it was dangerous to the health and welfare of the patients. The infrastructure was nearly forgotten. The hospital had a class of referral hospitals, but its infrastructure was below the expectation of the patients. As it was a government hospital, the poor went to it to get health service, but they were disadvantaged due to its dysfunctional infrastructure. This in turn decelerated the quality of the primary palliative care service. Nearly, the main facilities of the hospital (buildings, water and electric supplies) were not comfortable for the patients because they didn't provide consistent service; the patients' privacy was not kept as well. Infrastructure, in order for quality to be maintained, should have been well constructed and active, but the infrastructure, for chronic disease patients, at Felege Hiwot Hospital was dead in the water, it didn't make progress.

Dysfunctional Interaction

Patient claimed that the nurses and the doctors mistreated them. In what seemed to be their collective stance, the participants emphasized that the interaction between the patients and the participants was dysfunctional. As they explained, the maltreatment was a bit much; it was very annoying and excessive. It was striking that the service providers had been at odds with the patients— they seemed to be against patients; as a result, the quality of the primary palliative care service was at the back burner—it was being given low priority. The service providers insulted the patients. As nearly all the participants underlined, what the service providers said was below the belt—they treated the patients unkindly and unethically. Respecting patients seemed to be outlawed; the whereabouts of empathy, responsiveness, reliability, and assurance were unpredictable. The patients, since they didn't have alternatives due to their poverty and severity of their pain, they, shockingly, went to the hospital and this was the tip of the iceberg. The process refers to what is being done. In other words, process comprises the way of the service provision. The findings above asserted that the service provision was distorted and the quality of the primary palliative care service deteriorated. Hune's articulation about the maltreatment he faced was also the stance of the other participants. His voice is read as:

> Ethiopian physicians hate being questioned. They refuse compliant and they are annoyed. This [annoyance] may bring about an effect on my treatment. So I don't complain …. As I told you before, the health service providers don't have ethics.

As Hune attested, the maltreatment was beyond the patients' ken:

> When we complained [about the poor service], the medicinal director warned that he could quit the dialysis service. …Alas! It is very difficult! Are we administered by a government, rule and regulations? No, we are not! … . I lose hope. If I don't get a fair response when I complain, to whom do I complain? Our [renal failure patients'] age, at most, is about 3 or 4 days. If the service quits today, I will not live tomorrow. [Silence… his tear dropped over his face].

Everything in his life is distorted by pain, pain of illness and bureaucracy. May be it is just some cruel joke. May be it is all just a game or illusion of the bureaucracy. Also, it (the maltreatment) was beyond the pale–it was too extreme to be acceptable morally, socially and

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ethnically. Hune said, “They don’t seem to be professionals. They are traders, as I tried to mention earlier. The medical profession has its own ethics. At least, they should have had empathy. In this hospital, the health professionals maltreated patients; they treated cruelly or with violence.” The patients bit their lips–they made a conscious effort not to react. They keep quiet about the displeasing words of the service providers, as the patients didn’t have alternatives.

Lemlem confirmed that the patients were not recognized as human beings, her expression is read as:

> They [service providers] don’t serve us fairly. …the doctors don’t examine me well. I suffer from their wrath and maltreatment. Their examination seems to be fake [as they don’t make enough time to examine patients]. …. .They don’t recognize and respect us as human beings. They despise us. They maltreat us. They don’t recognize us as human beings.

Her voice proved that the service providers’ words and actions opened a can of worms. In other words, the service providers created a lot of problems against the patients. Mulu described that the interaction between patients and service providers was a curve ball—it was deceptive. They used their knowledge, if it had been knowledge, to deceive patients. What she faced is read as:

> They treated us badly; they denigrate and insult us [Mulu and her husband]. They insulted my husband. They said, “You are imposture and thief!” Even the doctor whom I know well told my husband that I would die after ten minutes [no need for wasting time as she would die due to bleeding]. … . The doctor began talking to his friends **in English**. He told them that I would die after 10 minutes. I am not

> good at English, but the proprietor of the house where my husband and I live listened to them and he confronted them with what they were talking about.

The above quoted idea testifies that some of the medical professionals seemed to violate their sworn obligation to their patients because what they did was not expected of medical professionals. As she verified clearly, the interaction between the patients and the service providers was distorted. The chronic diseases patients were down in the doldrums, they were depressed and lacked energy. On the contrary, the service providers ignored them and didn't want to recognize the patients' chronicity of the disease and the severity of their pain as soon as possible. The primary palliative care service itself, therefore, seemed to be dead in the water, it wasn't making any progress.

Hillina also asserted that she was, due to the dysfunctional interaction, down in the dumps–she was depressed. Her claimed is read as:

> They [service providers] treat us badly, they tease us. They insult us as well. They don't listen and understand us. They don't recognize us as human beings. … .They are not willing to help us [silence]. I don't know what their problem is. They ignore us. [Silence… face turned to ale; strong emotion emanated from her face]. Everything is strenuous at this hospital; very difficult than expected.

She confirmed that the dignity of patients was violated. This in turn decelerated the quality of the primary palliative care service. The nurses and the doctors dropped the ball—they were not doing their job or taking responsibilities seriously and they let things go wrong which spoiled the quality of the primary palliative care service. In addition, they [the nurses and the doctors] got away scot-free—they were not punished when they had done something wrong. Birtukan testified that the interaction was scaring. Her expression is read as:

> The service providers don’t give us a quick response. One of the service providers maltreated me. … .He came to me and said, “You are to break our stretcher laying down on it!” We are dried like wood due to their aggressive behavior. … .They maltreated me. I suffer from their bad behavior.

Mohammed attested that the nurses and the doctors were unconcerned. As he asserted, though they worked hard, their negligence devalued their effort of helping patients. This reveals that the service providers devalued their responsiveness, assurance, empathy and competence. In contrast, Sofia claimed that the interaction between patients and the service providers was active and solid. She, when asked about the interaction, said,” It is good. The service providers have a good approach and communication.”

Among the key informants, Yelibe was unsure to claim whether the interaction had been active or dysfunctional. Whereas, Beza confirmed that there was no interaction problem between the health professionals and the patients. Yelibe confessed that there was dispute between the patients and the health professionals. The renal failure patients became aggressive due to the diseases. In view of their aggressiveness, there happened dysfunctional interaction. She said, “….We tolerate their aggressive behavior. They even insult us.” Bekalu, through his implicit tone of expression, attested that there was an interaction problem.

The finding reveals that there was dysfunctional interaction between the patients and the health professionals. It gnawed the patients’ vitals—it troubled them greatly and affected them at a very deep level. This banished the condition where the quality of the primary palliative care service could be maintained. As there was dysfunctional interaction, the reliability, responsiveness, credibility, and courtesy of the professionals couldn’t be practical. Safe, effective, patient centered, timely and efficient treatment was unthinkable for the condition became inconvenient. The interaction was the bridge between the patients, and the nurses and the doctors; as it was dysfunctional, the professionals hung the patients out to dry—the service providers abandoned the patients when they had been in trouble. They were wearisome of treating or serving the chronic disease patients.

Incapacity

Incapacity was one of the hurdles that decelerated the quality of the primary palliative care service, as asserted by the participants. Medical errors had occurred due to the incapacity of the health professionals at the hospital. A medical error can be a surgical error, surgical and diagnostic errors, equipment failure, injuries and misinterpretation of other medical errors (Lazarou *et al.,* 1998). As Lemlem testified, doctors committed a serious medical error. She confirmed that one of the doctors prescribed her medicine wrongly:

> The doctors and nurses seem to be unknowledgeable and novice. As a result, they commit error. This [medical error] makes the treatment nonsense. These problems prevent them from providing us with quality service and the service cannot satisfy us as well…. . Especially, doctors commit very serious medical errors. For your surprise, once, one of the doctors prescribed me medicine. I bought the medicine and went home. I do have a brother who is a health professional. I showed him the medicine I bought, but as he attested, the medicine was not for cancer patients; it was a medicine that should have been prescribed for diabetic patients.

In the primary palliative care service, things went awry—what was done went wrong. What the doctor did was to cure the patient, but what he prescribed had gone pear-shaped, it had gone wrong. The prescription was written devoid of evidence or knowledge. In view of this fact, the prescription had gone to pot—it went erroneous and didn't work anymore. What if the patient had taken the medicine? Things would have been devastating; the patient could have faced an unexpected and undesired result. Couldn't it be death? But, she had taken the prescription with a grain of salt as her brother helped her—she did not necessarily believe it all. As a result, she saved herself. The doctor should have prescribed carefully as a health professional.

Mulu attested that she faced renal failure due to the medical error she faced at the hospital. Here, her voice is read as:

> When I was pregnant, I became sick and a certain doctor prescribed me medicine and I began taking it. When I went to the hospital, another doctor asked me, "Why do you take this medicine?" and he threw the medicine. … .The doctor told me that my kidney failed due to that medicine.

She was confused with the problem she faced. She suffered from nightmare. Was it blood or death? Was it her last breath? She was fighting her past that could be her last; she didn't know where she was going, and where her daughter shall be living! Hilina contended that she became a cervical cancer patient due to a surgical error. As she testified, there happened a wrong doing when she had been operated on for delivery. Here, her word is read as:

> When I gave birth, I was operated on. … .They [the doctors and nurses] did not remove the blood from my womb; they didn't clean my womb during the two operations and they did not sew my womb properly. … . I was exposed to infection and that infection exposed me to cervical cancer.

Also, she asserted that the hospital was devoid of its basic goal, recovery of patients. She said, "If you go to the hospital and visit its different parts, you will notice that patients acquire another disease in addition to what they are suffering from, so it is not a place where patients recover."

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Sofia confirmed that the health professionals had incapacities. She asserted that they could not identify the health problem she faced. She said, “They inform me that they can’t identify the diseases and the problem that caused the pain. There was swollenness; but they attested that they couldn’t find out what it was caused by [what the swollenness was].”

This reveals that the professionals could not make head nor tail of her disease; they could not understand her problem all or make any sense out of it. Also, Birtukan attested that due to the incapacity of the health professionals, there was no health progress. She, with anger, asserted that the service providers were not good; they rushed to insult her instead of treating. They ordered her to buy medicine; only prescribing medicine and ordering her to buy it from a private pharmacy. She said, “If they helped me, I would recover.”

Hune also faced a problem due to the incapacity of the professionals. He confirmed that the hospital [health professionals] was weak. Except providing technical assistance, they didn’t do anything. Ayele, believing that the service providers were incapable, proved that the service providers, instead of treating, referred the patients to Gamby Hospital. As he confirmed, they frequently instigated patients to go to Gamby while the patients expected to get help, including the primary palliative care service, from Felege Hiwot Hospital as it was a referral hospital. Mohammed affirmed that he did not get credible treatment on his sexual dysfunction that he faced due to the diabetes case. He, with regression, claimed that the service providers should have investigated the sexual dysfunction he faced and cured him. He has not, as he attested, got the remedy due to the incapacity of the service providers. He also confirmed that the service providers made a medical error in view of carelessness.

The patients attested that they got in to hot water—trouble—due to the incapacity of the professionals; this asserted that the incapacity of the health professionals was decelerating the quality the primary palliative care service at Felege Hiwot Hospital. The patients were in health chaos or a mess due to the incapacity of the health professionals. There can never be a quality of the primary palliative care service as long as the service is distorted due the incapacity of the professionals. Therefore, the patients were in a jam or in a pickle–health trouble/mess.

A healthy and strong body is seen as crucial to wellbeing—not just for a sense of physical wellbeing in itself, but as a precondition for being able to work. A person who is sick and weak cannot work or cannot work well. The patients' wellbeing was dissolving itself in their ill-being due to the incapacity of the service providers in addition to the chronicity of the disease they [the patients] were suffering from.

With regard to the incapacity of the service providers, Yelibe [key informant] confirmed that the nurses faced problems for they did not take training on how to provide dialysis service. She said, "It will be better if the service is provided by its professionals." This indicates that the incapacity appeared due to, to some extent, the deprofessionalization [assigning a professional in a department without his educational background] of the nurses and the doctors. In other words, the incapacity of the professionals seemed to appear since they had been assigned in a unit where they did not have knowhow. Also, Hana [key informant] confessed that her colleagues and she were assigned to the cancer treatment center to provide chemotherapy without taking training and having a practice guideline. Due to these problems, she claimed that if the incapacity of providing the service happened, they would not be blamed or it would not be their fault. Beza and Bekalu [key informants] had no idea about the incapacity of the nurses and the doctors.

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Scarcity of Medicine and Supplies

The participants confirmed that, due to the scarcity of medicines, they were susceptible to death. It was a fine cry—loud and long—but it had no bottom and it had no top, just circles and circles of sorrow due to the lack of medicine the patients needed. Hune, being angry, confirmed that he was suffering from a lack of medicine. Here is his voice:

> There is very high scarcity [of medicine]. … . The medicine is found there, with the traders [private pharmacies]. For example, a medicine that we are supposed to buy for 75 birr from the hospital's drug store is sold for 400 birr in the private pharmacy.

The lack of medicine put the patient in a state of panic. In addition, the medicine cost an arm and a leg when found in a private pharmacy— it was very expensive; so much amount of money was needed to buy. Also, Hune asserted that the dialysis center was not equipped. As he asserted, the dialysis service sometimes interrupted due to a lack of medicine. Lemlem confirmed that patients received prescription paper rather than medicine. Here, her idea is read as:

> They [doctors] prescribe me medicine, but when I go to the pharmacy of the hospital, the pharmacist tells me that the medicine is not there and I should buy it from private pharmacies. Outside [in the private pharmacies], the medicine is very expensive. … .They [service providers] don't have supplies to treat us. … . The medicine of cancer is expensive; it cannot be found when needed. ... .When we find the medicine in private pharmacies, it is too expensive for us to buy.

The patient faced ill–traveling life; her life was cloud and mist. She said that empty she entered this world, empty she was to leave it due to lack of medicine. She believed that she came to this world to suffer and was to go without living; things were entangled. Ayle testified that there was a lack of medicine in the pharmacy of the hospital. His complaint is read as:

> There is no medicine we need in the pharmacy of the hospital. As, a result, they refer us. They refer us to Gamby Hospital for laboratory and other services. I think they have a business relationship with Gamby Hospital. I do have a complaint in this regard. The medicine I need is very expensive in private pharmacies. If we don't take medicine timely, the disease aggravates and we die.

Mulu confirmed that what she got in the hospital was prescription paper. Her expression is read as:

> There is a lack of material for dialysis. … . I have bought medicine from private pharmacies so far. … . When I had gone to the hospital's pharmacy, I didn't get the medicine and the pharmacists ordered me to buy from outside [private pharmacy]. … . I also bought from brokers. … . I can't afford to buy medicine from the private pharmacy as the medicine is very expensive … [silence…sobbing…].

Hilina's saying was nearly similar to Hune's, Lemlem's and Mulu's claims. Here goes her idea:

> We patients don't get medicine at the hospital's pharmacy. … . When we go [to the hospital's pharmacy], we don't get medicine. The pharmacist informed us that we would get the medicine in the pharmacies around the hospital; the medicine is very expensive in the private pharmacies, I can't afford to buy. The first and biggest problem is a lack of medicine.

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Birtukan confirmed that the worst problem was the lack of medicine. She attested that she sometimes left out buying medicine as she couldn't afford to buy from the private pharmacies. She said, "There is no suffice access [of medicine in the hospital]. … . We go to a private pharmacy. The cost of medicine is overpriced. I buy [the medicine] what I afford and leave out the medicine which I can't afford to buy." Sofia's idea was a bit different from other participants' voices. She proved that the pharmacists of the hospital refused her to give her medicine because she was treated for free as she was very poor. In addition, she attested that they refused to impart her expensive medicines. She said, "If the cost of the medicine is high, though the medicine is available in the hospital's pharmacy, they refuse to give me the medicine and refer me to the private pharmacies because I am treated for free due to my poverty."

The patients suffered from a lack of medicine. The medicine they wanted to buy was found in the private pharmacies, but it was expensive and this was the other pain the patients suffered from. The patients could not take the medicine as soon as they were told to do so because they couldn't find it in the pharmacy of the hospital and they could not afford to buy from the private pharmacies. Searching for medicine by itself exacerbated their pain. The patients, though they knew it, were heading to death due to a lack of medicine. It seemed to be that they had to grin and bear it; they had to accept death although they didn't want and like it. The patients were heading towards death due to the lack of medicine and the quality of the primary palliative care service was heading towards its grave. Medicine access, for the patients, was as high as a sky and equipping medicine and supplies, for the hospital, seemed to be as difficult as neurosurgery.

The key informants' stance with regard to the lack of medicine and supplies proved the patients' claims. Beza confirmed that there was a scarcity of medicine. She also indicated that the medicine of the hospital seemed to be sold to the proprietors of the private pharmacies. Here, her claim is read as:

> There is also a lack of medicine. … . Patients face lack of medicine. As it is said, the medicine seems to be sold to private pharmacies by the hospital's pharmacists. I think this makes medicine scarcity. … .As I told you, there is a high scarcity of medicine. Drugs and supplies are not well accessed.

Hana strongly confirmed that there was a scarcity of medicine and supplies. She also added that a scarcity of medicine became a very difficult problem for the patients. Here is what she claimed:

> … . the big problem in this hospital is a lack of medicine. …. . The patients suffer from traveling and searching for medicine in addition to the pain. … .On the other hand, many of the patients can't afford the cost of treatment and medicine. … .There is a scarcity of supplies. … . We don't even have a biosafety cabinet. We put medicine, when there is, on tables; this makes the medicine accelerate its side effects because they (chemo-medicines) are volatile in nature.

Yelibe asserted that there was a lack of supplies; due to this, patients faced problems. She testified that they sometimes quitted the dialysis service due to a lack of supplies. Bekalu confirmed that there was a lack of medicines and supplies. As he stated, his unit was asked to list and report medicine and supplies needed the concerned body, but they were not bought.

As all of the participants revealed, finding medicine was not a bed of roses: it was too difficult for the patients to find and buy. The patients confirmed that they faced two big problems with regard to medicine: lack of medicine and its expensiveness when it was found in private pharmacies. The patients paid through the nose for the medicine from private pharmacies–they paid a very high cost for it. This made it difficult to know the whereabouts of the quality of the primary palliative care service that was the life of the patients; that was it—the sun in the evening, the moon at dawn and the still voice!

The patients were in Queer Street–they were in a lot of troubles, especially the expensiveness of medicine in private pharmacies. These problems exacerbated their pain as they did not take medicine timely. This indicates that the patients' wellbeing and social functioning were not restored. This in turn decelerated the quality of the primary palliative care service. Overall, the lack of medicine and the associated problems accelerated their pain and death. Couldn't this be the other threat of the quality of the primary palliative care service for chronic disease patients? It was, for sure, one of the threats of the quality of the primary palliative care service because medicine is one of the resources that maintain the quality of the primary palliative care service.

Lack of Manpower

The patients confirmed that there was a lack of man power. Due to this, the patients didn't get enough examination time, and they couldn't get specialist doctors who might meet their expectations. Hune asserted that he has never been examined by a nephrologist. He said, "A nephrologist didn't examine me. … . Firstly, the disease is new. Secondly, there is no nephrologist." Lemlem attested that she waited for a long a period as there was no enough manpower. She also revealed that there was no specialist doctor. Mulu, being in trauma, said that she would not have had the injuries that made her face renal failure had there been a specialist doctor. Hlina testified that waiting for a turn for a long time was due to a lack of man power. She also attested that she did not get what she had expected from this hospital as she had never been examined by a specialist doctor.

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Birtukan attested that the doctor did not treat her as she wanted for he was not a specialist doctor. Due to this, she went to a private clinic –"kidanemihiret Clinic"— to be examined by a specialist doctor. Also, Ayele and Mohammed asserted that there was a lack of manpower in the hospital. Ayele testified that there was no professional who could provide patients with a pathology service. Mohammed attested that he was tired of waiting for a turn for a long period. He said, "I wait for long time for a turn; I feel hungry as I am diabetes patient. So what can I do? Do I go to a restaurant abandoning the queue for my turn? This was due to lack of doctors."

Lack of manpower was one of the problems that patients faced. Due to this problem, they suffered from long waiting times. They didn't get timely service; this aggravated their pain. The examination, when it was their turn, was not up to their expectation because they were not examined by a specialist doctor. They did not get a specialist doctor at all. Specialist doctors sometimes came to the hospital from Addis Ababa, but many of the patients didn't get the opportunity of being examined by the specialist doctors. This made them lose hope of recovery; they didn't rely on the primary palliative care service of the hospital. The doctors, even, didn't make suffice time to examine the patients well because the doctors rushed to give the service for all patients waiting for a turn for examination. These problems intern resulted in poor primary palliative care service quality at the hospital. The lack of manpower put the patients in a tight spot, a difficult situation where they could do nothing, nothing and nothing. The hospital was a car without its engine and the patients were in that freezing cold and dark car that clots their blood and their hearts were being burnt in the radiation of the diseases.

Also, the key informants attest that there was a lack of manpower. Beza testified that there was a lack of specialist doctors. Here is what she expressed: "….So is there a lack of manpower. There is no specialist doctor. There are few general practitioners and some nurses who work at this center [the diabetic treatment center]. … . The manpower is not strong enough to serve the patients; this makes difficult to provide quality palliative care service." So did Hana confirm that there was no cancer specialist doctor. In the same spirit, Yelibe attested that there was a lack of nurses in the dialysis center. So did she attest that there was no nephrologist. Here is what she asserted:

> There is no enough number of nurses. … . The authorities told us that there is a lack of manpower in the hospital and they told us to be patient till they recruit. … . I think, the health bureau ordered them to halt recruiting. … . There is no nephrologist at all here.

Also, Bekalu attested that there was a lack of manpower. As there was a lack of manpower in a hospital, the primary palliative care service became dead as a doornail—lifeless service that could never maintain quality. Nor could it satisfy the patients as it became a car without an engine, it was static.

Long Waiting Time

Nearly, all of the participants asserted that they suffered from a long waiting time. As they noticed, they didn't get service timely. As Hune explained, he suffered from long waiting times for the service and; in contrast, the nurses quitted the dialysis service claiming that it had been time for them to leave. In other words, the nurses, assuring the patients that working time was up (5:30 PM), they quitted the service. Lemlem confirmed that the service was not timely as she waited for a turn for a long period. Also, she affirmed that the physician didn't make enough time to examine her. She said, "In addition, waiting for a turn is the other problem that annoys. They [service providers] don't serve us fairly. Shocking [due sickness], I wait for a turn. Their examination seems to be fake [as they don't make enough time to examine patients." Mulu, with trauma, elucidated that had she been assisted on time, her bleeding would have quitted and her kidneys could have been saved.

Hilina, asserted that the service providers wasted time by talking in their office and leaving out for tea. She said, "We go to the hospital in time, they [nurses and doctors] come late. They sometimes enter their office and begin talking while we [cancer patients] are waiting for treatment outside. Ouch! They even go out for tea, they ignore us." Birtukan explained that she was tired of long waiting time. Waiting for a long time aggravated her pain. As she testified, waiting for a long period to get service was another disease for her. Ayele and Mohammed affirmed that the waiting time was too long for them to resist. Due to the long waiting time, the patients didn't get timely service; this aggravated their pain and accelerated their death. In other words, the service was as slow as a snail, but the severity of their pain was faster than that. This decelerated the quality of the primary palliative care service. In contrast, Sofia affirmed that the primary palliative care service was timely. She explained that she got service on time and the service providers were punctual. They used their time properly to serve her.

Timeliness of health service, let alone chronic disease patients, is mandatory for every patient who goes to the hospital to get service. A pound, a euro or a dollar value may be assigned to time. Yet, in health care, the value of time is much more than that as it is associated with lives than it is with money or any other treasure. William Shakespeare said, "Better three hours too soon, than one minute too late." Delmore Schwartz, said, "Time is the school in which we learn, time is the fire in which we burn." The patients suffered from long waiting time because the service providers wasted the time of the service; they were against Shakespeare's stance of time. In addition, the patients asserted that time became the fire in which they burnt. It is apparent that the sooner a patient gets to the right care in the right place with the right resources, the better he/she will be. Health-care providers are expected rightfully to link timely care to positive patient outcomes. Time is, therefore, life for chronic disease patients, but it was to be their end at Felege Hiwot Hospital as they were not being provided with timely service. This was the other threat of primary palliative care quality while time was not the main thing, but it was the only thing the patients recover at. Whoever the specialist is, whatever the technology is, whatever medicine is available, if action is not timely, saving a patient is letting him/her run on an ocean. Above all, the long waiting time, together with the pain, made the chronic disease patients develop nihilism.

Medical Error

Medical errors had occurred due to the incapacity of the health professionals at the hospital. A medical error includes a surgical error, surgical and diagnostic errors, equipment failure, injuries and misinterpretation of other medical errors (Lazarou *et al.*, 1998). As Lemlem testified, the doctors and the nurses committed a serious medical error. She confirmed that one of the doctors prescribed her medicine wrongly:

> The doctors and nurses seem to be unknowledgeable and novice. As a result, they commit error. This [medical error] makes the treatment nonsense. These problems prevent them from providing us with quality service and the service cannot satisfy us as well…. . Especially, doctors commit very serious medical errors. For your surprise, once, one of the doctors prescribed me medicine. I bought the medicine and went home. I do have a brother who is a health professional. I showed him the medicine I bought, but as he attested, the medicine was not for cancer patients; it was a medicine that should have been prescribed for diabetic patients.

The prescription was written devoid of evidence or knowledge. In view of this fact, the prescription went erroneous and didn’t work anymore. She had taken the

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prescription with a grain of salt as her brother helped her; she did not necessarily believe it all. As a result, she saved herself.

Mulu attested that she faced renal failure due to the medical error she faced at the hospital. Here, her voice is read as:

> Once, I became sick and a certain doctor prescribed me medicine and I began taking it. When I went to the hospital, another doctor asked me why I was taking that medicine and he threw the medicine. … .The doctor told me that my kidney failed due to that medicine.

She was confused with the problem she faced. She suffered from nightmare. Was it blood or death? Was it her last breath? She was fighting her past that could be her last; she didn't know where she was going, and where her daughter shall be living! Hilina confirmed that she became a cervical cancer patient due to the surgical error the health professionals made. As she testified, there happened a wrong doing when she had been operated on for delivery. Here, her word is read as:

> I was operated on at the hospital. … .They [the doctors and nurses] made medical error during operation. As a result, I was exposed to infection and that infection exposed me to cervical cancer.

Sofia confirmed that the doctors aggravated her pain due to the medical error they made when they took sample from her breast. She said, "When they cut off my breast to take sample, they wounded me and I faced infection. The infection intensified and they, later, told me that they could not identify the health problem I faced."

Also, Birtukan attested a certain nurse gave her a wrong prescription. Her daughter identified that the nurse gave her the wrong prescription. Birtukan said, "I did not know what he gave me. What I was sure was that he gave me a prescription paper. What would I have faced hadn't my daughter identified that his prescription was wrong?" They ordered her medicine wrongly; only writing wrong prescription and ordering her to buy it from a private pharmacy. Hune also faced a medical error due to the incapacity of the professionals. He confirmed that the hospital [health professionals] was weak. He testified that he faced vein infection due to the medical error of the nurses. Ayele, believing that the service providers were incapable, testified that he faced a medical error. They wrote him prescription and he bought the medicine. He began taking it; he faced diarrhea. He went to Gamby Hospital and showed the doctor what he was taking. The doctor confirmed that Ayle was taking medicine which was wrongly prescribed. Mohammed, with regression, affirmed that the service providers made a medical error in view of their carelessness. Also, Kal confirmed that the service providers made medical error due to their incapacity and carelessness.

The patients confirmed that they got in to hot water—trouble—due to the incapacity of the professionals; this attested that the incapacity of the health professionals was decelerating the quality of the primary palliative care service at Felege Hiwot Hospital.

Poor Complaint System

The patients face a number of problems and they wanted to report what they faced, but the compliant system was poor. They faced problems with regard to structure, process and outcome and tried to report; nonetheless, they were not successful. Hune affirmed that he, together with other renal failure patients, went to the medical director's office to complain about the poor service, but they were told that he was in a meeting. After trying to meet him about four times, they met him and told him about the problems. He assured them that the problems would be solved soon, but he didn't solve any of the problems. They went to him again, but seldom did he solve the problems. Mulu had complaint about the poor dialysis service, but she didn't complain as she did not know how and where to complain.

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Birtukan, Mohammed and Ayele faced a number of problems with regard to the diabetes treatment service. They, for instance, had faced medical errors and wanted to complain about the problem or accuse the health professionals who committed the errors of their wrong doing; nevertheless, they didn't for there was no structured complaining system. As a result, Birtukan believed that the diabetes patients were in an evening sun light. Ayle confirmed that he was in the dim light of life. According to Mohammed's voice, the hospital was a prison in the name of a health institution.

Sofia, Kal, Hilina and Lemlem confirmed that the hospital itself was one the darkest places for cancer patients. They faced lack of medicine and medical error, but they didn't know they could go and complain. Hilina's voice mirrors the hospital with regard to its lack of complaining system. "There are a number of problems in the hospital, but there is no complaining system. These problems themselves are cancers that aggravate our pain."

The patients faced a number of problems in the hospital. Lacks of medicine, medical error, long waiting time, incapacity were some of the problems the patients faced; however, they did not have a system through which they could complain.

The data found through the observation checklist proved the findings discovered through the in depth interview. With regard to the hospital's structure, many issues were found which revealed that the hospital was not up to the expectations of the patients. There was no a waiting room for renal failure and cancer patients, but, though it was very narrow, there was waiting room for the diabetic. Concerning the examination rooms, they were not enough rooms when compared to the number of patients who sought service. The laboratory was not well equipped and it was not active regularly. The buildings and the road were not comfortable for the patients. The other finding revealed that there was no enough access to medicine for chronic disease patients; there were no enough supplies and equipment either.

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There was no scientific procedure and evidence based practice because there was no practice guideline in chronic disease patients' examination rooms and the practitioners didn't base the scientific procedures when they examined patients, as observed by the simulated patients employed by the researcher. The practitioners didn't have personal protective devices and detergents as much as expected. There was no specialist doctor for the diabetic, renal failure and cancer patients.

When the patients went to the hospital, they were in a state of panic for there was no information center or direction indicator sign. So were they in state of dread as they were puzzled to identify doctors and nurses because nurses, laboratory technicians, pharmacists and doctors wore the same gown. The dressing styles of the service providers, the doctors, nurses, pharmacists, laboratory technicians and others confused the patients. Especially, the illiterate patients believed that everybody who wore a white gown was a doctor.

Concerning the process (the service delivery), the finding of the checklist asserted that the patients were not provided with proper primary palliative care service which in turn decelerated the quality of the service. The doctors, nurses, laboratory technicians, pharmacists and clerks didn't give timely service. The primary palliative care service was not reliable, safe effective, patient-centered, efficient and equitable. The service providers were not responsive and didn't have empathy and didn't care about assurance.

The general practitioners and the nurses were not interested in solving the patients' problems as quick as possible; they didn't provide aid that could improve the patients' health status and promote the quality of the primary palliative care service; nor were they courteous towards patients; nor did they give patients individual attention.

The infrastructure (road, buildings, and electric power and water supplies) of the hospital was not fulfilled and comfortable. The renal failure and cancer patients didn't have a waiting room at all; the examination rooms of the diabetic, cancer and renal failure were not wide and equipped; they didn't have even screen to protect the privacy of the patients. The electric power and water supplies were not reliable for they quitted while the patients were under treatment, chemotherapy and dialysis. There was no specialist doctor for chronic disease patients and; as a result, the patients were not getting a standardized palliative care service; in addition, the patients believed that the primary palliative care service given by the general practitioners and the nurses didn't recover them. The scarcity of medicine and supplies darkened the hope of recovery of the patients.

The process was not heading towards the outcome. It was nearly static. The patients didn't get timely service. They went to the hospital in time, but the service providers went to the hospital late. The patients suffered from the long waiting time and this aggravated their pain. The primary palliative care service provided to the patients never brought the desired outcome; it rather brought undesired outcomes. There was no evidence based and scientific primary palliative care service for chronic disease patients as there were no practice manual and procedural practice. Above all, the dysfunctional interaction between the patients and the service providers made the quality the primary palliative care service as slow as a snail and this multiplied the hope of recovery of the patients by zero.

In sum, the above findings reveal that the quality of the primary palliative care service was below the expectation of the patients for it did not fulfill the three components of the quality of the primary palliative care service as intense as the patients expected. The service did not meet their expectation; they didn't have health improvement.

Quality of the Primary Palliative care service

Primary palliative care was provided to chronic disease patients at Felge Hiwot Hospital. The general practitioner and the nurses provided primary palliative care service.

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The patients asserted that they were provided with primary palliative care service. Lemlem confirmed that she was provided with a counseling service that focused on the social aspect of life. As she elucidated, she got counseling by the nurses and general practitioner how to protect and/or solve problems with regard to social life. Her expression goes:

> Claiming that our disease is acute that cannot cure, they sometimes provide us with advice. For instance, they teach us how to protect problems related to our social life, how to be strong spiritually, and how to be strong psychologically. They teach us how to maintain quality of life and to be happy with in our short life span.

Mulu attested that she got counseling on the food type she would eat and how to take care of her seven month's daughter with regard to the medicine she was taking. As she explained, they counseled her about the types of food she could eat and couldn't. So did they counsel her what she could feed her daughter when she took the medicine. Hilina asserted that the physician taught her how she could improve the quality of her life, how to live optimistically, how she could have a meaningful life, what could do and couldn't do, but she testified that what they taught her was not up to her expectation. She said, "They, telling us that our disease is serious, teach us. They state, while teaching us, how we can improve our quality of life, how we can have a positive life, how we can have a meaningful life, what we do and we don't."

Sofia confirmed that she was provided with primary palliative care service. She explained that the physicians counseled patients who were cancer and other diseases [she was breast cancer and HIV positive] positive. Also, she attested that they taught her about how to resist the side effects of the medicine she was taking. She asserted that the primary palliative care strengthened her psychological capacity:

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> Yes, they provide us [primary palliative care]. They advise patients who have associated diseases. … . Yes, they do [teaching about side effects of medicine]. Yes, their counseling is good. They strengthen my psychological capacity; no body discriminates us. We live happily. But I face a lack of money for house rent [when asked about satisfaction with palliative care service].

Birtukan attested that the physicians assured her that she would recover. So did they counsel her how to take the medicine and what she had to do when she faced side effects of the medicine she was taking. Here is her voice about what she was taught:

> Yes! Yes! Yes! They taught me that I should take a rest when I take medicine. They also told me that it is possible to live although I am diabetic. They told me that I would live long if I do properly what they counseled me. They told me an experience of a person who lived long for he did what his physicians had counseled him: abut food, medicine timing, thinking positively and about life.

In addition, Birtukan attested that she was satisfied with the palliative care service. Kal averted that primary palliative care was provided for her. As she testified, the palliative care service focused on different aspects of life. As she affirmed, the doctors and nurses counseled her, in addition to the regular health service, about nearly all aspects of life: psychological, social, spiritual and physical aspects. They [service providers] counseled them about how to manage pain and distressing symptoms. So did they teach them about how they could improve their resilience and social functioning. Here, her expression is read as:

> They counseled us [chronic disease patients] that it is possible to palliate pain; they assured us how we can feel better: not to worry, to take medicine timely, to take a walk,

> to take a rest, to talk with families [sharing problem], to consult my physician quickly, to sleep and, etc. … . Yes, the other issue is they told us that we should go to the hospital as soon as we face symptoms and get our physician's advice. Also, they advised us that we should take a rest and take medicine properly and have a good meal.

The issue focused on how to manage pain which is one of the goals of palliative care. She also revealed that what she learnt about the social aspects of life focused on her family and neighbors:

> They taught us about social aspects of life. They advised me how to live with my family and society in a harmonious manner. For instance, as I am the patient of breast cancer, I am afraid that my family and neighbors may discriminate me and I told my fear to a certain doctor and she said, "don't worry; you didn't become a patient due to your fault; so bring your family and let them consult me." My husband refused to go to the hospital, but I took my sons and daughters, including my nephew and she advised them. But my husband ignores me; he doesn't care about my pain.

Productive life (social functioning), as she articulated, was one of the focal points of the primary palliative care. Moreover, she asserted that the nurses and the doctors advised her about how to maintain the progress of life, improve quality of life, psychological aspect of life (self-esteem). She eventually confirmed that the primary palliative care service was partially holistic and in contrast she confessed that the palliative care service was not satisfying.

But, according to her voice below, all hell broke loose in her mind–there were chaos, confusion, and trouble though she got the primary palliative care service.

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> The other issue is they taught us about is……. [Silence] how to have a productive life. I was afraid that I would die, but I became hopeful and forget death when she [physician] taught us in the hospital. Will I live so? I became happy, too, believing that I will be productive. However, when I reached home, my hope evaporates; instead, my fear and death confront me. Alas! It is nothing! It is known; our fate is death.

Kal was not persuaded by the primary palliative care service providers. She was confused. While she took the service, she became happy, but when she went home, what she learnt disappeared and this indicates that the chronicity of her disease and weakness of the methodology of the primary palliative care service as it was not given by multi-disciplinary team members. Her confusion read as:

> About the progress of life, life change, what is it ………..? How to improve quality of life; they taught us about all these things! But I forget it as I don't have dairy; I am afraid that they take heart/soothed us [as they are to die]. You know, what so ever is said, that evil death [Silence…] is to come to me [melancholic emanated from her face, silence… sobbing…].

Lemlem asserted that the primary palliative care was not strong enough to meet her expectation. As she attested, it was not as such well-organized, nor was it regular. She said, "They seem to teach us for the sake of showing to an inspector who comes to evaluate what they are doing. The way of delivery of the education [counseling] is not different from the usual and traditional way of teaching."

Also, Hilina confirmed that the primary palliative care is not satisfying. Her voice is read as:

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> … .But it is not up to their heart [what they teach seems to be fake or pretending]. But it is like entering and getting out class [what they teach doesn’t satisfy us]. It is not as we expected. … . It is difficult to say it is holistic. I can’t say it is a holistic service for it is not strong enough to claim so. … . But it is so so. They teach us anyway.

Ayele attested that he got primary palliative care. The primary palliative care mainly focused on how and when to take medicine and what the consequences would be if he interrupted taking medicine. They frequently counseled him that he would develop heart failure if he interrupted taking the medicine and so did they advise him what the consequence would be if he distorted the schedule of taking the medicine. Hune asserted that the hospital was very weak with regard to palliative care. He explained that the nurses and the physicians did not provide him with palliative.

Also, he testified that the palliative care service was not provided for chronic disease patients due the incapacity of the physicians and the nurses. Mohammed, likewise, attested that the hospital was weak in providing primary palliative care service. He testified that the population of Ethiopia increased. Therefore, according to his perception, the primary palliative care was not provided well to decrease the population because many patients died if they didn’t get primary palliative care service focusing on how to live long.

The primary palliative care provided to the chronic disease patients was not evidence—based and up to the expectation of the patients and this, intern, became the threat of satisfaction of the patients as they didn’t get the desired outcomes. The service was provided by doctors and nurses who didn’t take formal training on palliative care. In addition, the service providers didn’t have palliative care guideline. Moreover, the service was not regular. In view of the reasons stated so far, the primary palliative care service, though what the service providers were doing was igniting hope for the chronic disease patients, had not maintained the desired expectation of the patients.

The key informants asserted that primary palliative care was provided for the chronic disease patients. Beza attested that primary palliative care was provided for the patients. But it was not well organized and the service providers didn’t take formal training, except the orientation they had when they had been at university. Here goes her idea in essence:

> There is [palliative care service] though it is not team based and well organized. We provide the service in this unit, but it is not well organized and the palliative care providers didn’t take training and nor do we have manual. It focuses on social, psychological and spiritual aspects of the patients to maintain quality of life. So does it focus on pain relief and symptom management. … . Also, it focuses on pain relief and symptom management…. . We provide them with palliative care service based on the orientation we had when we had been at university. The structure is under physiotherapy unit. It is stuck there.

Also, Beza attested that they refered some patients to psychiatry unit. The physician and the nurses helped the chronic disease patients. Bekalu confirmed that palliative care is provided for patients in unit level. The nurses and doctors, focusing on pain relief, provided palliative care service, but it was not team based and total care, it didn’t comprise physical, psychological, social and spiritual aspects of life as the service providers didn’t take a training on primary palliative care.

What service providers do, as a result, was any port in a storm. As the patients were in a serious problem, they (patients) accepted any solution, whether they liked the solution or not; the palliative care was provided in a primary level. It was, therefore, good for the patients as they were in chaotic circumstances. Hana, the other key informant, attested that they gave palliative care service based on the orientation they had. The service focused on how to manage social aspects and how to select meal. Also, the service comprised how to manage side effects of medicine and not to quit taking medicine. Hana's voice is read as:

> Though we didn't take formal training on palliative care, we have the orientation [as health professionals]. Based on the orientation, we educate the patients to palliate their pain. The education focuses on how to lead their families, how to manage social aspects of life and how to select meal. Also, we counsel them how they can withstand the side effect of medicine. We persuade them not to quit taking the medicine.

Hana attested that the patients were satisfied with the palliative care service. Also, she stated that the patients had good attitude towards the palliative care service. Yelibe [head, dialysis center] asserted that they provided palliative care service by their own initiation. She testified that they worked in collaboration with psychiatry department to let their patients get advanced counseling. She said, "It is not as strong as expected. The interest came from the patients. They are psychologically, socially, economically ill. They come here being aggressive and quarrelsome. … . So, we refer them to psychiatry department and the department gives the palliative care service to our patients."

The observation findings, with regards to the primary palliative care, asserted that the medical staffs of the hospital didn't have palliative care guideline. This revealed that the palliative care was not evidence —based practice and nor did it follow scientific procedures. This confirmed what the patients and the service providers stated about palliative care service. The service was not well organized and nor was it led by a guideline and the service providers did not take training about palliative care service.

The hospital should have fulfilled its tangibles: it should have had modern equipment, visual appealing facilities; doctors and other employees ought to have had a professional appearance and so should the hospital have included visually appealing materials associated with the chronic disease patients' service, as a referral hospital.

The primary palliative care didn't satisfy the patients for some reasons: the service providers did not take palliative care training, they did not have palliative care guideline and the service lacked the three appeals of rhetoric: ethos, pathos and logs. Ethos is about credibility. How trustworthy are service providers? How valid is the information that the service providers use? Logos deals with the kind of information used. It is related to the word logic or reasoning. If the service providers had used logos, they would have appealed to the patients' attitude; they could have persuaded the patients, or they could have provided research-based and convincing rhetoric of palliative care. How logical was the information? How reliable was the information? These questions should have been answered. Pathos is about appealing to emotion. How did the speaker appeal to the patients' emotions? How much did the speaker make them feel about the subject of his or her message? These rhetorical questions were not answered in the primary palliative care sessions. As a result, the patients were not satisfied with the primary palliative care service they had been provided with.

In sum, the tangibles should have addressed the patients' needs: its infrastructure, manpower, and drugs and supplies did not meet the patients' expectations. The reliability of the hospital service ought to have been practical: its mission should have been put in to practice. The responsiveness of the service providers (attentiveness and promptness) in dealing with the patients' questions, complaints and problems were not practical and timely. The assurance of the service providers (knowledgeable and capacity) to inspire trust and confidence in the patients' mind was not put into practice.

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As seen so far, the quality of the primary palliative was low for it did not comprise the three basic elements of a palliative care service [pain relief, symptom management and quality of life of patients] as intense as the patients expected. Its quality did not bring about change on the patients' health status. Nor was it holistic for it didn't focus on the psychological, social, physical and spiritual aspects of life consistently. The primary palliative care service focused only on counseling and advice. This confirms that the palliative care service was low; nor did it satisfy the patients.

Status of the Quality of the Primary Palliative Care

Background Characteristics of the Respondents

The data were summarized based on their sex, age, marital status, level of education, types of disease they faced and their residence. Regarding their sex, the majority (63.1%) of them were female and concerning their age, there were six categories and the majority of the respondents (27.5%) were from 58 to 67 years old. With regard to their marital status, many of them (40.7 %) were married. Concerning their levels of education, many of the respondents were (27.1) degree holders. With regard to their residence, many of the respondents (66.1%) were urban dwellers. Vis-à-vis the types of diseases, many of the respondents (37.7%) were diabetes patients. The detailed information has been tabulated below. The table highlights the background information based on the six categories.

Table 3 Demographic Characteristics of the Respondents

Characteristics		Number	Percent
Sex	M	87	36.9
	F	149	63.1
	T	236	100
Age	18-27	7	3.0
	28-37	23	9.7
	38-47	42	17.8
	48-57	54	22.9
	58-67	65	27.5
	>67	45	19.1
	Total	236	100
Marital status	Single	24	10.2
	Married	96	40.7
	Widow	57	24.2
	Widower	25	10.6
	Divorced	34	14.4
	Total	236	100
Educ	illiterate	44	18.6
	1-6	21	8.9
	7-12	35	14.8
	certificate	14	5.9
	diploma	58	24.6
	degree & above	64	27.1
	Total	236	100
Residence	Rural	80	33.9
	Urban	156	66.1
	Total	236	100
Disease	Breast cancer	73	30.9
	Cervical cancer	51	21.6
	renal failure	23	9.7
	Diabetes	89	37.7
	Total	236	100

Palliative Care

The Status of Quality the Primary Palliative Care Service and Patients’ Satisfaction

To examine the quality of the primary palliative care service and the satisfaction of the chronic disease patients with it, descriptive statistic was computed. Concerning the quality of the primary palliative care service, the result reveals that the calculated mean is 2.56 and the mean of the satisfaction of the patients with the primary palliative care was 2.53.

Table 4 Status of Quality of PPC and Satisfaction

Disease type	Quality of PPC			Satisfaction with PPC			Remark
	M	SD	T	M	SD	t	
Breast & cervical cancer, renal failure & diabetes	2.56	0.67	-10*	2.53	0.64	-11*	M < 3

- *P<0.05*

One sample *t-test* was applied to see whether the status of the quality of the primary palliative care service and the level of satisfaction of patients with it were above or below the expected mean [3]. The test result of one sample *t- test* reveals that the *t-test* score [*t* (235) = -10, p < 0.05] is statistically significant. This finding has proved that the mean about the quality of the primary palliative care service for chronic disease patients was less (*M*=2.56; *SD* = 0.67) than the expected mean (*M* = 3.00). This implies that the quality of the primary palliative care service for chronic disease patients [renal failure, diabetes, breast, and cervical cancer patients] was low. In addition, one sample t-test was run to determine whether the level of patients’ satisfaction with the primary palliative care service was below or above the expected mean value. The test result [*t* (235) = -11, p < 0.05] proved that the level of satisfaction of chronic disease patients with the primary palliative care was low. The result has been tabulated below.

Palliative Care

Table5 Quality of PPC and Satisfaction of patients with it

Disease type	Exp. M	Quality of PPC				Satisfaction with PPC			
		M	SD	t	Sig/*p*	M	SD	t	Sig/*p*
Breast & cervical cancer, renal failure & diabetes	3	2.56	0.67	-10*	0.00	2.53	0.64	-11*	0.00

- *P < 0.05 in both cases*

When one sample t-test was computed, without splitting the data, the result attested that the quality of palliative care was poor and the patients' satisfaction was low, but the one sample t-test result doesn't show the view of the patients in terms of the types of diseases they faced. The data were split by SPSS software into four groups. Splitting the data was conducted based on the types of diseases. Then, one sample t-test was computed and the results are shown in tables 6 and 7 respectively.

The first table reveals that the quality of the palliative care is poor, but the diabetes patients were the least beneficiaries of the quality of the primary palliative care service.

Table 6 Quality of Palliative Care

Diseases the participants faced		One-Sample Test			Test Value = 3		
		t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
						Lower	Upper
breast cancer	Quality of PPC	-22.255	72	.000	-.84536	-.9211	-.7696
cervical cancer	Quality of PPC	-20.802	50	.000	-.91830	-1.0070	-.8296
renal failure	Quality of PPC	-6.041	22	.000	-.43478	-.5840	-.2855
diabetes	Quality of PPC	2.599	88	.011	.17041	.0401	.3007

So does the table below reveal that the satisfaction of the patients with the primary palliative care service was low, but the lowest satisfaction was the diabetes' patients' satisfaction.

Table 7 Satisfaction of Patients

Diseases the participants faced		One-Sample Test t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference Lower	Upper
		Test Value = 3					
breast cancer	Satisfaction with PPC	-18.761	72	.000	-.87591	-.9690	-.7828
cervical cancer	Satisfaction with PPC	-22.740	50	.000	-.96770	-1.0532	-.8822
renal failure	Satisfaction with PPC	-6.041	22	.000	-.43478	-.5840	-.2855
diabetes	Satisfaction with PPC	3.145	88	.002	.15466	.0569	.2524

The one sample t-test did not reveal the clear difference between groups; so, a one way ANOVA was run to see if there was a statistically significant difference among the patients with regard to the quality of the primary palliative care service and their satisfaction with it in terms of the types of diseases. The result concerning quality, as shown in the following table, attests that [F ((3) (236)) = 89.9, $p < 0.05$]. This implies that there was a statistically significant difference among the groups of patients based on the types of diseases. In addition, the result with regard to satisfaction [F ((3) (236)) = 122, $p < 0.05$] attests that there was a statistically significant difference among the groups patients based on the types of diseases.

Table 8 Patients stance about the quality of PPC and their satisfaction

One way ANOVA- Quality & satisfaction						
Disease	Quality of PPC			Satisfaction		
	df	F	Sig/*p*	df	F	Sig/*p*
Breast cancer, cervical cancer, renal failure and Diabetes	3	89.9	0.000	3	122	0.000

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The post Hoc test shows that breast cancer and cervical cancer patients did not have a statistically significant difference with regard to the quality of the primary palliative care service at *p* [0.8] > 0.05, but had difference with renal and diabetes patients at p [0.001] and [0.000] respectively. When the cervical cancer patients were compared with breast cancer, renal and diabetes patients, they did not have a statistically significant difference with breast cancer patient at *p* [0.8], but had difference with renal [at *p* (0.000)] and diabetes [at *p* (0.000). When renal failure patients were compared with breast, cervical and diabetes patients, they had a statistically significant difference at *p* (0.001), (0.000) and (0.000) respectively. When the diabetes patients were compared with breast and cervical cancer, and renal patients, they had a statistically significant difference at *p* (0.000), (0.000) and (0.000) respectively.

Table 9 Comparing the Patients' Stance about Quality of PPC

Multiple Comparisons

Dependent Variable: Quality of PPC
Tukey HSD

(I) Diseases the participants faced	(J) Diseases the participants faced	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
breast cancer	cervical cancer	.07294	.08374	.820	-.1437	.2896
	renal failure	-.41058*	.10971	.001	-.6945	-.1267
	diabetes	-1.01577*	.07245	.000	-1.2033	-.8283
cervical cancer	breast cancer	-.07294	.08374	.820	-.2896	.1437
	renal failure	-.48352*	.11524	.000	-.7817	-.1853
	diabetes	-1.08871*	.08058	.000	-1.2972	-.8802
renal failure	breast cancer	.41058*	.10971	.001	.1267	.6945
	cervical cancer	.48352*	.11524	.000	.1853	.7817
	diabetes	-.60519*	.10733	.000	-.8829	-.3275
diabetes	breast cancer	1.01577*	.07245	.000	.8283	1.2033
	cervical cancer	1.08871*	.08058	.000	.8802	1.2972
	renal failure	.60519*	.10733	.000	.3275	.8829

*. *The mean difference is significant at the 0.05 level.*

Palliative Care

When the breast cancer patients were compared with cervical, renal and diabetes patients, they did not have a statistically significant difference with cervical cancer patients at *p* [0.5], but had difference with renal [at *p* (0.000)] and diabetes [at *p* (0.000) ; when cervical cancer patients were compared with breast, renal and diabetes patients, they did not have a statistically significant difference with breast cancer patients at *p* (0.59), but had difference with renal failure [at *p* (0.000) and diabetes [at *p* (0.000)] patients respectively. When the renal failure patients were compared with breast, cervical cancer, and diabetes patients, they had a statistically significant difference at *p* (0.000), (0.000) and (0.000) respectively and when the diabetes patients were compared with breast, cervical cancer, and renal failure patients, they had a statistically significant difference at *p* (0.000), (0.000) and (0.000) respectively.

Table 10 Comparing the Patients' Satisfaction with PPC

Multiple Comparisons

Dependent Variable: Satisfaction with PPC

Tukey HSD

(I) Diseases the participants faced	(J) Diseases the participants faced	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
breast cancer	cervical cancer	.09180	.07351	.596	-.0984	.2820
	renal failure	-.44112*	.09631	.000	-.6904	-.1919
	diabetes	-1.03057*	.06360	.000	-1.1952	-.8660
cervical cancer	breast cancer	-.09180	.07351	.596	-.2820	.0984
	renal failure	-.53292*	.10117	.000	-.7947	-.2711
	diabetes	-1.12236*	.07074	.000	-1.3054	-.9393
renal failure	breast cancer	.44112*	.09631	.000	.1919	.6904
	cervical cancer	.53292*	.10117	.000	.2711	.7947
	diabetes	-.58944*	.09422	.000	-.8333	-.3456
diabetes	breast cancer	1.03057*	.06360	.000	.8660	1.1952
	cervical cancer	1.12236*	.07074	.000	.9393	1.3054
	renal failure	.58944*	.09422	.000	.3456	.8333

**. The mean difference is significant at the 0.05 level.*

CHAPTER FIVE: DISCUSSION

The discussion includes summary of the findings, what the findings mean, the difference between the findings of this study and other related studies and theoretical explanations.

The study came up with the factors that decelerated the quality of palliative care service. The findings include dysfunctional infrastructure, dysfunctional interaction, incapacity of the professionals, scarcity of medicine, lack of manpower, long waiting time, medical error and poor complaint system. The quality of the primary palliative care service was poor for it did not fulfil the structure, process and outcome; nor did it manage the symptom and pain; nor did it improve the patients' quality of life. The status of the quality of the primary palliative care service was lower than the patients' expectation. Their satisfaction, as a result, was low. The findings were discussed below in terms of their themes.

Dysfunctional Infrastructure

As the qualitative and quantitative findings confirmed, the infrastructure of the hospital was dysfunctional. The infrastructure is the base of the hospital or it is the setting where health care is provided. There was no waiting room for cancer and dialysis patients. They sat under the trees around the dialysis and cancer treatment centres and waited for their turn. This aggravated their pain. They were hurt psychologically believing that they didn't have a waiting room for they were ignored; for they were not considered as human beings; as they were believed to die; as they were believed to be objects as if it had finished its functions of this world. The possible explanation for the dysfunctional aspects of the hospital is that the hospital administration ignored the tangible aspects of the hospital. Also, the administration did not pay attention to the problems the patients faced due to the dysfunctional aspect of the hospital.

In other words, the hospital administration ignored the infrastructure of the hospital; so did it forget the facilities of chronic disease patients and the patients themselves. Infrastructure, as Donabedian (2005) stated, refers to the health system characteristics that affect the system's ability to show the readiness of providing health service, but Felege Hiwot Hospital lacked this readiness. This didn't meet the patients' expectations; they faced undesired outcomes for they sat, stayed and slept on stones, corridors, and veranda of the hospital. They attested that the hospital didn't have one of the components of the primary palliative care service quality as they expected—infrastructure— which is the subset of structure. The patients were juggling frogs—they were trying to do something very difficult—staying in a place for service although the dysfunctional infrastructure of the hospital aggravated their pain. In quality assessment and monitoring, Donabedian (2005) presented his idea schematically: structure influences process and process influences outcome. This model implies that the structural characteristic of the places where care takes place influences the process of care so that its quality decreases or increases.

Dysfunctional Interaction

Interaction is the only bridge that connects the patients and the service providers, but there was distorted interaction between the patients and the service providers. This discarded professionalism, friendliness and responsiveness. The service providers were not willing to understand and help the patients as soon as the patients had wanted the service. Chronic diseases patients needed a response as quick as a knee-jerk reaction as they were in complete darkness; they had needed the service providers to be a knight in shining armour, someone who could save them from the great trouble and danger (pain and death). However, as the interaction was dysfunctional, the patients and the service providers had miscommunication. The patients shouted for help, but the service providers didn't respond to the patients as quickly as they had been supposed. They didn’t perform the mission of the hospital dependably and accurately.

The service providers didn’t put their assurance into practice; they didn’t inspire trust and confidence for the patients. Empathy seemed to be unthinkable for the service providers seemed to ignore the patients. In addition, the dysfunction interaction banished person-centred care. The patients didn’t involve in their care and decision making about the care they were provided with. The service providers’ competence was not disclosed in practice, their skill and knowledge were not applied in saving the patient from pain. In other words, the service providers (the nurses and the doctors) did not apply their skills and knowledge to restore the patients’ health as quick as possible. Moreover, the service providers, due to the distorted communication, didn’t keep the patients informed in the language they [patients] could understand.

The patients indicated that the service providers were devoid of the expected ability, knowledge, empathy, and trustworthiness. The patients didn't have the best interest at heart towards the service providers, but they went to the hospital because it was a case of Hobson’s choice—the choice between taking what was offered and getting nothing at all. Furthermore, the patients felt that they didn’t acquire primary palliative care service that was adherent to an evidence-based practice to bring about the desired outcome of an effective health service. As Donabedian (2005) affirmed, process is the way systems and processes work to deliver the desired outcome. Interaction is one of the elements of process of palliative care that makes meaningful communication between the patients and the service providers, but, at Felege Hiwot Hospital, the interaction between the patients, and the doctors and the nurses was distorted. The system and the process didn’t deliver the desired outcome— there was no credible and safe service delivery.

Palliative Care

Incapacity

The other finding of this study is incapability of service providers. The service providers had been incapable of performing their duty as effective as they had been expected, their treatment reflected their incapacities. They administered wrong drugs; they wrote wrong prescription, they ordered the patients to take very high dosage, and improper operation. The above findings mean that the patients were not getting the desired outcomes of a referral hospital— security (the freedom from danger, risk, and doubt), credible and accurate palliative care service, effective and timely treatment, pain relief, health improvement and wellbeing. The survival rates of the chronic disease patients were diving and its destination seemed to be taking the patients till a grave.

The patients were a lame duck; they were in a great trouble because the incapacity of the service providers brought about risk in addition to their pain due to the deadly diseases. The patients' wellbeing was in the lap of gods in view of the incapacity of the service providers—their fate would decide the outcome. Donabedians (2005) postulated that the nurses and the doctors should strive in order for quality to be gained, but at Felege Hiwot Hospital, the service providers' [the nurses' and doctors' capacities] capacity of providing the palliative care service did not maintain the desired outcome— did not improve the health status of the patients. The possible explanation about the incapacity of the nurses and the doctors is that they might not have attractive salary; they might not have incentive. In addition, they might be reluctant to improve their professional competence and they might not have continuous professional development program to instigate them.

Scarcity of Drugs

Scarcity of drugs is the other finding of this study. The patients couldn't get medicine from the pharmacy of the hospital. They tried to buy from private pharmacies where the medicine was too expensive for patients. Nearly, all of the patients were poor and they couldn’t afford to buy the medicine from the private pharmacies. Searching for medicine, the inability of buying the medicine, wasting time and force, and facing anxiety due to the lack of medicine were also the serious problems the chronic disease patients faced. The lack of medicine was the last straw (the final problem that made the patients lose their temper and hope or the problem that finally brought about the collapse of the dream of pain relief and recovery of patients) darkened their hope [of well-being/ pain relief and/or recovery]. They had got a prescription paper, but they couldn’t buy the medicine due to its high cost and/or scarcity even in the private pharmacies. The patients, as a result, felt like a fish out of water, they were nearly in death’s palm for they didn’t have the medicine that could make them gain pain relief and prolong their lives. Donabedian (2005) affirmed that a structure of a hospital has to have drugs and supplies to provide the patients with quality of the primary palliative care service, but this postulate was not put in to practice at Felege Hiowot Hospital for chronic disease patients. The possible explanation of this issue is that the health bureau of Amhara National Regional State and the hospital administration itself ignored to access medicine to the chronic disease patients.

Lack of Manpower

Lack of manpower was also the other finding of this study. Due to this problem, the patients didn’t get standardized, accurate, credible, patient-centred, reliable and risk-free or safe services. They had never been examined by specialist doctors. They asserted that the patients didn't get effective and efficient services. They were mainly treated by nurses. The service was not provided by the right doers—doctors and specialist doctors. This couldn't maintain the quality of the primary palliative care service; as a result, the patients faced the risk of treatment. Due to this problem, the patients were to lose their marbles, they were to go mad. Mulu was, for instance, one of the patients who had become a patient of renal failure due to the medical error made at Felege Hiwot Hospital. She had nearly gone mad. She had a daughter who was about 7 months old. The kid couldn't get breast feeding regularly due to the mother’s sickness. The husband was ready to donate one of his kidneys to Mulu, but they didn't have money for transplantation. She, therefore, began an official fund raising program (begging being in a mini-bus). She was begging publicly [fund rising in public] in Bahir Dar in May and June, 2019. Had there been a specialist doctor, the woman wouldn't have faced a renal failure. Lack of manpower at Felege Hiwot Hospital resulted in risk, medical error, weak examination and short examination time and long waiting for the service.

Donabedians (2005) claimed that manpower is one of the core components of health service that helpful to achieve quality of palliative care service, but due to the lack of manpower and the associated problems, the chronic disease patients faced problems; the remedy of their pain was as high as the sky and; as a result, they were as mad as a hornet, they were very angry. So were they as mad as a badger, they were nearly crazy. The patients, therefore, didn’t make headway; they didn’t progress/ have improvement of health status. The lack of manpower delayed their treatment, made the patients face improper treatment and risk. As a result, their pain aggravated and death made their hair stand on end— it terrified them and they felt that it would under control them soon.

They felt that they were dead in the water; they were not going, as they had been very sick and tired of searching for a remedy, anywhere or making any progress of health. The problems stated so far, in turn, decelerated the quality of the primary palliative care service at the hospital. The possible explanation of the lack of manpower is that the health bureau and the hospital administration ignored the value and result of professionalization; they rather deprofessionalized the doctors and the nurses by assigning them in the units where they did have a specialization. As a result, they could not treat patients well based on what they had learnt.

Palliative Care

Long Waiting Time

Long waiting time is the last finding that decelerated the quality of the primary palliative care service for chronic disease patients at Felege Hiwot Hospital. The patients, hoping that they would get timely service, went to the hospital in time, but the service provider went to the hospital late. They didn’t even begin the service as quick as possible when they had reached the hospital.

Unless the patients get timely service, they never exhibit progress. The chronic disease patients waited for a long time for service in the setting which was uncomfortable. This problem aggravated their pain and suffers. This happened time and again, but time and tide wait for no man and the speed of severity of the pain of the patients was quicker than the speed of their age.

The service providers didn’t understand the problem of a long waiting time as the service providers turned a deaf ear to the patients—they didn't listen to the patients’ complaint of long waiting time. The pain kept on its aggravation twenty-four-seven; they were suffering all the time (24 hours a day and 7 days a week). A long waiting time doubled the severity of the pain of the patients. They suffered from the diseases, in seven days, as long as 14 days. They were worried for four days to live for three days. This attests how poor the quality of the primary palliative care service was. The possible explanation for the long waiting time was that as the doctors and the nurse worked in private health institutions, some doctors and nurses might have become weak. Also, they might have forgotten their responsibility.

Medical Error

The medical error made by the doctors and the nurses was the other hurdle the patients faced. The patients, believing that they could get remedy for their pain, went to the hospital; nonetheless, they faced the medical errors that aggravated their pain. They even faced medical errors that could kill them. The finding implies that many of the doctors and the nurses performed their duties without a practice guideline. Some of them were novice practitioners. As a result, they made medical errors that aggravated the suffering of the patients due to the chronic diseases.

Poor Complaint System

The patients faced a number of problems. What have been discussed were the problems that patients faced. The patients faced problems that decelerated the quality of the primary palliative care service; they did not get a professional who could understand them. Above all, they suffered from the poor compliant system. The hospital was supposed to design a complaint submission to solve the problems the patients faced and to improve the primary palliative care service. The patients attempted to complain, but no one heard what they complained; as a result, they became hopeless; they believed that they were ignored; they were not considered as human beings. The possible explanation for the poor complaint system is that the hospital did not have quality assurance unit.

Quality of Primary Palliative Care Service

The finding with regard to the palliative care deals with primary palliative care. The nature (type) of palliative care which was provided for chronic disease patients was primary palliative care. It was provided for the patients by health professionals who had not taken palliative care training. It was provided by primary care clinicians, physicians who were disease-oriented specialists and nurses, but there were no oncologists and cardiologists and social workers. In addition, there was no palliative care service team. As a result, the service was provided for the patients in a dispersed fashion and it focused only on advice and counselling. The goals of palliative care [symptom management, holistic care, pain relief, quality of life, rehabilitation, fund raising, drug donation and bereavement] were not achieved. It did not address symptom and pain. Nor did it improve the quality of life of patients.

Primary palliative care is the clinical management and care coordination including assessment, triage, and referral using a palliative care approach for patients with a life limiting illness and/or end of life care. It has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary, but these procedures and contents were not fulfilled at Felege Hiwot Hospital.

The primary palliative care service focused on pain and symptom management and quality of life. But it was not holistic not because it had been offered by health professionals who had not been certified in palliative care, but precisely because it didn't consistently focus on pain relief, symptom management and quality of life. In addition, the service providers didn't have a palliative care practice guideline. It was not formal enough to help patients acquire pain relief; it was not capable of managing symptoms. This attested that the health professionals didn't provide evidence-based and scientific primary palliative care services. The primary palliative service was not basically different from the usual education and information service of the hospital.

As stated so far, there was no specialty palliative care service at Felege Hiwot Hospital. The primary palliative care service itself seemed to be casual. It was sometimes provided for the chronic disease patients and it was not sometimes provided. As a result, the patients suffered from physical, social, and psychological pain. Their pain and symptoms were not managed. The patients did not get rehabilitation. The chronic disease patients and their families didn't maintain quality of life. They didn’t acquire holistic primary palliative care service.

Palliative Care

To end with, regarding quality of the primary palliative care service, the study asserted that it didn't fulfil its three components of as a health service: structure, process, and outcome. It didn't have a well-established infrastructure; it did not have enough manpower; it did not have drug access for chronic disease patients. Nor did it have a well accelerated and strong process as there was a dysfunctional interaction between the patients and the service providers. There was no reliable service—the professionals didn’t put the mission of the hospital dependably and accurately. They were not responsive as quick as they were expected—they were not willing to help patients timely. They lacked empathy and assurance.

Concerning outcome, the patients didn’t have a progress of health; nor did they acquire their expected wellbeing. In other words, their health status didn’t show improvement. Their social function was static because they didn't get relief of pain from the service. They were swinging between life and death. Relief of pain, recovery, wellbeing and social functioning became a night mare for those chronic disease patients. As a result, they were not satisfied with the primary palliative care service as it was below the patients’ expectation.

The doctors and the nurses seemed to be deprofessionalized and the patients developed nihilism. The patients were swinging in the tree of pain towards life and death as the primary palliative care service was nearly devoid of the three quality components as a health service: structure, process, and outcome. Satisfaction with the primary palliative care service was pie in the sky, it was utterly impractical.

The components of the health service quality in terms of palliative care service were not fulfilled; as a result, they could not meet the patients’ needs. The quality the primary palliative care service was poor because the findings affirmed that the service did not fulfil its structure, process and outcome up to the heart of the patients and the symptom and the pain that the patients faced were not managed; as a result, the patients did not achieve quality of life. The quality of the primary palliative care service was low in view of the hurdles which have been discussed so far. As a result, the patients' satisfaction with the primary palliative care service was low, too.

The findings of this study was compared and contrasted with previous studies. Hiwot, Murugan, Fisisha, MIgnot and Desalegn (2014) conducted a study on knowledge, attitude, and practice and associated factors towards palliative care among nurses in selected hospitals in Addis Ababa. They found out that the nurses had a "favorable attitude", but they had poor knowledge and practice towards palliative care. Samuel, Hiwot, Tesfaye, and Tadesse (2016) conducted a study on the issue and found out that "the majority of the nurses had a favourable attitude" and "good knowledge" on palliative care. Temamen, Yeamanuelwork, and Admasu(2018) conducted a study on palliative care practice and associated factors among nurses in Jimma medical centre and found out that "almost two-thirds of the nurses had poor palliative care practice. Whereas, this study was conducted on the hurdles decelerating the quality of the primary palliative care service, the status of the quality of the primary palliative care service and the patients' level of satisfaction with the primary palliative care service. The issue was investigated from the patients' point of views. Overall, this study is different from the previous studies (those reviewed so far) in its title, objectives, methodology, participants, and results.

With regard to theoretical aspects of the study, the hurdles that decelerated the quality of the primary palliative care service, the status of the quality of the palliative care and the patients' satisfaction were explored through Donabedian's (2005) model of health service. He claimed that health service, including palliative care service, comprises structure (infrastructure, manpower and drugs and supplies), process (system and process of service delivery) and outcome (improved health status, satisfaction and wellbeing).

Palliative Care

The structure of the hospital was distorted. The infrastructure was not as expected by the patients. The infrastructure was not fulfilled. There was lack of medicine and manpower. This affirms that Felege Hiwot Hospital did not fulfill the elements of structure that could improve the patients' health status. This reveals that what Donabedian (2005) postulated as elements of structure were not fulfilled.

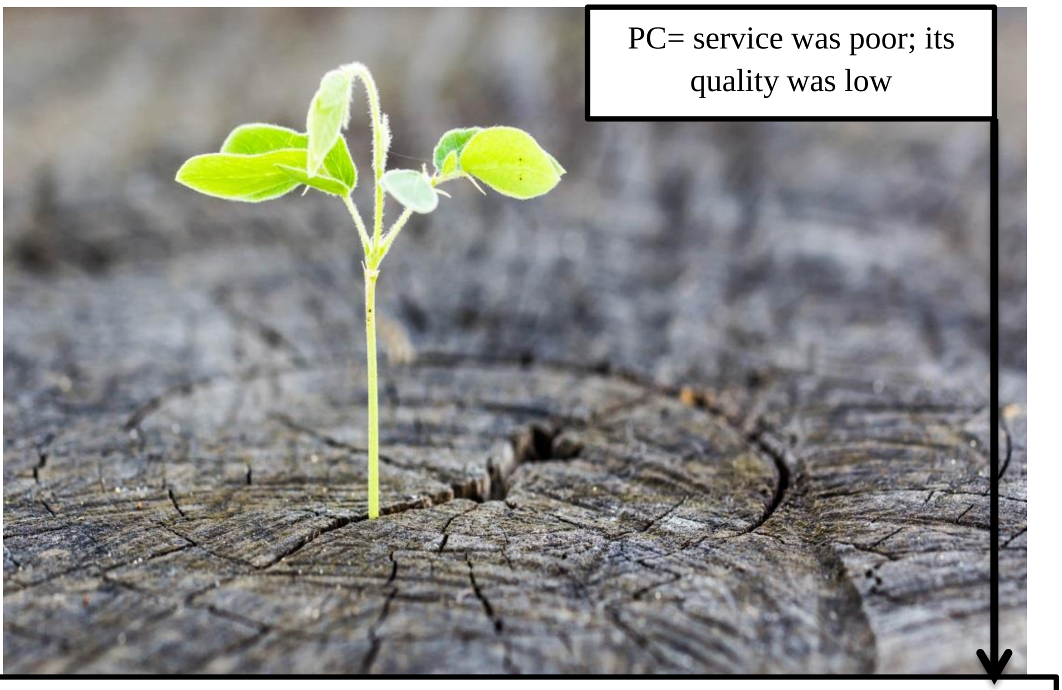
With regard to process, the system and the process were not interwoven. The interaction between the patients and the service providers was distorted. Interaction is the bridge between the patients and the service providers (the nurses and the doctors), but as it was nearly broken, the interaction was dysfunctional. The primary palliative care service delivery was not strong as it was expected by the patients. This again affirms that the second element of health service of palliative care postulated by Donabedian (2005) was not fulfilled.

Concerning outcome, the findings the study affirmed that the patients did not have health progress of palliative care service. The findings rather affirmed that their pain aggravated due to the distorted palliative care service. The symptoms and the pain that the patients had faced were not managed; nor was the quality of life of the patients achieved. This attests that the third element of health service quality of palliative care (outcome) proposed by Donabedian (2005) was not fulfilled.

The Donabedian model suggests a relationship where each factor is affected by the previous factor. From the above theoretical exploration of the primary palliative care service, the heart of the findings is that the quality of the primary palliative care service for chronic disease patients was poor at Felege Hiwot Hospital for it did not fulfill the elements of quality of palliative care service and for it did not maintain the desired expectations of the patients.

Palliative Care

Figure 2 essence of the finding of the study in symbol form



PC= service was poor; its quality was low

The patients were in a dim light heading towards complete darkness: renal patients—candle in the wind; cancer patients—an evening sun light and diabetes patients—moon at down. All of them were at the cliff of a grave in the circle of death, but their resilience did not totally melt away.

Everything they needed was not food or love; all they needed was the cures for cancer, the remedies for renal failure; the relief from diabetes!

It is said that death is more universal than life; everyone dies, but not everyone lives. The patients didn’t know what was happening to them. It seemed to be only a fine cry—loud and long—but it had no bottom and it had no top, just circles and circles of sorrow. So did it seem that death was to come before life. They knew that death was to shade their physical bodies. That was it; they were to go, but they didn’t come! They were to die, but they had not lived for they were only to bloom and the palliative care service itself was to die!

CHAPTER SIX: CONCLUSIONS and IMPLICATIONS

Focusing on palliative care service for chronic disease patients, the study had been conducted at Felege Hiwot Hospital. It has four objectives. The objectives were achieved. The data were gathered, dissected, organized and examined and what each part meant was explained; then, meaning was made.

The overall findings implied that the primary palliative care service for chronic disease patients did not comprise structure, process and outcome in such a way that they could help patients manage symptom and pain, achieve quality of life and rehabilitate them. The primary palliative care service was not holistic for it didn’t consist of the physical, psychological, social and spiritual aspects of life up to the patients’ expectation. So, it was poor and the patients’ satisfaction was low.

Their pain was going on fast and furious; their suffering was going on. They were depressed since they had got into hot water (trouble due to chronic diseases and the distorted palliative care service). The primary palliative care service was dead as door nail, it was nearly lifeless as it was not principle-based because it was not provided based on palliative care guidelines. Nor was it a team-based action and well-organized. So, the pain of the chronic disease patients was devastating them very quickly. They were in a condition that was a fate worse than death since they were in the evening sun heading towards the cliff of death. This affirms that the quality of the primary palliative care service and the patients’ satisfaction with it were squat.

The chronic disease patients’ time end before they begin it for the chronicity of the disease flies like a cheetah in their nervous system and for the primary palliative care service drags by at the ponderous pace of a snail ascending stadium stairs.

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The patients affirmed that there were a number of hurdles that made them develop nihilism, but “the rest,” as Shakespeare said, “is Silence”; Nonetheless, the patients seemed to be disturbed by the noise of the silence.

Implication of the Study

Implications to the Social Work Practice

The findings of this study enlighten social work practitioners and contribute to the field as working with chronic disease patients is one of the areas of interest for macro social work practitioners. This study informs those who work on palliative care for chronic disease patients what the qualities of the service should comprise; what the constraints that decelerate the quality of the primary palliative care service are; what the dimensions of palliative care include, what the quality of life of patients and managing pain mean and how they can be maintained. Professional counsellors, nephrologist, oncologist, psychiatrists, social workers, psychologists, and nurses would gain bases for action to improve the quality of the primary palliative care service; to evaluate how the interaction between patients and service providers matters; to see how it is difficult to provide palliative care service for chronic disease patients without palliative care training and guideline. The study can also be a baseline to establish palliative care team and to conduct in-service training for the team members.

So does this study persuade social work teachers and students to evaluate critically what the chronic disease patients suffer from due to the lack of well-organized and evidence-based palliative care service. It may instigate them to advocate that the primary palliative care service for chronic disease patients should be restructured. They might also be motivated to establish a specialist palliative care team.

Implications for Future Study

Palliative care service remains a serious concern with expected outcomes not predictably achieved. Felege Hiwot Referral Hospital needs to optimize resources and manpower uses and expand the chronic disease patients' system of health service delivery. So does it need to establish a specialist palliative care service team as the number of chronic disease patients increases in an alarming rate.

So that at the end, there is no end because the quality of the primary palliative care service needs further investigation for improvement. The palliative care service for chronic disease patients seemed to have been ignored at Felege Hiwot Hospital. To bridge the above gaps, the following potential areas of investigation have been proposed from the finding of this study.

One of the areas of future studies ought to focus on is the causes of medical error and its consequences on patients. Patients and their families complain many times. Patients suffer from the problems appeared due to medical errors. Much has been said about this problem, but the patients become the subaltern segment of the society—people who shout, but no one listens to them not because they can’t speak, but precisely because no one is willing to listen to their complaint. The causes and consequences of medical errors should critically be investigated.

The other study area is the prospects of chronic disease and its burden on family. In our society, chronic disease is increasing. The burden of the disease on the patient and their families is horrifying. The pain, associated diseases, economic crises, hopelessness, and social pressure accelerate the death of the patients and their families’ disintegration. This intern disperses the family members that may become the problem of the society later. Sequential explanatory research could be conducted on this issue.

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The third potential study area can be chronic and associated diseases, social and economic crises on patients. Chronic disease patients suffer from chronic disease and other chronic diseases acquired due to the first chronic disease. A diabetic person, for instance, faces hypertension, heart failure, eye defect, and sexual dysfunction. Social and economic crises are also associated problems that accelerate the death of the patients and the disintegration of the family. This area can be critically evaluated and explained through sequential exploratory research.

The palliative care service has not been paid attention at Felege Hiwot Hospital. Therefore, the Health Bureau of Amhara National Regional State and Felege Hiwot Referral Hospital should strive to improve the palliative care service by establishing specialist palliative care team. The Department of Social Work of Bahir Dar University should help the hospital administration in establishing the specialist palliative care team. But, as a short term remedy, the hospital, the bureau and the Department of Social Work of Bahir Dar University should, in cooperation, organize an in-service training on palliative care service for the nurses and the doctors.---------------------------------//---.

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Appendixes

Appendix 1 Informed Consent Form [Amharic Version]

ውድ ተሳታፊየ

ስሜ አለባቸው ፈንታው ይባላል፡፡ በባህርዳር ዩኒቨርስቲ የሶሻል ወርክ ትምህርት ክፍል ተመራቂ ተማሪ ነኝ፡፡ የሶሻል ወርክ ትምህርትን ለማጠናቀቅ በከፊል ማሟያነት የሚሆን ጥናት እያካሄድኩ ሲሆን የጥናቱ አላማም በፈለገ ሂዎት ሪፈራል ሆስፒታል የሚሰጠው ማስታገስ ህክም [palliative care] ምን እንደሚመስል ለመፈተሽ ነው፡፡ ለዚህም እርስዎ ለሚከተሉት ጥያቄዎች የሚሰጧቸው ትክክለኛ ምላሾች ለጥናቱ መሳካት ከፍተኛ አስተዋፅኦ ያደርጋሉ፡፡

በመሆኑም ለሚደረግልኝ ቀና ትብብር እያመሰገንኩ ቃለመጠይቁ በድምፅ መቅረጨ የምቀርጽ ሲሆን በቃለ መጠይቁ ሂደት ውስጥ የማገኘው መረጃ ለጥናቱ አላማ ብቻ የሚውል ሲሆን ሚስጥራዊነቱም የተጠበቀ ይሆናል፡፡ በተጨማሪም ከዚህ ጥናት ውጭ ለሌላ አላማ ማሳኪያ እንደማይሆን አረጋግልጣለሁ፡፡ ከዚህ ጥናት ጋር በተያያዘ ሊያጋጥሙ የሚችሉ የታወቁ ችግሮች የሉም፡፡ በዚህ ጥናት ውስጥ ለመሳተፍና ልምድዎትን ለማካፈልና ለመመለስ ፈቃደኛ ካልሆኑ በማንኛውም ጊዜ የማቆም መብትዎ የተጠበቀ ነው፡፡

ይህን ጥናት አስመልክቶ ማንኛውም አይነት ጥያቄ ወይም ሀሳብ ካለዎትና ማንኛውም ችግር ካጋጠመዎት በማንኛውም ጊዜ በስልክ ቁጥር 0920182921 በመደወል ማነጋገር ይቻላሉ፡፡

ስለትብብርዎ ከፍተኛ ምስጋና አቀርባለሁ፡፡

ጥናቱን የሚያካሂደው፡- አለባቸው ፈንታው

ከላይ የተዘረዘሩትን ሀሳቦች በጥንቃቄ በማንበብ ይህንን ስምምነት ተረድቻለሁ፡፡ በመሆኑም ከላይ በተዘረዘሩት ሀሳቦች ተስማምቸ ለጥናቱ ተሳታፊ ለመሆን ፈቃደኛ መሆኔን በፊርማየ አራግጣለሁ፡፡

ፊርማ………………………………………………….……ቀን…………………..

Appendix 2 Informed Consent Form [English Version]

Dear Participant

My name is Alebachew Fentaw. I am a graduate student at Bahir Dar University in the Department of Social Work. The objective of this study which I am conducting in partial fulfillment of the requirements of Master of Social Work (MSW) is to investigate the primary palliative care for chronic disease patients at Felege Hiwot Hospital. Thus, your response and correct answers to interview questions are of a great help to the study findings.

I admire your cooperation and I assure you that any information you provide will be used for academic purposes only, strictly confidential and won't be used for any other purpose

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.There are no risks associated with this study. If you are not interested in giving answers, you have the right to withdraw from participating in the study at any time.

If you have any questions or concerns about this study or if any problem occurs, please let me know dialing at 09 20 18 29 21

Thank you very much for your cooperation.

Researcher: Alebachew Fentaw

I have carefully read the above note and understood this agreement. Hence, I agree to participate in the study under the conditions described above.

Signature: --- Date: ---------------------------------

Appendix 3 Interview Guideline for Participants [Amharic Version]

ክፍል አንድ፡- መነሻ መረጃዎች

1. ፆታ
2. እድሜ
3. የትምህርት ደረጃ
4. ቦታ (ከተማ/ገጠር)
5. የስራ ሁኔታ
6. የጋብቻ ሁኔታ
7. ያጋጠመ በሽታ

ክፍል ሁለት፡- የማስታገስ ህክምና [palliative care]ጥራት የሚያጓድሉ እንከኖች

1. በፈለገ ሂዎት በሆስፒታል የሚሰጠዎት የማስታገስ ህክምና አገልግሎት ምን ይመስላል?
2. የማስታገስ ህክምናዉን ጥራት እንዴት ይገመግሙታል?
3. የማስታገስ ህክምና አገልግሎቱን ጥራት የሚጓደሉ እንከኖች አሉ ብለው ያስባሉ?
4. የሆስፒታሉ ግንባታ፣ አገልግሎት ሰጭዎችና የመድሀኒትና ቁሳቁስ የማስታገስ ህክምና አገልግሎቱን ጥራት በሚያሳልጥ ሁኔታ ተሟልተዋል ብለው ያምናሉ?
5. በእርሰዎና አገልግሎት ሰጭዎቾች መካከል ያለው ግንኙነትና የአገልግለት አሰጣጥ እንደሚጠብቁት ሆኖ አግኝተውታል?

ክፍል ሶስት፡- በፈለገ ሂዎት በሚሰጠው የማስታገስ ህክምና እርካታ

1. የአገልግሎቱ ይዘት ምንምን ላይ ያተኩራል?

Palliative Care

2. የማስታገስ ህክምናውን እንደሚጠብቁት አግኝተውታል?
3. የማስታገስ ህክምናው ከመደበኛው የትምህርተና መረጃ አገልግሎት ይለያል ብለው ያምናሉ?
4. የማስታገስ ህክምናው የልብዎን አድርሷል ብለው የምናሉ? እረከተዋል?

Appendix 4 Interview Guideline for Participants [English Version]

Section One: Background Information

1. Sex

2. Age

3. Level of Education

4. Place of residence [urban/rural]

5. Occupation

6. Marital status

7. Disease Faced

Section Two: The Hurdles Decelerating Quality of the Palliative Care Service

1. How do you find the primary palliative care service at Felege Hiwot Hospital?
2. How do you evaluate the quality of primary palliative care service?
3. What are snags that decelerate the quality of the palliative care service?
4. Are the infrastructure, man power drugs and supplies fulfilled in such a way that they can accelerate the quality of the primary palliative care service?
5. Are the interaction between service providers and you, and the health service provision as you expected?

Section Three: Satisfaction with palliative care at Felege Hiwot Hospital

1. Do you think that palliative care service meets your needs?
2. What is the content of the palliative care?
3. Is the palliative care as you expected?
4. Is the palliative care different from the regular education and information service?
5. Does the palliative care servicesatisfy you?

Appendix 5 Questionnaire on Satisfaction for Participants [Amharic Version]

ይህ መጠይቅ የተዘጋጀው እረስዎ ስለሚያገኙት የማስታገስ ህክምና መረጃ ለመሰብሰብ ነው። ስለሆነም ስምዎትን መፃፍ አያስፈልግም። ለነዚህ ጥያቄዎች ትክክለኛ መልሶችዎን መስጠትዎ ለዚህ ጥናት ወጤታማነት ብዙ አስተፃኦ ያደርጋል። ስለሆነም ትክክልኛውን መልስ እንዲስጡ በአክብሮት ተጠይቀዋል። የሚስጡት መረጃ ለጥናት አገልግሎት ብቻ የሚውል ሲሆን ሚስጥራዊንቱም ይጠብቃል። ጊዜዎትን ሰውተው ይህን መጠይቅ ስለሚሞሉልኝ በጣም አመሰግናለሁ።

ክፍል አንድ

መመሪያ፡- እባክዎ ምርጫዎን የሚዎክለውን አማራጭ የራይት ምልክት በትክክለኛው ሳጥን በማስቀምጥ ያመልከቱ

1. *ፆታ፥-* *ወንድ፡-* ☐ *ሴት፡-* ☐
2. እድሜ፡- ☐
3. *የጋበቻሁኔታ፡-* *ያላገባ፡*☐ *ያገባ፡-*☐ የትዳር ኣጋር የሞተበት፥-☐ *የፈታ/ች፡-* ☐
4. የትምህርት ደረጃ፥-☐ *ያልተማረ፡-* ☐ 1ኛ-6ኛየተማረ/ች፡-☐ ከ7ኛ-12ኛየተማረ፡-☐ ሰርተፊኬት ☐ ያለው፡-☐ ዲፕሎማ፡- ☐ ዲግሪና ከዚያ በላይ፡-☐
5. *መኖሪያ-* *ገጠር፡-*☐ ከተማ፡- ☐
6. የበሽታ ዓይነት፡- የጡት ካንሰር፡-☐ የ ማህፀን ካንሰር ፡- ☐ የኩላሊት በሽታ፡- ☐ የስኳር በሽታ፡- ☐

ክፍልሁለት

ከዚህ በታች ለተመለከቱት ሀሳቦች የመርካት አለመርካት ደረጃዎን የራይት ምልክት በትክክልኛው ሳጥን በማስቅመጥ ያመልክቱ፤ የምላሾቹም አማራጮች እንደሚከተለው ተዘርዝሯል፡-

1. በጣም አልረካሁም 2. አልረካሁም 3. እርግጠኛ አይደለሁም 4 እረክቻለሁ
5.በጣም እረክቻለሁ

ተቁ	ጥያቄዎች	አማራጮች				
		1	2	3	4	5
1	የመሰረታዊ የማስታገስ ህክምናው የተሻለ የጤና አይበገሬነትና ደህንነተዎን ከማሳደግ አኳያ					
2	ሁለንተናዊ ህይወትን ከማሻሻል አኳያ የመሰረታዊ ማስታገስ ህክምናው ውጤታማነት					
3	የመሰረታዊ የማስታገስ ህክምናው የሚፈልጉትን መረጃ እንዲያገኙ ከማድረግ አኳያ					
4	የመሰረታዊ የማስታገስ ህክምናው ህመምዎትን ከመቆጣጠር አኳያ					
5	የመሰራተዊ የማስታገስ ህክምናው የመድሀኒቶችን ተጓዳኝ ችግሮች ከመቆጣር አኳያ					
6	ሀኪሞችና ነርሶች ችግሮችዎን ከመለየት አኳያ ያደምጡዎታል					

7	የመሰረታዊ የማስታገስ ህክምናው ውጤታማነት ማለትም ትርጉም ያለው ህይወት እንዲኖሩ ለእርስዎ ተገቢውን መረጃ ከመስጠት አኳያ					
8	የመሰረታዊ የማስታገስ ህክምናው ስቃይን ከመቀነስ አኳይ					
9	የመሰረታዊ የማስታገስ ህክምናው ማህበራዊ ችግሮችዎን ለምሳሌ መካድና መናቅ ከማስወገድ አኳያ					
10	የመሰረታዊ የማስታገስ ህክምና ማህበራዊ፣ስነልቦናዊ፤አካላዊና መንፈሳዊ ይዘቱ አኳያ					
11	በእርስዎና የመሰረታዊ የማስታገስ ህክምና ሰጭዎች መካከል ያለው መስተጋብር የበሽታ ምልክቶችን ከመቆጣጠር አኳያ					
12	የመሰረታዊ የማስታገስ ህክምና ችግሮችዎን ከመፍታት አኳያ ለምሳሌ የመልሶ ማቋቋምና የምክር አገልግሎት ከመስጠት አኳያ					
13	የማስታገስ ህክምና የአኗኗር ደረጃዎን ከማሻሻል አኳያ ለምሳሌ ማህበራዊ ውጤታማነት					
14	የበሽታ ምልክቶችን ለመቆጣጠር የሀኪሙ የማማከር ጊዜ ቆይታ					
15	የመሰረታዊ የማስታገስ ህክምናው የበሽታ ምልክቶችን ከመቀነስ አኳያ					
16	የመሰረታዊ የማስታገስ ህክምናው መንፈሳዊ ችግሮችዎን ከመቅረፍ አኳያ					
17	የመሰረታዊ የማስታገስ ህክምና ጊዜን ያገናዘበ ከመሆን አኳያ					

Appendix 6 Questionnaire Satisfaction for Participants [English Version]

This questionnaire has been prepared to gather information about the palliative care service you receive. So, there is no need to write your name. Your genuine responses to all items of this questionnaire contribute a lot to the successful completion of this study. You are, therefore, kindly requested to provide genuine information. The information you give will be used only for research purpose and it will be kept confidential. I thank you very much for taking your time in filling in this questionnaire.

PART ONE

Instruction: Please put a tick mark in the appropriate box which represents your choice.

1. Sex: Male ☐ Female ☐

2. Age ☐

3. Marital status: single ☐ married ☐ widow ☐ widower ☐ divorced ☐

4. Educational Background: illiterate ☐ 1-6 ☐ 7-12 ☐ certificate ☐ Diploma ☐ degree & above ☐

Palliative Care

5. Residence: rural ☐ urban ☐

6. Disease type: breast cancer ☐ cervical cancer ☐ renal failure ☐ diabetes ☐

PART TWO

For each of the statements below, please indicate the extent of your agreement or disagreement by placing a tick in the appropriate box. The response scale is as follows:

1.very disagree 2. Disagree 3. Unsure 4. Agree 5. Very agree

Palliative Care

No	Item	Alternatives				
		1	2	3	4	5
1	The general palliative care with regard to developing better health, resilience and wellbeing					
2	The effectiveness of the primary palliative car in improving your holistic life aspects					
3	The primary palliative care service in providing you with information you need					
4	The primary palliative care service in managing your pain					
5	The primary palliative care in managing side effects of medicine					
6	Physicians and nurses listen to you to identify what your concern is					
7	Effectiveness of the primary palliative care: way of persuasion to get you live meaningful life					
8	The primary palliative care service in maintaining pain relief					
9	The primary palliative care in minimizing social problems: dread of denigration and abandonment					
10	The primary palliative care service regarding its social, psychological, physical and spiritual contents					
11	The interpersonal communication (the relationship between you and the service providers) to manage disease symptoms					
12	The primary palliative care service in addressing your and your families' needs, including counselling and rehabilitation.					
13	The primary palliative care service in improving the quality of your life—social functioning					
14	Duration of the doctor's consultation time with you to palliate disease symptoms					
15	The primary palliative care service as soon as you are in need in minimizing the symptoms					
16	The primary palliative care service in resolving problems regarding spiritual aspects (existential issues, faith, and meaning of life, personal value)					
17	Timeliness the primary palliative care– reducing waits and sometimes harmful delays					

Appendix 7 Sample of Participant's Interview about Primary Palliative care [Amharic version]

አጥኚ ፡ በመጀመሪያ ፤ቃለ መጠይቁ ፈቃደኛ ስለሆንሽ አመሰግናለሁ፡፡ በመጀመሪያ እራስሽን ብታስተዋውን፡፡ ሰም፣ እድሜ፣ የትምህረት ደረጃ፣ ስራ እና ለምን ያክል ጊዜ በፈለገ ሂዎት ሆስፒታል ህክምነ እንደምትከታተይ ብትገልጭልኝ

ቃል፡ ቃል ይባላል፡፡ እድሜ 37 ነው፡ የትምህርት ደረጃየ ዲግሪ ሲሆን የእንግሊዝኛ መምህር ነኝ፡፡ በሆስፒታሉ ለሶስት አመት ያክል ክትትል እያደረኩ ነው፡፡

አጥኚ፡ ፓሌቲቭ ኬር ይሰጣል የሚያተኩረበትን በዝርዝር እንድናወራ ቀጠሮ ይዘን ተለያየን

ቃል፡ አወ

አጥኚ፡ የፓሌቲቭ ኬሩ ይዘት ምን ይመስላል?

ቃል፡ ህመም ማስታገስ ስልት_አለመጨነቅ፣ መድሀኒት በወቅቱ መውሰድ ጉዞ ማድረግ፣ ከቤተሰብ ጋር ማውራት (ችግር ማካፈል)፣ ቶሎ ሀኪምዎን ማማከር፣ በቂ እረፍት ማድረግና መተኛት እና ሌሎችንም ይነግሩና፤ አይ ሁሉንም እንዴት አስታውሳለሁ? ይኸው ነው ፡፡ ሳስታውስ እነግርሀለሁ፡፡ አወ፡፤ ሌላው የህመም ምልክት ሲታይ ወደ ሀኪም ቤት መሄድና የምክር አገልግሎት ማግኘት፣ እረፍት ማረግ፣ መድሀኒቱን በአግባቡ መውሰድ፣ አመጋገብን ማስተካከል ጥሩነው ይሉናል፡፡

አጥኚ፡ ከዘረዘርሽልኝ ሌላ ምን ምን የመ፣ስታገስ ህክምና ይሰጧችኋ?

ቃል፡ ስለ ማህበራዊ ኑሮም ያስተምሩናል፡፡ ከቤተሰብና ከማህበረሰቡ ጋር እዴት ተስማምተን መኖር እንዳለብን ሁሉ ይነግሩናል፡፡ ለምሳሌ እኔ የጡት ካንሰር ታማሚ ስለሆንኩ ቤተሰቦቸ ብሎም ጎረቤቶቸ ያገሉኛል ብየ አንደምፈራ ለአንዷት ሀኪም ነገርኳት እሷም አትጨነቂ አንች ወደሽ አላመጣሽውም፤ ስለሆነም ቤተሰቦችሽን አምጭና እኔጋ ይነጋገሩ አለችኝ፡፡ ባለቤቴ እምቢ ሲል ልጆቼንና እህቴን ልጅ ወስጀ አስተማሩልኝ ደስ አለኝ፡፡ ባለቤተ ግን አሁንም ለኔ ግድየለውም፡፡

ሌላው (ዝምታ) ውጤታማ ኑሮ ስለመኖሩ አስተምረውናል፡፡ አንዷት ቀይ ዶክተረ ስታወራን ደስ ይለኛል፡፡ እሞታለሁ ብየ የፈራሁ ሰው እዛው ሀኪም ቤት ስታስተምረኝ ደስ ይለኛል፡፡ ለካም እኖራለሁ? ውጤታማም እሆናለሁ ብየ ደስ ይለኛል፡፡ ግን እቤት ስደርስ ያለችኝ ተስፋ ይጠፋኝና ፍርሀቴ ሞቴ ይጠፉብኛል፡፡ ወዲያ! ያው ነው የኛ ነገር ሞት ኑሮ!

አጥኚ፡ ሌላስ ሰላም ያስተምራችል?

ቃል፡ የኑሮ መሻሻል፣ የኑሮ ለውጥ፣ ምንድን ነው እጤ የኑሮ ደረጃን እንዴት ማሻሻል ይቻላል እያሉ አስተምረውናል ግን እረሳዋለሁ፡፡ ማስታወሻም የለኝም፤ እያፅናን የውሸት ነው … እፈራለሁ፡፡ አንተ የተባለ ቢባል አልድን፡፡ ያ መናጢ ሞት……ዝም…ትክዝ

አጥኚ፡ ይቅርታ አንዴ! ወደፊት ማለቴ አለአ ይደል ምን ተጨማሪ ትምህርት ይሰጥ ትያለሽ

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ቃል፡ ምንም! ካላደናኝ ምን ዋጋ አለው፡፡ ሞት መንጋጋ ውስጥ ያለ ሰው ለወሬ ይድናል? ዝም ትክዝ፡፡ ይበቃል እባክህ፡፡ ስትጠይቀኝ ያመኛል፡፡

አጥኝ፡ሌላ የማይቀር የምትይው ለማስታገስ ህክምና ውስጥ የተሰጠሽ

ቃል፡ ስለ ሳይኮሎጂ ምንድን ነው

አጥኝ፡ ስነልቦና…

ቃል፡ አወ በስነልቦና የጠከከረ ሰው ወይም በራሱ የተማመነ ተስፋ ይኖራል አሉ፤ እኔ ግን እያበቃሁ ነው! ዋጋም የለኝ ስማርም አላዳምጥ! ኡሁ! ኡሁ! ስማር ደስ ይለኝና ቤት ስመጣ ሁሉም ይተናል፡፡፤ አለመለከፍ ደጉ፡፡ መቼ ጥሩ ነው ምንም አይል፡፡ ፡፡ ዝም…

አጥኝ፡ ስለሰጠሽኝ ማብራሪያ አመሰግናለሁ፡፡

ቃል፡ ችግር የለም

Appendix 8 Sample of Participant’s Interview about Primary Palliative care [English version]

Researcher: Thanks for your willingness to be interviewed. Name, age, education and job

Kal: Ok: Kal, 37 degree, English teacher. I am married and have a son and 2 daughters.

Researcher: As you told me last time palliative care is provided for you

Kal: Yes

Researcher: What is it about? What is the content?

Kal: They counseled that it is possible to palliate pain, they assured us how we can feel better: not to worry, taking medicine timely, taking a walk, taking a rest, talking with families (sharing problem) consulting my physician quickly, sleeping and etc.; they taught we other issues but how can remember? That is all! I will tell you when I remember! Yes, the other issue is they told us that we should go to the hospital as soon as we face symptom and get our physician’s advice. Also, they advised us that we should take a rest –take medicine properly and have good meal.

Researcher: In addition to what you have so far, that content of palliative care did get?

Kal: They taught us about social aspects of life. They advised how to live with my family and society in a harmonious manner. For instance, as I am the patient of breast cancer, I am afraid that my family and neighbor may discriminate and I told my fear to a certain doctor and she said, “don’t worry; you didn’t become a patient due to your fault; so bring your family and let them consent me.” My husband refused to go to the hospital, but I took my sons and daughters including the son of my sister and she taught them and I became happy. But my husband ignores me; he doesn’t care about my pain.The other issue is they taught us about is………..[pause] how to have productive life. When that red [white] doctors taught, I became happy. While I was afraid that world dies, I became hopeful and forget death when she taught us in the hospital. Will I live so? I became happy, too believing that I will be productive. However, when I reached at home, my hope evaporates; instead, my fear and death confront me. Alas! It is nothing! It is known; our fate is death

Researcher: Excuse, what else did they teach you?

Kal: About progress of life, life change, what is it ………..? How to improve quality of life; they taught us about all these things! But I forget it as I don’t have dairy; I am afraid that they take heart/soothed us [as they are to die]. You know, what so ever is said, that evil death [Silence…was melancholic /sign] [sobbing]

Researcher: sorry for a moment! In future, I mean like; what additional education did they teach you?

Kal: nothing! What value does it have unless it cures me? How can a person, who is in …………………, recover through talk? [Silence….sign] It is enough. I became sick when you ask me.

Researcher: Anything you think shouldn’t be left out among the issues you learnt in the palliative care service?

Kal: Psychology…what is it

Researcher: Psychological issues…?

Kal: Yes, they taught us that a patient who is strong psychologically and who has self-confidence and who is hopeful can cure! But I am to be finished. I am valueless person. When they advise us, I don’t listen to them. I am happy when I am advised, but everything evaporates when I come home. What is good is not being victim. It is good; so so! [silence… tear drops]

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Researcher: Sorry, I mean; thank you for your explanation and the last question, does it satisfy you

Kal: What is holistic?

Researcher: does it include psychological, social physical and spiritual issues

Kal: If it is so, it is partly holistic, they sometimes teach us holistically and sometimes they don’t. They appoint us but they are not punctual, they enter their examination room, they dress, talk and sometimes get out for tea or something; but we wait for them and begin after long period. Satisfaction? No I and not satisfied because I am still sick, no progress.

Researcher: Thank you for your clarification

Kal: No problem.