The lived experience of Lebanese oncology patients receiving palliative care

Myrna Doumit

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DUQUESNE UNIVERSITY
PhD PROGRAM
SCHOOL OF NURSING

APPROVAL OF FINAL DEFENSE OF DISSERTATION

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The purpose of this study was to uncover the lived experience of Lebanese oncology patients receiving palliative care. The study design was based on the Utrecht School of phenomenology based on the Dutch school of phenomenology. This study followed purposeful sampling in which ten participants six women and four men with a mean age of 54.4 years were selected. The proposed research was approved by the Institutional Review Boards at the American University of Beirut and Duquesne University. In-depth semi-structured interviews along with observation-field notes were used as the source for data collection. Data were analyzed using the hermeneutic phenomenological approach based on the Utrecht School of Phenomenology. The participants highlighted their distress from being dependent; their dislike for pity; their worry for the family and the worry about the family’s worry; their reliance on God and divinity; their dislike of the hospital stay; their need to be productive; their fear of pain; and the impact of communication on them. Specific nursing action to help decreasing patients’ fear include exploring patients’ ideas, beliefs and experiences regarding pain and analgesics treatment, and encouraging patients’ participation through proper communication. Nursing education need to emphasize palliative care in the curricula. At the policy level, policy makers need to take into account patients’ needs while deciding on national health policy. Further research is suggested to explore the new emerging themes and to study the lived experience of caregivers of cancer patients.

Dissertation Advisor: Dr Joan Such Lockhart, RN, PhD, CORLN, AOCN®, CNE, FAAN
DEDICATION

This work is dedicated to the soul of my grandmothers Linda and Myriana. Your memory will always be in my heart.
My thanks and praise to God, who sustained and guided me throughout this entire process.

To my dissertation committee I would like to extend my sincere feelings of gratitude and appreciation. I would like to first thank Dr Joan Such Lockhart my Dissertation Chair, who touched me with her genuine assistance in this endeavor; who empowered me with her exceptional ability to critique in a way that simultaneously taught and changed me in a positive way; for her amicability in making this an agreeable and rewarding undertaking. To Dr Gladys Husted, for her unconditional encouragement, guidance and tolerance. To Dr Huda Abu-Saad Huijer, my committee member and my Director, who provided grounding, support and guidance not only during this dissertation process but throughout my last three years of PhD studies. Thank you to each of you.

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CHAPTER I
INTRODUCTION

Background

Cancer is now a major cause of mortality throughout the world, and in the
developed world is generally exceeded only by cardiovascular diseases (World Health
Organization [WHO], 2003). There are at least ten million new cancer cases every
year worldwide, resulting in five million deaths each year (WHO, 2003). The WHO
reports that cancer is the second leading cause of death in most developed countries,
and parallel trends are emerging in developing countries as well. Statistics of cancer
incidence and mortality illustrate that this disease is progressively increasing in
significance, both in terms of mortality and morbidity. Between 2000 and 2020 the
overall number of cases of cancer in the developing world is estimated to increase by
73% and in the developed world to increase by 29% largely as an increase in the
rising proportion of older people (Parkin, 2001). The relative significance of cancer as
a cause of death is growing mainly because of the rising proportion of old people due
to medical and technical developments, and also in part because of the reductions in
mortality from other causes such as infectious diseases (WHO, 2003).

Lebanon is one of the world’s smallest countries situated on the Eastern coast
of the Mediterranean Sea, with a surface area of 10,452 square kilometres and a
population around four million (Daher et al., 2002). Attempts at establishing a
national cancer registry in the early 1970s failed due to a shortage of financial and
technical resources caused by the civil war from 1975 to 1991 (Shamseddine et al.,
2004). As a result, cancer registry data in Lebanon have been deficient for over three
decades. Only one study reported the incidence rate of cancer in Lebanon and was
based on eight institutions where histological diagnoses were made (Abou-Daoud, 1966).

Later in 1998, several physicians from different hospitals in Lebanon convened and instituted a group called The Lebanese Cancer Epidemiology Group. The group’s goal was to study the incidence of cancer in Lebanon. This group collected the first plausible data on the incidence of cancer in Lebanon during the years 1993 and 1998 (Shamseddine et al., 2004). Their reports revealed that the most frequent cancers were breast cancer in females and bladder cancer in males. The overall increase in the crude rate of cancer was relatively more pronounced in females than in males with no clear etiology.

In 2002, the National Cancer Registry (NCR) was revived as an information system designed for the collection, storage, management, and analysis of data on cancer cases throughout Lebanon (Ministry of Public Health, WHO, & National Non-Communicable Diseases programme [NCDP], 2002). Patients registered under this system receive cancer drugs paid for by the Lebanese ministry of health. So, the number of patients in this registry excludes individuals who have insurance or are self-payers. Data presented in the 2002 NCR report remain comparable to earlier accumulated results from Lebanon in terms of relative importance of cancer sites. Moreover, it is estimated that the number of new cancer cases in Lebanon ranged between 3,500 to 4,000 yearly (Daher et al., 2002). Due to the early detection and enhanced methods of treatment, patients live longer with a diagnosis with disseminated cancer. Therefore, every health care worker caring for cancer patients might deal with patients who are in their palliative stage. Compared to some western countries, Lebanon has not yet espoused palliative care as a practice speciality or as a clinical research interest. Despite the fact that cancer is one of the leading causes of
mortality in Lebanon, and that a majority of patients reach the palliative stage (Daher et al., 2002), very little is known about the lived experience of the Lebanese oncology patients receiving palliative care.

Cancer is a disease, but it is as well a chain of experiences that deeply impinge on the person who has cancer and those individuals who share the experience. In spite of existing advances in anti-cancer treatments, most adult cancer patients will still eventually die from their disease or from side effects and complications arising from its treatment (Byock, 2000; WHO, 1990).

However, when cure is unachievable, the objectives of treatment change from the intention to cure to the maintenance of life and palliation of symptoms. Health care professionals are becoming increasingly conscious of the need to change the aim of cancer treatment in select patients from “curative” to “life prolonging” or palliative (Ahmedzai & Walsh, 2000). Cohen and Mount (1992) strongly advocate that in palliative care, quality of life is not only a primary concern, but is the very “raison d’être” of every intervention. The authors stress that palliative care strives to add life to years instead of years to life.

Purpose of the Study

The purpose of this study is to uncover the lived experience of Lebanese oncology patients receiving palliative care, and to obtain an increased understanding of the meaning and interpretation of their experience. It is worth noting that the diagnosis of cancer conveys with it the cultural beliefs of each individual. Cultural elements are learned and shared by families. What people believe in, what is important to them, what has meaning for them, and what they value may vary among the many diverse cultures of the world.

The specific aims of the study are to:
1. Obtain descriptions of the experience of Lebanese oncology patients receiving palliative care
2. Describe the meaning that Lebanese oncology patients receiving palliative care ascribe to their experience
3. Understand the meaning that Lebanese oncology patients receiving palliative care attribute to their experience
4. Propose implications for oncology nursing practice related to patient outcomes based upon participants’ descriptions.

Palliative Care as a Movement

The term palliative is derived from the word “palliate”. In modern English, palliate is a transitory verb, which means, “to make disease less severe, without removing its cause” (Oxford Advanced Learner's Dictionary, 1998). Etymologically, the earliest recorded occurrence of the world “palliate” can be related to the late 14th century. The word came into view by French surgeon Guy de Chauliac (1290-1368) in the famous treatise, La Grande Cyrurgie (Barnhart, 1998; Kuhn, 1981). Most current definitions emphasize that palliative care is not substitutive or sequential to curative care. Rather, it is a vital approach in which innovations of medical science and virtues of humanism are unified with the aspiration of granting proficient, yet empathetic care to patients with an acute, or chronic, actual, or potentially life-threatening illness (American Academy of Hospice and Palliative Medicine, 2003; National Hospice and Palliative Care Organization, 2003; Vun Gunten, Ferris, Portenoy, & Glajchen, 2001). Total, active and individualized patient care emerges as a vital attribute of the palliative care concept. While comprehensive symptom management is an important aspect of palliative care, total patient care warns against
reducing suffering to merely physical pain and symptom management, and to overlook emotional, spiritual and social pain (Roy, 2000). The literature demonstrates that palliative care has implications for both patients and families. Patient-oriented consequences comprise improved quality of life (Choi & Billings, 2002), relief of suffering, and enhancement of human dignity (Krisman-Scott & McCorkle, 2002).

Since the hospice movement of the 1960s in London, United Kingdom, palliative care has emerged on the international field in various shapes and forms. In any given country, the development or a lack of development of palliative care models and services may be related to social, economic, cultural, geopolitical, and health system realities. Hospice was considered as a resting place for fatigued voyagers in ancient times, several of whom were ill. Hospice first became associated with the dying in France in 1942; the first modern hospice, St Christopher’s Hospice, was founded in London by Dame Cicely Saunders in 1967. It was the first facility established as a “place” to care for the dying. In 1974, the first United State (US) hospice was established in Connecticut based on a home care model. In 1975, Balfour Mount started the Palliative Care Service in the Royal Victoria Hospital in Montreal; the concept of “palliative care” in North America was recognized (Sheehan & Forman, 1996). The word” hospice”, as it is currently used in the US, refers to a specific, programmatic model for delivering palliative care (Byock, 1998). Currently, palliative care is much more in avant-garde in Europe, Australia, and Canada than in the US, and includes what is called “complementary therapies” or “alternative therapies” into everyday practice. In these countries palliative care needs are tackled earlier in the disease process and along the health care continuum. In the US palliative care is linked with end-of-life care, though there are considerable governmental reimbursement limitations through the Medicare program restrictions (Williams &
Wheeler, 2001). Hospice care and end of life care, therefore, constitutes a subset of palliative care. From 1997 to 2000, researchers in the US at the City of Hope National Medical Center (COH) conducted a project titled, “Strengthening Nursing Education to Improve End-Of-Life Care.” The research performed throughout the course of this project reported major inadequacies in palliative care education in the US nursing school curricula. Therefore, a national project, End-Of-Life Nursing Education Consortium (ELNEC), was initiated in February 2000 to support nurses in reducing the burden and distress of those facing life’s end and to propose assistance for the many physical, psychological, social, and spiritual needs of patients and their families (Matzo, Shermann, Penn, & Ferrell, 2003).

Even among the developed nations, the development of palliative care is far from uniform. At present there is no consensus on the definition of palliative care (Ahmedzai et al., 2004; Vun Gunten et al., 2001). The most widely adopted definition is the one presented by the WHO Expert Committee of the Cancer and Palliative Care Unit as “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and psychological, social, and spiritual problems is paramount” (WHO, 1990 p.11). This definition has been exceptionally vital and influential in raising the recognition of palliative care across the world. However, it came to be considered as somewhat limited and ambiguous, as it rests on the interpretation of responsiveness to “curative” anti-cancer treatment. The WHO itself acknowledged this feature; therefore, in 2002 the WHO amended the 1990 definition of palliative care and introduced an updated definition. The WHO currently defines palliative care as an approach that:

…improves the quality of life of patients and their families facing the problems 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, psychological and
spiritual. (WHO, 2002 p. 83)

This definition of palliative care will be adopted in this study. This new WHO
definition was welcomed as it highlights the need to start palliative care earlier in the
disease process. Therefore, the need for palliative care may occur at any time in the
patient’s illness. For the purpose of this study, palliative care is the care delivered to
cancer patients with low expectations for cure or remission as confirmed by the
treating physician. Moreover, throughout the palliative care, quality of life issues are
particularly important (Cella & Tulskey, 1995). Furthermore, most clinicians and
researchers agree that improvement of the patient’s quality of life is the ultimate goal
in palliative care (Abu-Saad, 2001; Ferrel, 1996; Kaasa, 2000). Literature implies that
palliative care is appropriate over the continuum of a progressive, life-timing illness
and may be started at any point in the illness course and definitely in conjunction with
curative treatment (Byock, 2000; Choi & Billings, 2002). It is worth noting that
palliative care is not only confined to cancer disease, but relates to any chronic,
ultimately fatal illness. (WHO, 2002). In the current study, however, the sample
participants will be limited to Lebanese cancer patients receiving palliative care.

Palliative Care in Lebanon

Palliative care is a new concept in the Lebanese health care sector and it is
mainly linked with cancer disease. A thorough literature search yielded no published
articles on the topic. Moreover, anecdotal evidence from this investigator’s experience
in the Lebanese health care system supports the conclusion that palliative care is not
well addressed along with end-of-life care. It is worth noting that cancer in the Lebanese society is believed to be a protracted illness causing great disability and suffering that finally leads to a painful death. Cancer is therefore not a preferred word to use, and euphemisms, such as “growth”, “lump” and “that disease” have been developed as alternatives.

Palliative care was first tackled in Lebanon in 1995 during a workshop with national health leaders and supported by the Ministry of Health and the WHO (Daher et al., 2002). During this workshop the need for palliative care was emphasized, but, dispensing free cancer chemotherapeutic drugs was the only major outcome. Later, in May 1999, a special full-day symposium on Palliative Care and Ethics was organized during the “Congrès d'Oncologie du Moyen-Orient, COMO IV” (Oncology Congress of the Middle East). This workshop was organized by the Lebanese Cancer Society and sponsored by WHO. It became obvious that a positive conversion regarding palliative care had happened over the past four years between these two workshops.

Recommendations to the Ministry of Health, and a request to WHO for help and action, were agreed upon. The recommended points were as follows: 1) a clear national policy is needed to offer pain-free treatment; 2) an essential drug list, not only for cancer chemotherapy drugs, but also for pain and palliative care drugs should be established; 3) undergraduate training of nurses and doctors in palliative care is essential; 4) reimbursement of treating physicians for palliative care services should be sought; 5) a multidisciplinary approach to palliative care is a must; 6) strengthening home care and social assistance is essential; 7) provision of palliative care is a right for all patients suffering from a chronic and fatal disease (Daher et al., 2002).
Afterwards in 2000 the *Lebanese Pain and Palliative Care Initiative* was launched (Daher et al., 2002). The members consisted of oncologists, deans and directors of the academic medical and nursing schools in Lebanon. The purposes of this initiative were to: 1) educate physicians and nurses about palliative care and the concept of quality of life in that context; 2) to develop postgraduate training programs for physicians and nurses who wish to develop special expertise in palliative care; and 3) to introduce palliative care into medical and nursing curricula (Daher et al., 2002).

Two national workshops were conducted in 2000 and 2001 in order to discuss the principles for establishing good pain and palliative care and to identify potential barriers for implementation of palliative care (Daher et al., 2002). These workshops were sponsored by the Lebanese Minister of Health, the WHO, the Lebanese Cancer Society, and the Clinical Research Institute in Montreal, Canada. Immediately after the 2000 workshop nine fellows from different universities were chosen to attend a two and a half day course provided by the Education for Physician on End-of-life Care (EPEC) in the US to become an EPEC trainer. This course covered the entire content of the EPEC curriculum. After the EPEC course, the fellows spent a week with bedside training under the auspice of the EPEC team to experience the practical approaches used to provide palliative care (Daher et al., 2002). However, despite all efforts the subject of palliative care in Lebanon is still not approached scientifically. Research is lacking at all levels, and palliative care is delivered by non specialized physicians and registered nurses.

However, it is worth noting that a study led by Huijer Abu-Saad and funded by the American University of Beirut, Medical Practice Plan is currently in progress (H. Huijer Abu-Saad, personal communication, April 15th, 2005). The goal of the study, entitled *Palliative Care in Lebanon: Needs Assessment for Palliative Care*
Services for Children and Adults is to determine the availability, type, and adequacy of palliative care services provided in Lebanon to meet the needs of terminally ill adults and children. This study, with a focus on a “needs assessment”, includes the experiences of patients, family, and health professionals with palliative care as well as a survey of Knowledge, Attitudes, and Practice (KAP) of health professionals. The current study builds and expands on the lived experiences of patients in palliative care, and as such compliments the results of the previous study. The results of both studies will present a holistic and more global picture of the palliative care in Lebanon (H. Huijer Abu-Saad, personal communication, April 15, 2005).

Although palliative care is still not officially institutionalized, patients are financially covered by private insurance companies and the ministry of health to receive palliative care in hospitals. Chemotherapeutic drugs are dispensed free of charge by the Ministry of Health.

In Lebanon, health care professionals caring for patients with cancer are likely to highlight the survival rates associated with particular types of the disease or treatment, but they seldom document the quality of that survival (Shamseddine, 2004; Shamseddine et al., 2004). Patient survival is discussed and documented in studies as disease-free intervals, changes in tumor volume, toxicity of the treatment and, on occasions, patients’ performance status. The approach used in these studies provides little information about the physical, emotional or social well being of the patient. One approach to capture the personal and social context of patients is to study their lived experience using a phenomenological approach.
Definition of Concepts

Palliative Care

The WHO currently defines palliative care as an approach that
...improves the quality of life of patients and their families facing the
problems 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, psychological and spiritual

This definition acknowledges that the standards of palliative care should be applied as
early as possible in the course of any chronic, ultimately fatal illness. This alteration
in thinking surfaced from a recent understanding that problems at the end of life have
their beginning at an earlier time in the course of disease. Symptoms not treated at the
start become very difficult to handle in the last days of life. In Lebanon, in parallel
with the WHO definition, palliative care delivered to patients diagnosed with cancer
is associated with low expectations for cure or remission.

The WHO approach to palliative care has also been extended. While pain
relief continues to be a central component, it is by no means the only concern. The
physical, emotional, and spiritual needs of the patient are all thought to be essential
components in palliative care (Sepulveda, Marlin, Yoshida, & Ullrich, 2002).

In addition, the WHO consideration of palliative care has expanded beyond the
patient to include considerations of the health and well-being of family members and
caregivers working with the patient. The palliative care definition used for this study
is the WHO definition of this concept. Moreover, the confirmation that the participant
is receiving palliative care will be validated by the treating physician according to the
below mentioned criteria. It is worth noting that in Lebanon there are still no official
written guidelines defining the provision of palliative care. Palliative care as it exists in Lebanon today as described by two prominent Lebanese physicians practicing in the field of oncology:

1. is applicable early in the course of illness, in combination with other therapies that are intended to prolong life, such as chemotherapy and radiotherapy, and comprises those examinations necessary to better understand and manage stressful clinical complications.

2. affirms life and considers dying as a normal process

3. integrates the psychological and spiritual aspects of patient care

4. intends neither to accelerate nor delay death

5. suggests a support system to aid patients live as actively as possible until death

6. is trying to follow a team approach to assist the family cope during the patient’s illness and in their own bereavement

7. physical care entails relief of pain and other distressing symptoms.

8. spiritual care involves sessions with appropriate religious figures. It is worth noting that spiritual care in Lebanon is highly interconnected with religious identity

9. psychological care implies the use of therapeutic communication and assessment as a basis for appropriate referrals to the psychiatric nurse, psychologist or psychiatrist (A. Shamseddine & Z. Salem personal communication, June 8, 2005).

*Lebanese Cancer Patient*

Lebanese cancer patient is any Lebanese citizen, living in Lebanon, speaks
Arabic, diagnosed with any type of cancer, has low expectations for remissions or cure, able to communicate clearly, and is the recipient of palliative care as confirmed by the treating physician.

Assumptions

1. The researcher assumes that the research method is appropriate; the subjective material obtained through the use of the phenomenological approach represents not only a valid, but also a crucial research strategy, in our endeavours to comprehend the complexity of the experience on the personal, psychological, physical and spiritual levels.

2. The researcher believes that the participants’ stories will reflect their perceived reality of their experience and represent a truthful narration of their experience.

Limitations

Research in palliative care is difficult and is not simple to undertake.

1. As a qualititative study, participant selection is based on purposeful sampling which is not reflective of a larger population

2. The study will not include participants who do not know about their diagnosis, therefore, results will be applicable to those who know.

Significance to Nursing in Lebanon

Lebanon is unique in many aspects unlike any other country in the Middle East. It is a land of contrast and diversity. Before the civil war in 1975, Lebanon’s advanced health services and medical institutions made Beirut a health care center for
the entire Middle East region. However, the war led to the closure of the most state centers and triggered the expansion of the private sector with a focus on the war emergency needs. Until recently, health care facilities were mainly curative with an oversupply of hospitals and highly technical equipment.

Since 1995, health care interests in Lebanon have started to change, and palliative care was highlighted as a need for the first time (Daher et al., 2002). Currently, palliative care is still not institutionalized and specialty units are deficient. Patients who need palliative care are admitted to general hospitals on regular inpatient units and are cared for by the health care team members (nurses, physicians, nutritionists and physiotherapists) who are unfortunately lacking palliative care educational preparation. National demographics and studies which look at cancer patients’ perceptions of their condition are still lacking.

Most studies of palliative care of cancer patients have been conducted on Western populations. Because of the cultural differences, it is difficult to generalize these findings to the Lebanese population; thus, the necessity arises to conduct this study.

Understanding how patients perceive their illness and treatment has the potential to guide nurses to understand patients’ needs, concerns, and fears, and to learn how to interact in ways that may differ from people who lack that understanding. Qualitative research may allow health care providers to recognize the phenomenon the patient is experiencing from a connoisseur perspective. This study will serve as basis for further research leading to improved care for this patient population. Results may provide a valuable basis for nurse educators to incorporate palliative care in nursing curricula and to prepare student nurses to provide care for oncology patients in palliative stages. In addition, findings may provide the
foundation for staff development programs for strengthening the competencies of practicing nurses in Lebanon.

Therapeutic relationships necessitate care, self- awareness, and awareness of other’s emotional needs. In comprehensive cancer care, it is therefore, imperative to underline what the person with cancer receiving palliative care is going through in order to provide quality patient care and improve professional development.
CHAPTER II
REVIEW OF THE LITERATURE

Introduction

An initial review of the literature indicated that a number of studies on the lived experience of cancer patients receiving palliative care have been conducted in several countries around the globe, but so far, no research paper has examined these issues in Lebanon. For the purposes of this literature review, research studies exploring palliative care in cancer patients and conducted worldwide were examined.

Several databases were systematically searched, including: Medline 1980-2005; CANCERLIT 1980-2005; and CINAHL 1980-2005. A manual search was conducted to search and retrieve information not available on the web such as Arabic articles if available, WHO reports and articles published in journals not included in the above databases. It is worth noting that the researcher was not able to find any related Arabic article. The electronic search was limited to English language studies with abstract or full text. Search terms included: palliative care, end of life care, terminal care, cancer, fatal disease, culture, ethnic groups. Articles and abstracts that were considered potentially useful were retrieved for further selection. Eligibility was based on whether the article was able to provide recent and different information on the topic. In order to have a global picture of the topic, articles from the quantitative paradigm describing the patients’ views were also considered. The focus was on selecting recent research studies preferably published in the new millennium. However, the final decision for inclusion was based on the article’s findings. Selected articles were distributed into subcategories according to the main idea discussed in the article. Some of the articles had an overlap between main ideas. Subcategories were formed according to the main idea highlighted in the article. Identified subcategories are:
palliative care and cultures; palliative care and autonomy; palliative care and communication; and palliative care and pain.

Palliative Care Literature

Palliative Care and Culture

Telling stories is one of the important habits in which people construct and express meaning. Thus, their narrations may represent a basis for an improved understanding of their experience. The knowledge derived from such narrations can, in turn, provide an important basis for delineating nursing care that will assist the patients through the disease and the treatment.

A phenomenological study by Appelin and Bertero (2004), conducted with six Swedish cancer patients suffering from cancer of the bladder, prostate, stomach, kidney, as well as lymphoma and receiving palliative care at home revealed one major theme called “uncertain safety”. This one major theme illustrated the essence of the experience. Four sub themes were identified: 1) “safe but unsafe at home”, 2) “a sense of powerlessness”, 3) “change of everyday life”, and 4) “hope and belief in the future”. Findings of this study showed that all participants reported that the home was the place of safety as well as closeness to relatives, all memories, and private property. But there was anxiety about home care, which constituted a burden to the family members through enlarged responsibility. The state of uncertainty and the feeling of not being able to influence one’s life situation gave them an experience of powerlessness.

A triangulated study was conducted by Astradsson, Granath, Heedman, and Starkhammer (2001) to identify patients in need of palliative care in eleven different care units with a total of 256 beds at Linköping University Hospital, Sweden. The
study looked at the patients’ overall situations with respect to assessed symptom control and quality of life. Forty-six patients (19 men and 27 women) satisfied the inclusion criteria of incurable cancer and need for palliative care. Each was assessed with the aid of a questionnaire (five oral questions on life situation) and a single Visual Analogue Scale (VAS) about their overall quality of life. Patients also assessed themselves on the Edmonton Symptom Assessment Scale (ESAS). Reported symptoms included reduced appetite, a dominant sensation of well-being and activity, and less intense reports of pain and nausea. Thirty-seven patients answered the open question, “What in your current situation troubles you the most?” Seven patients answered nothing, and ten patients reported the present symptoms, whereas, 20 patients had different concerns (existential, social and psychological). Results of this study highlight not only the importance to control the physical symptoms, but to address to a greater extent the non-physical dimensions in palliative medicine. This is vital if the purpose of the intervention is to achieve total palliative care.

Osse, Vernooij-Dassen, Schade, and Grol (2005) conducted a descriptive, cross sectional study to examine the problems that patients with disseminated cancer live through and their met and unmet needs for professional help. Ninety-four cancer patients in the Netherlands experiencing metastasized cancer regardless of specific cancer type completed a validated checklist with 90 potential problems and needs for palliative care. The five most dominant problems were: 1) fatigue; 2) heavy house work; 3) coping with the unpredictability of the future; 4) fear of metastases; and 5) frustrations because I can do less than before. The five issues most in need of extra consideration were: 1) informational needs; 2) coping with the unpredictability of the future; 3) fear of metastases; 4) fear of physical suffering; and 5) difficulties
remembering what was told. Younger patients experienced more social,
psychological, and financial problems.

Harstad and Andershed (2004) performed a qualitative study in Gotland,
Sweden using grounded theory to illustrate what patients with cancer who were in the
final stage of life believed to be good palliative end-of-life care and the physical
location in which they believed such care should be delivered. Nine Swedish patients
receiving palliative end-of-life care were interviewed. In the analysis three main
categories emerged concerning what constituted good palliative end-of-life care: 1) safety; 2) participation; and 3) trust. Participants spoke of the need for safety because
of the feeling of not being safe that was signified by the diagnosis of cancer. The
safety category had two subcategories: continuity and competence. Participating in
the care was very important for participants. Participation was explained by patients
to be at three levels: 1) participating in discussions on care; 2) being able to question
care; and 3) discussing alternative care. Furthermore, the trust category was divided
into two subcategories: 1) trusting the judgment of the staff; and 2) trusting in the
care. The majority of participants said that they wanted to receive care in a hospital.

In order to describe the experience of quality of life while dying from the
perspective of terminally ill men, Vig and Pearlman (2003) conducted a descriptive
study involving semi-structured interviews. Patients attending clinics at two university
affiliated medical centers in Seattle, Washington were recruited. The sample consisted
of 26 men identified by their physicians as having terminal cancer or heart disease.
The interview contained open-ended questions, such as, “What are the most important
things in your life right now?” The interview also included closed-ended questions
about symptom intensity, presence of depressed mood, and other items related to
quality of life. The open-ended questions were tape-recorded, transcribed, and
analyzed using the grounded theory method. The closed-ended questions were analyzed using descriptive statistics. Results revealed that participants believed death was near and they saw engaging in hobbies and other pleasant activities as an alternative to moving into the final stage of illness, in which they saw themselves as actively dying. They confessed to irregularly ignoring prescribed diets; these actions enhanced their overall quality of life but aggravated symptoms. New symptoms brought concerns about progression to active dying. Participants believed that their actions in the present could improve the quality of their dying and reduce the burden of their deaths on others. Many participants therefore were preparing for death by engaging in such tasks as putting their finances in order and arranging their funerals, to ease anticipated burden on loved ones.

Wong, Liu, Szeto, Shan, and Chan (2004) conducted a prospective study in Hong Kong, using clinical records and nursing anecdotes to investigate the health problems encountered by dying patients receiving palliative home care from referral to home care until death. Thirty-two subjects suffering from lung, gastrointestinal, nasopharyngeal, breast, brain, and other cancers with unknown primary origins were recruited in the study. The clinical records were content-analyzed using the Omaha System as a framework (Martin & Scheet, 1992). The Omaha system is a classification scheme which was primarily derived inductively from the practice of community health. The adapted and validated form was used to document the patients’ condition and needs based on the four dimensions mentioned in the Omaha system: environmental, psychological, physiological and health-related behaviors. Furthermore, the anecdotes of the nurses were used to explain the numerical findings registered on the system used. Results revealed that patients who were discharged home were living in good environmental and social conditions. The physical
symptoms were, in general, controlled except for dyspnea. The psychological aspects created the most concern for patients, families, and health care professionals. The frequently noticed psychological reactions among these patients were guilt, stress, fear, anger, anxiety, grief, and spiritual distress.

In an effort to study palliative care services in a Portuguese culture, Goncalves, Alvarenga, and Silva (2003) accomplished the following prospective study. Patients’ charts were audited during the last 48 hours of life prior to death in the palliative care unit of the Portuguese Institute of Oncology of Porto, Portugal. Data were recorded for four general domains: general demographic information, symptom prevalence, patient performance status, and perceived level of comfort. The inclusion criteria for patients were: older than 15 years of age, diagnosis of cancer, no active-direct treatments, and patients who were on the unit for longer than 48 hours. The audit was completed when the 300th eligible patient died in the unit. Reported results revealed that delirium was the most frequent symptom, along with pain and dyspnea. Fever and sweating occurred in high percentages. A relatively small number of patients (10%) required palliative sedation.

Lammi, Kosumen, and Kellokumpu-Lehtinen (2000) conducted a study to evaluate palliative treatment of inpatient cancer patients in two health centers and in one hospice in Finland. The study sample consisted of 36 patients from health centers and 36 hospice patients. A structured questionnaire containing information on diagnosis, duration of the illness, current medication, daily activities, and socioeconomic background was administered by nurses. Patients completed a questionnaire about their feelings and needs. Results revealed that the two groups of patients were similar in terms of gender, marital status and social situation. The hospice patients were notably younger and better educated than the health center
patients, and their disease had lasted longer. During the treatment period, nurses reported more anxiety and depression in the hospice patients; staff in the health centers were more often unable to report on their patients’ feelings. Hospice patients were significantly more concerned about the wellbeing of their relatives than were the patients in the health center. In the hospice, patients expressed more spiritual needs than did health center patients. Therefore, this study indicated that more education was required to enhance the recognition of the multidimensional needs of terminally ill cancer patients in primary health care in Finland.

Yeung, French, and Leung (1999) carried out a study in Hong Kong to investigate the needs and concerns of patients with terminal cancer in a hospice environment and to appraise the quality of life of these patients as they connect to the care and services currently being offered. A total of 52 patients terminally ill with cancer from 11 hospice units in Hong Kong joined the study. Data were collected from patients by asking them to respond to a Hospice Care Performance Inventory (HCPI), which was developed by the researchers after a thorough review of the literature on quality of life and cancer. Each item was rated by the patient on a Likert-like scale in terms of its importance and the perceived effectiveness of the care provided. This study presented a picture of what is judged to be essential aspects of care for patients who are dying. The major incongruity between expectations (importance) and experience (effectiveness) appeared to be maximized in self-care and mobility. Even though dying patients were weak and sick, being autonomous was important for them. Helping patients to dispel fear toward death was regarded as the second priority. Gaining enough rest and sleep was the third most important issue. Another area showing a need for improvement involved in providing a satisfying diet and helping to improve the patient’s appetite. The intervention that patients perceived
as the least helpful seemed to be the care team’s assistance in the fulfilment of their unfinished business. One of the most astonishing discrepancies between expectations and effectiveness was in the relief of pain. An ex post facto analysis of the data showed that 75% of the participants claimed that they had pain. Moreover, the need for religious faith seemed unimportant to the patients in this study.

In order to describe the experiences of illness and needs and use of services in two groups of patients with incurable cancer, one group in a developed country and the other group in a developing country, Murray, Grant, Grant, and Kendall (2003) conducted a longitudinal study with a qualitative survey in Scotland and a cross sectional study with qualitative interviews in Kenya. Twenty patients with inoperable lung cancer and their caregivers were enrolled in Scotland, and 24 patients with common advanced cancers and their main informal caregivers were recruited in Kenya. Results reported that the emotional pain of facing death was the prime concern of Scottish patients and their carers, while physical pain and financial worries dominated the lives of Kenyan patients and their carers. In Scotland, free health and social services were available, but sometimes underused. In Kenya, analgesia, essential equipment, suitable food, and assistance in care were often inaccessible and unaffordable, resulting in a considerable number of unmet physical needs. Kenyan patients thought that their psychological, social, and spiritual needs were met by their families, local community, and religious groups. Some Scottish patients thought that such non-physical needs went unmet.

Proot et al. (2004) conducted a grounded theory study to determine the needs of terminally ill patients at home in the Netherlands. Thirteen patients were interviewed. All participants were Dutch, Roman Catholics and lived in the province of Limburg in the south of the Netherlands. All participants had cancer.
Retrospectively, it was found that for 70% of the participants, the time between the interview and death was less than three months. Results revealed that the most commonly recurring theme identified in the analysis was “directing”. The subcategories found were: 1) directing one’s life by taking initiatives, being assertive, anticipating and seeking support; 2) directing one’s own health and health care by being assertive, taking initiatives, anticipating, self-managing, making choices, seeking information and deliberating; and 3) directing things related to beloved others by directing things that make future life as comfortable as possible for their beloved ones. The participants’ “directing” was affected by impeding and facilitating factors at the physical, psychological and existential/spiritual domains and the backup by family members and providers.

The concept of culture as it connects to people’s beliefs in health and illness is complicated (Ferrell, 2005). The diagnosis of cancer brings with it the cultural beliefs of each individual. Cultural elements are learned and shared by families (Shibani, 1999). What people believe in, what is important to them, and what they value differ among the many diverse culture of the world. Thus, how each culture approaches cancer, responds to the diagnosis once made or addresses palliative care will not be the same.

Palliative Care and Autonomy

In order to reinforce cancer patients’ autonomy and to improve the quality of palliative care, it is indispensable to discern the patients’ preferences for treatment at the end-of-life. Sahn, Will, and Hommel (2005) compared in Germany cancer patients’ preferences with respect to particular treatment options at the end of life, acceptance of the idea of advance directives, and preferences for who should initiate writing such a document. The comparison groups consisted of a healthy control group
of patients, nursing staff, and physicians. The structured questionnaire used was
developed by the researchers. Subjects were chosen from newly diagnosed or
advanced cancer patients treated at the Oncological Clinic and the Breast Cancer
Center of the German Clinic for Diagnosis. As a control group, healthy people who
had visited the clinic for a medical check-up were asked to fill out the questionnaire.
In addition, nursing staff and physicians working at that clinic were interviewed.
Results revealed that cancer patients’ preferences for treatment at the end-of-life
differed notably compared to the healthy control, nursing staff and physicians.
Outcomes of the study revealed that cancer patients required treatment with
antibiotics and infringing treatments, such as chemotherapy and dialysis, significantly
more often than was indicated by healthy controls, nursing staff, and physicians. The
researchers suggest that oncologists should begin a discussion about an advance
directive when the course of the illness seems to make this suitable, which concurs
with the desire of the majority of cancer patients, healthy controls, and medical staff.

The focus of end-of-life care is to respect terminally ill patients’ preferences
regarding the way of dying. Siew (2003) conducted an exploratory and descriptive
study to explore the preferences for the place of death among terminally ill patients
with cancer, to identify the reasons for selecting a preferred place of death, and to
examine the importance of dying at one’s preferred place of death. One hundred and
eighty terminally ill patients with cancer were recruited by a convenience sampling
strategy from six study sites in Connecticut. Analysis of the data revealed that
terminally ill patients with cancer in this study preferred to die at home. They reported
multiple considerations in deciding where they preferred to die, including quality of
life, availability and ability of family caregivers, concerns of being a burden to others,
long standing relationships with health care providers, and quality of health care.
Without exceptions, quality of life considerations motivated the subjects to choose home as the preferred place of death. They reported being with their families, enjoying a more normal life, having greater autonomy, and being surrounded by a familiar and comfortable home environment as the principal reasons they preferred for spending the rest of their life at home and dying there. Consideration of the huge difficulties associated with taking care of a dying patient at home influenced several terminally ill patients with cancer to select a place other than the home to die.

In palliative cancer treatment, the selection between palliative chemotherapy and best supportive care may be difficult. Therefore, Koedoot et al. (2003) conducted a prospective study in the Netherlands to understand the decision-making process of patients with various types of metastatic cancer. One hundred forty patients participated in the study. In order to understand the decision-making process in palliative chemotherapy, the researchers investigated the actual treatment choice of patients with metastatic cancer. The researchers assessed patients’ preferences for palliative chemotherapy or best supportive care before the patients consulted their medical oncologist. Researchers also investigated whether this treatment preference, patient or disease characteristics, quality of life, attitudes or preferences for information and participation in decision-making were predictive of the actual treatment choice. Results revealed that the patients’ preference for chemotherapy, as assessed before they met their medical oncologist, most strongly predicted their eventual treatment choice. A conclusion therefore must be that what was said during the consultation did not change much of the patient preferences and ultimate choices. Another finding was that the initial treatment preference was strongly explained by striving for length for life. Treatment choice was also envisaged by having a deferring style of decision-making. Patients having such decision-making styles were more
likely to undergo chemotherapy than were others. Since medical oncologists, being experts in systemic treatment, wish to offer treatment and spend more time explaining chemotherapy than explaining best supportive care, they may communicate the suggestion that they favour chemotherapy to the supportive palliative care.

**Palliative Care and Communication**

Discussing end-of-life issues is of major significance to terminally ill cancer patients and their families and a difficult topic for both health professionals and patients and caregivers. In order to explore the most select content and phrasing of information when discussing the dying process and end-of-life issues with terminally ill cancer patients and their caregivers, Clayton, Butow, Arnold, and Tattershall (2005) conducted focus groups and individual interviews with 19 palliative care patients and 24 caregivers from three palliative care services and 22 palliative care health professionals in Sydney, Australia. Participants’ narratives were analyzed using a qualitative methodology. Six distinct themes emerged for discussing end-of-life issues: 1) treatment decisions at the end of life; 2) potential future symptoms; 3) preferences for places of death; 4) the process of dying; 5) what needs to be done immediately after death; and 6) existential issues. Patients and caregivers believed it was advantageous to go over the pros and cons of treatment decisions with a physician from palliative care who would not, in fact, be giving the treatment. Patients and caregivers mainly wanted to know that pain could be controlled in the future. Many patients expressed that they did not desire exhaustive information about future symptoms, but they wanted a broad picture of what to expect and to know that they would be supported through whatever problems may arise. They emphasized the importance of reassurance that pain will be controlled when they die, that they would preserve their dignity and have plenty of support. The patients did not talk about place
of death or the information they would like on this topic. Moreover, many health professionals noted that many patients were hesitant to discuss this issue directly; however, patients felt thankful when the topic was finally discussed.

To get feedback from patients receiving palliative care and their relatives from different ethnic backgrounds about their experiences of the disclosure process and their contentment with information sharing during the illness Kirk, Kirk, and Kristjanson (2004) conducted a qualitative study with semi structured single interviews. Seventy-two participants registered in palliative care in Perth, Western Australia and Winnipeg, Manitoba, Canada were recruited. Twenty one patient-family dyads were interviewed in Perth and fourteen dyads and two patients in Winnipeg. The analysis pointed out that, in information-sharing, the process is as significant as the content. The timing, management, and release of information and perceived attitudes of practitioners were central to the process. This was relevant to information exchange at all stages of the illness. Main content areas reported related to prognosis and hope. All patients, despite origin, required information about their illness and wanted it fully shared with relatives. Almost all patients asked for prognostic information, and all family members respected their wishes. Information was perceived as important for patient-family communication. Patients expressed a continuing need for hope even when they knew and accepted that they were in the terminal stages of the disease and had limited life expectancy. Two dimensions of hope were portrayed: patient/family orientation to hope and messages from healthcare providers supporting hope. Information needs of patient and family changed and diverged as illness evolved and communication between them became less verbally explicit.
Mok and Chiu (2004) carried out a phenomenological study in China to explore aspects of nurse-patient relationship in the context of palliative care. Qualitative data were collected from ten hospice nurses and ten terminally ill cancer patients by means of open ended unstructured interviews. The interviews with patients started with the question, “Can you tell me about how you have experienced your illness and about your relationship with your nurse?” Interviews with nurses started with the question, “Can you tell me about your experience caring for patients with incurable cancer and about your relationships with your patients? I am particularly concerned with what this relationship is like for you”. This study focused on some dimensions of the nurse-patient relationship, including its context, relational qualities and patients’ and nurses’ interpretations and meanings of the relationship. Four major categories surfaced from the viewpoints of patients and nurses: 1) forming a relationship of trust; 2) being part of the family; 3) refilling with fuel along the journey of living and dying; and 4) enriched experiences. Responses revealed that a relationship of trust is formed, and that nurses were not only viewed as health professionals, but also became part of the family or a good friend. Nurses who built up trusting relationships exhibited a holistic approach to caring, demonstrated their understanding of patients’ suffering, were conscious of their unvoiced needs, offered comfort without actually being asked, and were dependable, proficient, knowledgeable and dedicated in their care.

It is believed that nurses are significant players in patients’ major decisions about their care; however minimal information is available about the complexity of patient-nurse interaction in palliative care, and patients’ views of the impact of such interactions on decisions that are made. Clover, Browne, McErlain, and Venderberg (2004) conducted a study exploring patients’ understanding of their discussions about
end-of-life care with nurses in a palliative care setting. A modified version of grounded theory was used to gather data and analyze interviews conducted with a convenience sample of 11 patients in a palliative care setting in Victoria, Australia. Processes were identified between nurses and patients that helped or blocked open discussion and discernment of patients’ preferences for care. Six approaches that patients employed in their conversations with nurses about their care were: 1) wait and see; 2) quiet acceptance; 3) active acceptance; 4) tolerating bossiness; 5) negotiation; and 6) being adamant. Results highlighted that palliative care patients often assumed passive roles and, for several reasons, learned not to engage in important decision-making. Professionals ought to be made aware of this, and must ease an open, trusting relationship with patients in order to make sure that important information passes freely in both directions. Professionals should learn to prioritize patient participation and negotiation in their work. More research is needed in order to discover the factors that will permit patients to acquire a more pro-active role in making decisions about their care.

Palliative Care and Pain

Pain is still a substantial problem for many patients with cancer, in spite of numerous, clear and concise strategies for the treatment of cancer-related pain. In the aim to describe how patients with cancer-related pain in palliative care can assist in the management of their pain Bostrom, Sandh, Lunderberg, and Fridlund (2004) in an explorative descriptive study interviewed 30 cancer patients receiving care from two hospital–based palliative care teams in a health care and medical county council in southwest Sweden. Patients described ten different perceptions of pain and pain management portrayed in three categories: communication, planning and trust. In terms of communication, patients articulated a need for an open and honest dialogue
with health care professionals about all problems concerning pain. Patients uttered an imperative need for planning their pain treatment, including all caring activities around them. When they felt trust in the health care organization as a whole, and in nurses and physicians particularly, they described enhanced ability and readiness to partake in pain management.

Simonson-Rehn, Sarvimaki and Benko (2000) conducted an explorative-descriptive study to portray cancer patients’ experiences of and expectations on care related to pain. Nineteen cancer patients from different parts of Finland took part in the study. Data were collected by means of focus interviews and essays and analysed by qualitative content analysis. The results revealed that patients wanted pain to be alleviated by medication, but they also stressed the significance of contact and communication, of professional expertise and kindness, of an active assessment of the pain, and of receiving cognitive means for pain control. The patients perceived respects for human beings and for the patient’s integrity as an essential facet of pain related care.

In order to understand the role of patients’ beliefs in pain management in a cancer population treated in a primary care setting, Dawson et al. (2005) carried a secondary analyses of data from the baseline phase of a randomized study. Eight of the largest primary care clinics in a managed care system in central Massachusetts were included. The sample consisted of 342 patients with cancer who reported pain that would not dissipate on its own or when treated by over-the-counter medication. Data collection was done through telephone interviews. Researchers used the Brief Pain Inventory (BPI) to measure recent pain and pain treatment. Patients’ beliefs about pain and pain treatment were measured on a single item from the BPI as recommended by the American Pain Society Quality of Care Committee. History of
pain and pain treatment and patients’ willingness to report pain and take medication were assessed using five point Likert-type scales. Findings revealed that patients’ beliefs were not associated strongly with reporting pain or taking medication. Regression analysis showed that patients’ beliefs had a partial role in predicting recent pain intensity, whereas the providers’ pain management practices appeared to have a far greater predictive role. Additionally, among patients with recent moderate to severe pain, the relationship between patients’ beliefs and their history of pain and pain treatment further suggested that beliefs are likely to be formed, in part as a consequence of the care they receive. Results of this study highlighted that nursing interventions should examine the effect of evaluating patients’ beliefs in conjunction with pain assessment on pain-related behaviors and pain relief, in addition to the ability of patient educational efforts to strengthen accurate beliefs and enable patients to assert themselves when interacting with less knowledgeable providers.

In a study to assess the relationship between quality of life, pain and desire for hastened death in advanced cancer patients, Mystakidou, Parpa, Katsouda, Galanos and Vlahos (2004) interviewed 120 Greek patients with advanced cancer. Patients were interviewed with the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire, C30, version3.0 (EORTC QLQ-C30) (Mystakidou, et al.,2001), the Greek Brief Pain Inventory (G-BPI) (Mystakidou, Mendoza, & Tsilika, 2001), the Greek Hospital Anxiety and Depression Scale (G-HADS) (Zigmond & Snaith, 1983) and the Greek Schedule of Attitudes toward Hastened Death (G-SAHD) (Mystakidou, Rosenfeld, & Parpa, 2004). Results revealed that in multivariate analyses, emotional functioning, social functioning, financial impact, and the interference of pain in general activity and mood were significant predictors of G-SAHD. Therefore, quality of life and pain seemed to have
a statistically significant relationship with a patient’s desire for hastened death.
Adequate palliative care should lessen pain and the wish for accelerating death thus improving quality of life.

In a study exploring the effectiveness of a pain education program to overcome patient-related barriers in managing cancer pain for Taiwanese home care patients with cancer, Chang, Chang, Chiou, Tsou and Lin (2002), developed a pain education program. The Barriers Questionnaire- Taiwan form (Lin, 2000), the brief Pain Inventory (Wang, Mendoa, Gao, & Cleeland, 1996), the Medical Adherence Questionnaire (Morisky, Green & Levine, 1986), and a demographic questionnaire were used for data collection. The sample consisted of 18 patients in the experimental group and 19 patients in the control group. Results of this study revealed that patients who received the pain educational program had significantly greater reduction in Barrier Questionnaire-Taiwan from scores and more improvement in medication adherence compared with patients who did not participate in the program. The results of this study support the effectiveness of the pain education program on overcoming the barriers to cancer pain management for Taiwanese home care patients with cancer.

Coyle (2004), in describing cancer patients experience with pain conducted a phenomenological study on seven individuals living with advanced cancer, who were followed by a pain and palliative care service at an urban center in New York. Analysis of interviews revealed that all of these patients, while striving to live, made big efforts to guarantee good pain relief in their dying. The fear created by pain was sometimes linked to its meaning, perhaps the implication of disease progression and nearness to death. Loss of hope and desire for death followed episodes of severe unrelieved pain for many of these patients. Relief of pain was crucial to them, but on
the other hand, they were disturbed by worry that the use of opioid drugs would affect their mental clarity.

Summary and Conclusion

The purpose of this proposed study is to uncover the lived experience of Lebanese oncology patients receiving palliative care, and to gain a better understanding of the meaning and interpretation of their experience. A review of research conducted in the US, Europe and the Far-East yielded the following categories: palliative care and culture; palliative care and autonomy; palliative care and communication; and palliative care and pain.

Studies conducted in different countries and cultures revealed that patients living in developed and developing countries have different and unique lived experiences of their illness. Culture was considered an important principle in comprehending individual perceptions of their lived experience, in terms of physical, psychological, social and spiritual needs.

Studies on palliative care and autonomy related mainly palliative care to end-of-life care. Autonomy was believed to be a vital element in improving the quality of palliative care delivered to patients.

Palliative care and communication studies revealed the important role that professionals need to play in order to facilitate communication through an open, trusting relationship with patients. Results reported that building trusting relationship with patients helped the health care workers to exhibit a holistic approach to care.

While the goal for some patients may be to prolong life at any cost, reviewed studies on palliative care and pain indicated that the majority of seriously ill patients desire to obtain comfort from their pain and other symptoms, improve their quality of
life, avoid being a burden to their family, have a closer relationship with loved ones, and preserve a sense of control.

Although several studies have examined palliative care from the patients' perspective (Appelin & Bertero, 2004; Osse et al., 2005; Proot et al., 2004; Siew, 2004), no studies focused on palliative care in Lebanon. This area constitutes a major gap in the literature and provides support for conducting this study. Results of this study will provide key information on a group of Lebanese patients’ perception of being cancer patients receiving palliative care.
CHAPTER III
METHODS

This chapter summarizes the philosophical underpinning of the phenomenological movement. It also describes the study design, identifies the study sample and setting, and defines the method of data collection and analysis. In addition, procedures for protection of human subjects and the criteria for assuring trustworthiness of the data are described.

Philosophical Underpinning

The phenomenological movement began around the first decade of the twentieth century. As described by Spiegelberg (1984), the philosophical movement consisted of three phases: the Preparatory phase, the German phase, and the French phase. The Preparatory phase was controlled by Franz Brentano (1838-1917) and Carl Stumpf (1848-1936). Clarification of the concept of intentionality was the main focus during this time. Edmund Husserl (1857-1938) and Martin Heidegger (1889-1976) were the well-known leaders during the German or second phase of the phenomenological movement. The concepts of essences, intuiting and phenomenological reduction were developed and enhanced during the German phase. Gabriel Marcel (1889-1973), Jean Paul Sartre (1905-1980), and Maurice Merleau–Ponty (1905-1980) were the principal leaders of the French or third phase of the phenomenological movement. The principal concepts developed during this period were embodiment and being-in-the-world (Speziale & Carpenter, 2003). These concepts relate to the conviction that all actions are constructed on foundations of perception or original awareness of some phenomenon.
Phenomenology has its roots in philosophy and is equally a philosophical theory and a research method. As a research method in nursing, it has been used in a variety of settings such as practice, education, research, and policy (Cohen et. al., 2000; Thomas & Pollio, 2002). However, there is more than one philosophical school of phenomenology, and the research findings generated will depend on which philosophical approach is used (Lopez & Willis, 2004).

Husserl’s (1970) philosophical ideas about how science should be conducted gave rise to the descriptive phenomenological approach to inquiry (Cohen, 1987). An assumption particular to Husserl’s philosophy was that experience as perceived by human consciousness has special merit and should be an object of scientific study.

A central constituent of Husserlian phenomenology is the conviction that it is indispensable for the researcher to get rid of all previous personal knowledge to be able to grasp the essential lived experiences of those being studied (Cohen, Kahn, & Steeves, 2000). The aim of the researcher is to realize transcendental subjectivity, a Husserlian concept. Descriptive phenomenologists have suggested specific techniques to accomplish this end, such as bracketing. Bracketing requires researchers to remain neutral and to set aside their prejudices about the topic being studied; or to sort out one’s preconceptions and personal commitments toward the phenomenon being studied; to comprehend meanings as they are for those describing the experiences (Barritt, Beekman, Bleeker, & Mulderij, 1983; Cohen et al., 2000; Speziale & Carpenter, 2003).

A further assumption underlying Husserl’s approach to the study of human consciousness is that there are features to any lived experience that are shared by all persons who have the experience. These are referred to as universal essences, or eidetic structures (Natanson, 1973). For the description of the lived experience to be
considered a science, commonalities in the experience of the participants must be acknowledged, so that a generalized description is feasible. The essences are considered to denote the true nature of the phenomenon being studied. The conviction that essences can be abstracted from lived experiences with no significance of the context reflects the values of traditional science and represent Husserl’s endeavor to make phenomenology a rigorous science within the existing tradition.

Husserl (1970) expressed the idea of radical autonomy. This means that humans are considered free agents who assume responsibility for influencing their environment and culture. The influences of culture, society, and politics on the individual’s freedom to choose are not pivotal to Husserl’s idea.

Heidegger (1962), a student of Husserl, challenged some of his assumptions about how phenomenology could guide meaningful inquiry, and developed the interpretive, or hermeneutic, research tradition (Cohen et al., 2000). The focal point of hermeneutic inquiry is what humans live through rather than what they consciously know (Solomon, 1987). A vital principle of Heidegger’s thought was that the relation of the individual to his world must be the hub of phenomenological inquiry. Heidegger insisted that humans cannot extract themselves from the world. Therefore, pure content of human subjectivity is not the center of a hermeneutic inquiry; rather what the individual’s narratives mean about what he or she experiences every day (Cohen et al., 2000).

A key concept to interpretive inquiry is that of freedom. Heidegger confirmed that humans are rooted in their world to such a degree that subjective experiences are inextricably connected with social, cultural, and political contexts (Cohen et al., 2000). This concept is called situated freedom (Leonard, 1999 pp 315-327).
The concept of situated freedom is in direct opposition to Husserl’s concept of radical autonomy. The hermeneutic phenomenologist, rather than seeking purely descriptive categories of the real, perceived world in the narratives of the participants, concentrates on describing the meanings of the individual being-in-the-world and how these meanings affect the choices they make (Smith, 1987). In interpretive phenomenology, the analysis of the narratives provided by participants in relation to various contexts is foundational.

Another philosophical assumption underlying the interpretive phenomenological approach is that presuppositions or expert knowledge on the part of the researcher are precious guides to inquiry and, in fact, make the inquiry a significant undertaking (Koch, 1985). Consequently, personal knowledge, according to hermeneutic scholars, is both valuable and indispensable to phenomenological research (Geanellos, 2000). The technique of bracketing, as described by descriptive phenomenologists, is inconsistent and questionable within a hermeneutic approach (LeVasseur, 2003). Therefore, bracketing as highlighted by Husserl was not a requirement for this study.

An imperative concept that was expressed by Heidegger was that of constitutionality (Koch, 1985). This concept indicates that the meanings that the researcher arrives at in interpretive research are a combination of the meanings articulated by both the participant and researcher within the focus of the study.

The phenomenological movement gave rise to three schools of phenomenology. The Duquesne school of phenomenology based on Husserl’s descriptive philosophy; The Heideggerian hermeneutic school based on Heidegger’s interpretive philosophy; and the Utrecht School of phenomenology which combines characteristics of

Study Design

The study design was based on the Utrecht School of phenomenology which combines characteristics of descriptive and interpretive phenomenology based on the Dutch school of phenomenology as described by Barritt, Beekman, Bleeker, and Mulderij (1984). Barritt et al. (1984) provided an example of this combined approach in which researchers tried to grasp the essential meaning of the experience being studied.

The Utrecht School combines the ideas of Husserl in highlighting the importance of identifying the essences of each experience; yet, it stresses the importance of searching for meanings between lines and tries to find language that captures these essences (Van Manen, 1984). At the same time it integrates the concept of constitutionality as mentioned by Heidegger.

Phenomenology, specifically the Utrecht approach was the best fit for this study because it describes the meaning of the lived experience through the shared essences among participants, and it uses the language to interpret the connotations of the experience of the participants. Thus, a comprehensive, culturally competent understanding of the phenomenon was provided.

Phenomenological research is a useful method to follow when exploring a new area or a topic that has been studied, but for which a new perception is considered (Cohen et al., 2000), or when studying a phenomenon in a different culture as was the case in this particular study. The lived experience of oncology patients receiving palliative care has been extensively studied in different countries and cultures, but it has never been addressed in Lebanon; therefore, phenomenology was the best approach
to address this issue. This approach is most valuable when the activity at hand is to comprehend an experience as it is identified by those who are living it and to respond to questions of meaning. Holistic care and avoidance of reductionism are at the core of professional nursing practice. Because phenomenological inquiry requires that the integrated whole be explored, Speziale and Carpenter (2003) assert that it is an appropriate method for the exploration of phenomena essential to nursing practice, education, and administration. Phenomenological methodology, which aims to comprehend another’s experience, is well matched to the research of nursing care. Nurse theorists since Nightingale have talked about the necessity to recognize patients’ perceived needs in order to meet those needs efficiently. The connotations that patients ascribe to their experiences help create the picture of the needs they have and provide a guide for how to address these needs (Cohen et al., 2000).

A description of the elements that apply the study design follows in the next section of this chapter. These elements include: the sample and setting, data collection and analysis, procedures for protection of human subjects and a statement about the trustworthiness of the data.

Sample and Setting

Sample

Following the tenets of phenomenology, this study used purposeful sampling in which participants were selected based on their particular knowledge of the phenomena and their willingness to share that knowledge (Cohen et al., 2000; Patton, 1990). Purposeful sampling seeks information-rich cases which can be studied in depth (Patton, 1990). “A sample in a phenomenological study is drawn from a population that has experience with the phenomenon of concern. In this respect, it is purposive and participants are chosen to provide as much variability as possible in
their responses” (Kennedy, 1995 p.412). This definition of sampling fits the philosophical underpinning of this study underlined by the Utrecht School of Phenomenology.

Group diversity within purposeful sampling was observed. According to Lincoln and Guba (1985), the most useful sampling for the naturalistic approach is maximum variation sampling. This strategy aims at depicting and describing the central themes or principal outcomes that cut across great participant or program variation. For small samples, a large amount of heterogeneity can be a drawback because individual cases are so different from each other. However, Patton (1990) changes that apparent weakness into a strength by using the following logic: “Any common patterns that emerge from great variation are of particular interest and value in capturing the core experience and central, shared aspects or impacts of a program” (p. 172). Heterogeneity in this study was related to participants’ type, site, and duration of cancer diagnosis, and their level of education.

**Inclusion Criteria**

Participant inclusion criteria were: 1) Lebanese speaking Arabic; 2) living in Lebanon; 3) age of 18 years or above; 4) confirmed diagnosis of any type of cancer; 5) low expectations for remission or cure as reported by the participant’s oncologist; 6) receipt of palliative care, as described in the definition of the concept, based on the participant’s physician confirmation; 7) participant’s knowledge of his or her palliative condition, as reported by the referring person and later confirmed by the researcher’s assessment; 8) agreement to share personal experiences and participate in the study; 9) agreement to be interviewed without the presence of a third person in order to ensure liberty for the participant to express his or her feeling. (In the event that the researcher was unable to find participants who agreed to be interviewed alone,
the researcher intended to change the strategy and interview all participants in the presence of a significant other of his or her choice. However, this was not the case); 10) participant’s capability of signing his or her name on the consent form. (In case the participant did not know how to read and write, the researcher intended to read the consent form and have the participant indicate his or her agreement with a mark or symbol in the presence of a third person. The witness or third person would put his or her signature on the consent form (Appendix A). However, this was not necessary); and 11) participant’s capability of completing a coherent interview as indicated by the treating physician.

A suitable sample size for phenomenological research can vary from 6 to 12 persons (Morse, 1994). Evidence from the literature suggests that similar sample sizes were used in previous studies that yielded meaningful findings (Appelin & Bertero, 2004; Bulsara, Ward, & Joske, 2004; Larsson, Hedelin, & Athlin, 2004). Moreover, the number of participants asked to take part in this study was determined by data saturation. Saturation is reached when no new themes emerged from the participants and the data were repeating (Speziale & Carpenter, 2003; Thomas & Pollio, 2002). Not uncommonly, sample size was adjusted as the study progressed. If redundancy was obvious after hearing the narratives of six participants, the researcher might determine that it is not essential to interview further participants (Thomas & Pollio, 2002).

Recruitment Strategies and Techniques

Initially, the researcher discussed the study with community intermediaries and oncologists, a total of seven people. According to the researcher, who is Lebanese and knows very well the specificity of the Lebanese culture, the use of community intermediaries as one of the recruitment strategies was vital for participants’
enrollment. This approach was also recommended by Cohen at al. (2000). It is worth noting that this strategy conforms to the Lebanese culture. The idea of putting announcements in newspapers or distributing flyers was not considered a usable recruitment method in the Lebanese culture.

Meetings took place at the discretion of the oncologists and intermediaries. As the community intermediaries and the oncologists identified potential participants, the researcher was introduced to the potential participant and extended an invitation to participate in the study. The referring person provided the researcher with the addresses of potential participants. The researcher explained to potential participants that she knew about their condition from the referring person. The researcher further explained her role as a doctoral student in nursing and her interest in learning more about the experience of cancer patients in a palliative stage. She also mentioned her hope that learning more about this experience would contribute to better knowledge and understanding, and to the improvement of the quality of care offered during this time. Then the researcher agreed on an interview date and time with each participant.

It was initially agreed between the researcher and PhD committee members that in case of community referral, the physician would be informed of his or her patient’s participation in the study. All information pertinent to the study about participants’ conditions, such as specific information about treatment received, cancer site, and degree of the tumor, would be obtained by the researcher from the participants themselves.

Place of recruitment was not confined to a specific location, but rather, participants were sought at different places, such as oncologists’ clinics, hospitals, and their own homes in Lebanon. Based on the researcher’s clinical experience, these places were considered the most appropriate locations to recruit participants.
Interviews were conducted based on the participant’s preferences regarding place and time. Since the researcher has a well-established, long-term, collaborative relationship with oncologists and nurses working in oncology units and clinics, this facilitated her access to a sufficient number of participants for the study. A total of ten participants were recruited for the study; eight participants were directly recruited through physicians and two participants were obtained through intermediaries.

It is worth noting that national data on the prevalence of cancer and the number of Lebanese oncology patients is officially lacking. The tumor registry at the American University of Beirut-Medical Center (AUB-MC), which was during war time (1975-1990) the only registry in Lebanon, reported 20,088 cancer patients who were diagnosed with and/or treated for cancer at this center from 1983 to 2003 (Shamseddine, 2004). The latest National Cancer Registry (NCR, 2002) official report stated that 2,124 new cases of cancer were registered in Lebanon between January 1 and December 31, 2002 (Ministry of Public Health, WHO, & National Non-Communicable Diseases programme [NCDP], 2002). Cases listed in the NCR report are related to patients receiving free chemotherapy from the Lebanese Ministry of Health. Therefore, this number is not representative of all new cases in Lebanon. Based on the researcher’s experience and a discussion with a prominent Lebanese oncologist, it was estimated that 4,000 new cancer cases are diagnosed on a yearly basis and the estimated number of oncology patients receiving palliative care represents around 20% to 30% of the total number of cancer patients in Lebanon (estimated population of Lebanon is 4.5 million). Official data about the number of cancer patients receiving palliative care in Lebanon are lacking (Dr. Z. Salem, personal communication, May 10, 2005; January 13, 2006).
Setting

All interviews took place at the participant’s home, except for two cases where participants expressed the inclination to participate in the first interview in a private room in a general hospital. Conducting the interviews in the participant’s natural settings was intended to create a non-threatening environment. Interviews were conducted privately between only the researcher and participant. Participants were asked to be interviewed in private in order to give enough freedom for the participant to express his or her lived experience without any fear of offending caregivers. All participants agreed to be interviewed in private without the presence of a family member, which in Lebanon constituted a cultural challenge due to the family dominant culture. In Lebanon, sick individuals and especially cancer patients are over protected by family members who are always surrounding patients and fear that talking about cancer might be detrimental to their physical and psychological condition (Adib & Hamadeh, 1999). The researcher had participants sign a written consent form at the beginning of the first interview (Appendix A). All interviews were conducted by the researcher exclusively, thus eliminating the potential for variation in interview technique. The researcher possessed the experience and expertise needed to communicate in the interviews, appropriate theoretical knowledge in oncology, and the clinical skills in working with oncology patients. She encouraged each participant to talk at length about his/her experience. The open-ended interview guide (Appendix B) facilitated the interview. The interview was not limited by the researcher, but by the participant him or herself.
Data Collection and Analysis

*Demographic Data*

Demographic data collected included participants’ gender, age, marital status, diagnosis, geographical area of residence, occupation (past and current), educational background, time since initial diagnosis with cancer, cancer site and treatment followed (Appendix C). These data were collected from the participant at the beginning of the first interview and used to describe the participant group.

*Methods of Data Collection*

In-depth semi-structured interviews along with observation field notes were used as data sources to describe and gain an understanding of the lived experience of Lebanese oncology patients receiving palliative care. Collecting data using a variety of sources and methods is one form of triangulation (Fielding & Fielding, 1986). This approach lessens the risk of systematic biases or limitations of a specific source or method, and permits the researcher to obtain a broader and more secure understanding of the issues under investigation (Maxwell, 2005).

In qualitative research, the investigator is the instrument of data collection. Because the understanding of a phenomenon or experience was sought, in depth-interviews supported by a semi-structured open-ended question guide was used as opposed to a defined pre-worded questionnaire. The researcher resorted to the in-depth interview approach because she wanted to understand participants’ experiences without imposing any a priori categorization that may limit the field of inquiry. In the questionnaire approach, the problem is defined by the researcher before the interview. The questions are formulated ahead of time, and the participant is expected to answer in terms of the interviewer’s framework and definition of the problem. On the other hand, in an in-depth interview the format is non-standardized and the interviewer does
not seek normative responses. Rather, the problem of interest is expected to arise from
the respondent’s reaction to the broad issue raised by the researcher. Thus, interviews
are a fundamental part of data collection in most qualitative methods of inquiry and
can extract a diversity of types of data through the variety of questions that are asked
(Morse, 1994). Moreover, unlike the questionnaire approach, the in-depth interview is
concerned with the unique, the idiosyncratic, and the wholly individual viewpoint;
therefore, this was the best approach for this phenomenological study.

An invitation to participate in the study was offered to individuals who were
interested and who were willing to speak about the experience of living with cancer
and receiving palliative care. The researcher explained the study in detail, and then
initial interviews were scheduled according to each participant’s discretion. At the
beginning of each initial interview the researcher re-explained the purpose of the
study, each participant signed the consent form (Appendix A), and a demographic
sheet was filled out by the researcher (Appendix C). All participants agreed to be
interviewed twice and without the presence of a family member. The purpose of the
second interview was to validate with the participant the preliminary analysis and to
clarify previous statements in the first interview. The time lapse between the first and
second interview was one to two weeks. The length of the first interview varied
between 50 to 60 minutes; whereas the length of the second interview ranged between
30 to 45 minutes. Only one participant did not complete the second interview. He
deteriorated a few days after the first interview, was admitted to the Intensive Care
Unit, remained unconscious for ten days, and died.

Interviews were conducted in Arabic by the researcher who is fluent in both
English and Arabic. In each interview, the participant was the major speaker and the
researcher was mainly a listener and a facilitator. The researcher helped participants
portray their lived experience without leading the interview (Speziale & Carpenter, 2003). The participants were reminded that their participation was voluntary and that at any time they could decline or withdraw from the study without any obligation. Participants influenced the length of the interviews and were assured that they could end the interview at any time. Several times during the interview, the researcher asked the participant about his or her wish to continue the interview. None of the participants ended an interview session due to fatigue or emotional distress. The researcher was assured of their desire to continue.

The interviews were audio-taped and field notes were recorded. Each interview was coded so that only the researcher had knowledge of the individuals who participated. Participants were assured of confidentiality and pseudonyms were used. The code list and the original tapes were kept in a locked file cabinet in the researcher’s office.

The first set of interviews was based on the following broad or grand tour question as recommended by Polit and Hungler (1995), “Can you tell me about how you have experienced your illness?” Participants were asked to provide examples that helped to describe their experience. Probing technique was used to elicit more explanation such as: “Please tell more about it. What does that mean to you? Is it possible to give an example? Describe to me what that was like for you”. This type of inquiry typifies the format generally used in phenomenological interviewing (Kennedy, 1995). The following open-ended questions designed by the researcher were used as a general guide for interviews: “Where should I begin?”; “Pick a typical day and talk about it”; “Pick an unusual day and talk about it”. Other questions in response to participants’ interviews were added as was suitable to the individual situation. The interviews were flexible and based on participants’ responses, allowing
the participant to guide the interview. In keeping with the emergent nature of qualitative research designs, interview guides may be modified from one interview to another within the same study to focus on areas of particular importance, or to exclude questions the researcher has found to be unproductive for the goals of the research (Lofland & Lofland, 1984).

Patton (1990) recommends the use of an interview guide or “schedule” as a list of questions or general topics that the interviewer wants to explore during each interview. This guide was prepared by the researcher to insure that basically the same information was obtained from each person and the interviewer probed and explored within these predetermined inquiry areas. Questions were developed based on the phenomenological hermeneutic approach and thorough review of the hermeneutic literature on palliative care of cancer patients. Furthermore, as described by Lofland and Lofland (1984), interview guides ensure good use of limited interview time, make interviewing multiple participants more systematic and comprehensive, and help to keep interactions focused.

There can be a fear that in self-report of data the participant may be inclined to give socially pleasing answers (Lincoln & Guba, 1985). In an effort to discourage this, the researcher clarified at the beginning of the interviews that she was concerned about the individual’s thoughts, feelings and meanings about the experience of having cancer and receiving palliative care. This type of inquiry typified the format generally used in phenomenological interviewing (Kennedy, 1995).

The second set of interviews was designed to confirm the initial analysis of the researcher, and to provide an opportunity for the participant to add or change some information. The participants were requested to verify the descriptions and
interpretations when possible. It is worth mentioning that no two interviews were
expected to be precisely the same.

The researcher sent each community intermediary and oncologist who
identified potential participants a thank you card for their collaboration and support.
Likewise, at the end of the first interview, the researcher gave each participant a
coffee mug as a token of appreciation. This gesture was very well appreciated based
on the participants’ comments. It is worth noting that it is a Lebanese custom to offer
gifts to sick people when visited.

Method of Data Analysis

Data were analyzed using the phenomenological approach based on the
Utrecht School of Phenomenology as described by Barritt et al. (1984).

Analysis of the data began following the first interview (data collection and
analysis were concurrent). Each taped interview was repeatedly reviewed following
its completion. The tapes were transcribed by the researcher verbatim. Then each
interview was translated to English by the researcher and back translated to Arabic by
another bilingual person to check for accuracy of translation. This translation
technique was recommended by Maneesriwongul and Dixon (2004) to ensure
credibility of the translated data. This approach was similarly used in a
phenomenological study conducted in Italy by Vellone, Sansoni, and Cohen (2002).
The researcher read each interview line by line twice with a fresh eye, organized
transcriptions into themes, and extracted excerpts that supported the emerging themes.
Then the researcher compared themes between the different interviews. After the
analysis of the first interview, the researcher asked the participant to comment on the
accuracy of the interpretation and analysis and obtained their reactions; this procedure
is called member checking (Polit & Beck, 2004). Lincoln and Guba (1985) consider
member checking the most essential procedure for establishing the credibility of qualitative data.

A doctorally prepared researcher with experience in analyzing qualitative data of phenomenology assisted with peer debriefing. Peer debriefing occurs when an expert on the method checks the analytic steps, such as the reduction of categories to themes. During the debriefing session the researcher’s biases were explored and the basis for interpretations clarified. Questions pertaining to substantive, methodological, legal and ethical areas were posed. The duty of the debriefer is to be certain that the researcher is as fully aware of the process as possible (Lincoln & Guba, 1985). The doctorally prepared researcher compared codings, read and discussed with the researcher the first three transcriptions for description, interpretation, meaning and the formulation of themes. Peer debriefing helps to establish credibility through external validation (Polit & Beck, 2004). Intercoder reliability was concurrently performed with peer debriefing. The doctorally prepared researcher (coder) was presented with transcribed raw material from three interviews. She analyzed the material and came up with a list of themes. Then the researcher’s list and that of the other coder were compared for checking common understanding and interpretation. The agreement was almost 90 percent and the remainder were agreed upon and resolved. The purpose of doing intercoder reliability was to distinguish the level of coordinating interpretations between the findings of the other coder and the findings of the researcher (Polit & Beck, 2004).

Rich description was used in the excerpts from the interviews included in the report of the study. Analysis of data was ongoing throughout data collection, transcription, and repeated readings of the text (Barritt et al., 1984).

Data were managed using electronic software (QSR NVivo 1.2) (QSR
International, 2002; Morse & Richards, 2002). The NVivo software program allowed
the researcher to store materials, organize the data, store ideas, concepts, and
questions. It allowed the researcher to add theme labels to the text so that texts were
easily retrieved and grouped during analysis without the need for manual cutting of
transcripts and other data (Cohen et al., 2000; QSR International, 2002). Coded
transcripts within the QSR NVivo1.2 software were derived from the transcribed and
translated taped interviews of the participants.

A list of themes was created. While analyzing the fifth transcript, patterns
and commonalities started to emerge. The sixth transcript suggested saturation had
occurred; this meant that descriptions from the participants were becoming repetitive.
However, the researcher, in consultation with the dissertation chair, opted to continue
to ten interviews. So, four additional interviews were conducted to ascertain that no
new ideas were to be revealed. Based on the research results the researcher formulated
recommendations.

Procedures for Protection of Human Subjects

The proposed research was submitted to the Institutional Review Boards (IRB)
at the American University of Beirut and Duquesne University for approval.
Authorization was received for an expedited review. It is worth noting that procedure
for IRB approval at both institutions was comparable.

Each participant was informed of the purpose of the study, expected number
of participants to be included, the reason for the second interview, and the time lapse
between the first and second interview. In addition, participants were told that their
treating physicians were informed of the study and of their participation. The
researcher explained the personal contributions and human rights to the participants,
and provided them with the opportunity to ask questions about the study. Participants were informed that all interviews would be conducted in Arabic and would be audio-tape recorded. Once the participant was satisfied with the requirement and agreed to join the study, the participant was asked to read and sign a consent form devised in Arabic. All participants were able to sign the consent form. In the event that the researcher encountered a participant who did not know how to read and write, the researcher planned to read the consent form and ask the participant to put a mark under signature in the presence of a third person as a witness. In this case, the third person would have to put his or her signature next to the participant’s mark.

The consent outlined the purpose of the study, its voluntary nature, the right to withdraw at any time without penalty, and provided assurance that all information provided would be treated in a non-identifiable, confidential manner (Appendix A). A number identified each participant on the interview transcript and tape. Only the researcher had access to the master list that linked participants’ names with code numbers; this list was kept in a locked cabinet. The participant and the researcher signed the consent form, and each kept a copy.

It was planned that in case the participant became emotionally disturbed during the interview, the researcher would stop the interview and would use her nursing skills to provide basic emotional support. If necessary, the treating physician would be contacted and researcher would stay with the participant for the needed time. There were no instances of such emotional disturbance among the participants being interviewed.

The clerk typist and back translator hired for the job signed consent of confidentiality in which they promised to adhere to confidentiality in dealing with the material for this particular study (Appendix D). All data were kept in the researcher’s
office in a locked cabinet. Data will be maintained until the study is completed and all manuscripts and presentations are done. No identifying names or identifying information were used in the transcripts. Pseudonyms were assigned by the researcher to assist with discussion of findings.

Trustworthiness of the Data

Several steps were undertaken to support trustworthiness in this study. Trustworthiness is the term utilized by qualitative researchers to demonstrate rigor. The questions of rigor in qualitative research vary from those of quantitative research because rather than measuring the distribution of a characteristic within a population, one is interested in finding out meaning and attaining a deeper understanding of a phenomenon (Field & Morse, 1992). According to Lincoln and Guba (1985), within-method triangulation, peer debriefing and member checks are important means to assure trustworthiness of the study. Intercoder reliability as suggested by Polit and Beck (2004) was applied to serve as a great solidification to the research findings.

Audio-taping was used to ensure accuracy in recording data. Interviews were transcribed verbatim. Field notes were taken along with the interview by the researcher during the interview to describe observations such as participants’ body language, tone of voice, environmental distractions, contextual factors, changes in physical condition and comfort (Cohen et al., 2000). This technique is what Lincoln and Guba (1985) labeled as triangulation by different method or within-method triangulation. These notes were very important additions during data analysis because they provided validation for important points made by the participant and facilitated appropriate emphasis on extracted themes during data analysis. This combination of field notes and interviews gives a more comprehensive and truthful account than either method could alone (Maxwell, 2005).
One or two weeks after the first interview and preliminary analysis of the information was obtained, the researcher returned to each participant for a second interview and asked if the extracted themes mirrored the participant’s experience. The researcher integrated content added or deleted by a participant into a revised description (Barritt et al., 1984; Speziale & Carpenter, 2003). This technique is termed member check (Lincoln & Guba, 1985). One participant died before the second interview, but according to the previous plan, it was agreed that in case of failure to conduct the second interview, data obtained from that particular participant would be integrated in the study.

Summary

As the efficiency of cancer treatments has improved and the life span for cancer patients has been extended, palliative care has become one of the most significant foci in oncology nursing practice and research. The diagnosis of cancer brings with it the cultural beliefs of each individual. What people believe, what is significant to them, and what they value, vary among the many cultures of the world. An understanding of how patients perceive their palliative care experience may lead to improved care. Therefore, health care professionals must take care not to decide a patient’s experience from their viewpoints, but rather to estimate patient needs based on what the patients perceive as essential to their well being.

Review of the literature revealed few studies assessing the lived experience of cancer patients receiving palliative care, and none of the studies was conducted on Lebanese cancer patients receiving palliative care. Therefore, this hermeneutic phenomenological study, using the Utrecht method, was undertaken to begin to understand how Lebanese oncology patients receiving palliative care perceived their experience.
CHAPTER IV
FINDINGS

The findings of this phenomenological study illustrate the lived experience of Lebanese cancer patients receiving palliative care as described and explained by the ten participants of the study. This chapter portrays the description of the sample, lists the thematic findings of the study, and assembles the participants’ descriptions and interpretations into thematic categories with supportive verbatim excerpts from the interviews.

Description of the Sample

Following the tenets of phenomenology and saturation, the sample consisted of ten purposively selected Lebanese cancer patients with advanced cancer with low expectations of cure or remission and being in a palliative stage as reported by the treating physician. The participants were purposively selected according to the study inclusion criteria previously detailed in Chapter 3.

Ten participants were included in the study; six women and four men. Their ages varied between 23 and 71 years with a mean age of 54.4 years. Participants’ lived experience with cancer ranged between 2 months and 21 years. All participants were or had been married except for one. Three individuals were widows. At the time of the interview all participants were not working; however, before getting sick, five were working and the remaining five were not. Their primary diagnoses varied among breast, colon, lung and bone cancer with metastasis. Their educational backgrounds differed among primary education (n=4), intermediate (n=1), secondary (n=1) and university (n=4). Participants’ current treatments differed from palliative
chemotherapy (n=7) to symptomatic treatment (n=3). The location of participants’ residence varied between urban (n=7) and rural (n=3) regions of Lebanon.

Thematic Findings

Based on the principles of the Utrecht School of Phenomenology, a list of themes was created. The themes are ideas mentioned by all participants which seem to be at the center of the experience for all participants. The following eight themes were identified in the phenomenological analysis and are illustrated in Table 1.

Table 1.
List of Original Themes from 10 Interviews.

<table>
<thead>
<tr>
<th>Themes</th>
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<tbody>
<tr>
<td><strong>Theme I</strong></td>
<td>Distressed From Being Dependent: Loss of Control, Disease Reminder, and Burden on Others</td>
</tr>
<tr>
<td><strong>Theme II</strong></td>
<td>Dislike for Pity: Threat to Self-Perception</td>
</tr>
<tr>
<td><strong>Theme III</strong></td>
<td>Worry for the Family and the Worry about the Family’s Worry</td>
</tr>
<tr>
<td><strong>Theme IV</strong></td>
<td>Relying on God and Divinity</td>
</tr>
<tr>
<td><strong>Theme V</strong></td>
<td>Dislike of the Hospital Stay: Feeling trapped in time, Place, and Disease</td>
</tr>
<tr>
<td><strong>Theme VI</strong></td>
<td>The Need to Be Productive</td>
</tr>
<tr>
<td><strong>Theme VII</strong></td>
<td>The Fear of Pain and Suffering, Current and Future</td>
</tr>
<tr>
<td><strong>Theme VIII</strong></td>
<td>The Impact of Communication, Verbal and Non-Verbal</td>
</tr>
</tbody>
</table>
Participants’ Descriptions and Interpretations

**Theme One: Distressed from Being Dependent: Loss of Control, Disease Reminder, and Burden on Others**

In describing current experiences with cancer and palliative care, participants highlighted their disconcerting feelings derived from being dependent on others. A sense of loss of control emerged from the state of dependency. This sense of loss of control was described as life not being the same anymore. Participants verbalized their concerns of being dependent and becoming a burden on others in their daily activities. This state of dependency, whether actual or potential, created a state of powerlessness for the participants. Being dependent made them feel as if they are a burden on others, and for some participants it was a reminder of their condition (cancer). Samer, a 21 year old male with colon cancer and bone metastasis, explained how his state of dependency was a continuous reminder of his disease, and how it made him lose control over his life. Samer said:

> I am used to going and coming and to have my freedom. I do not like to be served. I like to be independent. I do not like to be dependent on others. I do not like people to tell me, ‘Come we will help you.’ I feel bothered because I am not used to this. I am used to serving all people. I like to serve others. I feel as if I am a burden on them. This makes me remember and think of my disease. I am not used to this; it is difficult for me to accept. I feel as if I am going to blow from inside.

For Samer, being dependent meant that he lost control over his life; he felt as if he was a burden on others and this state of dependency was a continuous reminder of his condition. Talking about this issue made Samer feel frustrated and...
apparent in his body language. He frowned, his eyes started to shine with tears and his tone changed and became a bit aggressive.

Likewise, Houda, a 51 year old woman with breast cancer and metastasis to breast and bone shared the same feelings regarding being dependent. “When I am served, I feel that I am sick,” said Houda. Regarding the loss of control she said:

By God’s will I hope not to stay in bed and be dependent on my family. This is something spontaneous because I am not used to it. I do not mean it, but I do not like to be served, I have been always like this. This is me. I like to serve as long as I am able to do it. I feel that I am not able to do anything and that I lost the power that I had before.

Whereas Dima, a 49 year old woman with colon cancer and lung metastasis, perceived the state of dependency as a sudden, complete loss of control-- like a child-- and said in this regard:

I mean this is my life… suddenly I lost control. Yes, I lost control. I like to be in control. I mean the way they talk to you… do this and that, eat this. I do not like to be told what to do as if I am a small child. They treat a patient as if he is a small child. I am not a small child. I know what I have and I know what I am supposed to do. Enough! I want them to leave me alone.

Dima, while talking about this state of dependency, became very agitated. Her frustration was very obvious on her face and in her hands movement and voice tone.

Anissa, a 62 year old woman diagnosed with colon cancer and metastasis to lung, brain and bone, mentioned in this regard:

I feel disturbed, because I am dependent on others. A sick person is a burden on others--give me this and take that. I do not like that. I like to do my own
things. I like to bathe myself, but I am unable. This condition reminds me of my disease. This is what bothers me. You see yourself as a burden on others. I feel that I am handicapped and that I am a burden on people.

For Samer, Houda and Anissa, being dependent was perceived as a reminder of their condition and a threat to their perceived control; whereas, Dima perceived it as a complete loss of control over her life.

Tania, a 55 year old woman with lung cancer and brain metastasis said, “To depend on others makes me feel very disturbed. I feel very disturbed when my children take me to do my shopping. I feel upset because I am bothering them.”

Anissa and Tania were partially dependent on their families, mainly children, and it was difficult for them to accept this shift in roles within their families.

Sonia, a 65 year old woman with breast cancer and metastasis to bone, lungs, liver, uterus and brain, fought with her disease and the idea of being dependent. She tried to remain independent as much as possible. She was trying to prove to her family that she was still capable; she had not yet lost control. Sonia mentioned that she refuses to be accompanied by her daughter to the oncologist’s clinic to receive blood or chemotherapy. She said the following, “Because I am not disabled, I am still capable and she [her daughter] has work to do. The disease did not disable me. I still can move and walk alone.”

Hind, a 65 year old woman with breast cancer and metastasis to lungs, brain and bone, had a fear of becoming dependent on others due to her inability of maintaining normal daily activity. She said:

I ask from God when I pray that when I reach the time to still be able to go to the toilet, not to bother anyone and to still be able to help myself.

Psychologically you feel more relaxed if you serve yourself, if you can go by
yourself to the toilet, cook your food. Psychologically you feel more relaxed, you feel yourself natural. You would not feel yourself as a burden on anyone.

Amine, a 71 year old man with colon cancer and metastasis to bone and lung, mentioned in this respect:

Let’s be realistic. I do not want to be a burden on any one. I do not want them to put diapers on me. This is the only thing that I think about and I say, “My God, please deliver me early because I do not want to be a burden. I do not want to be a burden on others.”

Hind and Amine were living in the fear of becoming dependent. At the time of the interview they were still independent; however, the idea of becoming dependent haunted their minds constantly. They did not want to lose control over their lives.

Participants of this study reported varied levels of experienced dependency. Some were fully dependent, others were partially dependent and some perceived themselves at risk for becoming dependent. However, regardless of the varied experienced levels of dependency, this condition provoked in all participants the feeling of being a burden on others, and triggered in them the feeling of loss of control over their lives. The situation of being dependent was also perceived as a reminder of their disease.

Theme Two: Dislike for Pity: Threat to Self-Perception

Dislike for pity was a second theme that was significant to the participants. All participants expressed very clearly that they did not like people to pity them, whether by action or by words. They all refused this kind of feeling that people showed to them. Being pitied by others provoked in all participants a threat to their self-perception. They perceived themselves as weak, different, not normal and being pitied
incited hurt dignity. In this perspective Ghandi, a 59 year old man with colon cancer and metastasis to the bone, said:

I mean, I do not like people to pity me, but I know that my friends like me. It makes me feel that I am weak. I do not want anyone to feel pity about me as long as I am capable of doing the thing that I want. He feels [his friend] pity about me, I do not need it. I feel that I am weak. I mean if someone is not able to do something they pity him… “Poor guy [YA HARAM] let’s help him”… and I do not like it.

Ghandi mentioned very clearly his understanding of his friend’s behavior, yet he could not accept it. Being pitied by others made him feel weak and inferior.

Anissa also perceived being pitied by others as a threat to her inner self, and expressed that as it made her feel different. She said:

You feel people feel sorry for you. They pity you, “Poor lady”, as if you have leprosy or something similar. I mean this is something that I have to face. I do not feel sorry about myself. When they pity me, and when they say “You look much better,” I feel that I am not normal-- that I am different. They make me feel that I am handicapped.

Houda spelled out very clearly that she refused people who pitied her and she said:

I mean when they see me they ask, “How are you? Are you ok? You changed. You have this disease and, etc...” I do not like. I do not like to talk about it. I do not like to talk about it because you feel as if people are looking at you differently and pity you. And this thing… I do not like it.
Houda tried to hide her disease by not talking about it, because she did not want people to pity her. Very similarly, Sonia was making extra efforts to hide her disease for the same reason. She explained:

I do not like people to pity me. I do not like it and I do not let anyone say it to me (the word YA HARAM) or to pity me even. I do not give them the chance to pity me. I always show that I am strong…

At this moment Sonia’s tone changed, it became more forceful.

Hind also made it clear that the word “pity” made her feel very disturbed, so she was trying her best not to tell others about it in order not to be pitied. She said:

My disease, I may not want to tell people about it because I do not want them to pity me. I do not like the word pity (YA HARAM). I do not like pity. They say, “Poor lady (YA HARAM), look at her how she is.” It means that it hurts my dignity. For example, “Poor lady look how she looks.” Do you know how I feel?... upset. It bothers me.

Anissa stressed that being pitied by others was more difficult than the disease itself and said, “I am not afraid from the disease, but I am afraid from people who look at you and pity you and say, “Poor lady (YA HARAM). She has cancer and she will die soon.”

Being pitied by others aroused in all participants the feeling of being different and weak. It hurt their inner self. It was also perceived as a kind of diversion from normal and it made them feel sorry for themselves. This condition made them perceive themselves as different; it created a threat to their self-perception.

Theme Three: Worry for the Family and the Worry about the Family’s Worry

Participants shared their worries about their family members and significant others. These worries were related to the present and future, as if participants wanted
to secure their family members or significant others before they left this world. Also, they were worried because they did not want their family members to worry about them. Falling ill changed their everyday lives and family routines, and these changes involved a great deal of sorrow to self and others. Participants explained that not being able to perform their habitual role within their families made them feel more worried about the future of their families. They were worried that their death would leave a gap in the lives of people who have shared their lives with them.

Tania said in this regard, “I am worried about my children. I want them to get married. I mean I would like my daughter to get married before I die. I do not like them to worry about me.” Interestingly, as each participant provided information regarding his or her lived experience, all reported this worry about family members.

Anis, a 55 year old man with colon cancer and metastasis to lung, bone and brain, was very disturbed about his family after his death. This issue constituted a big worry during his illness and he said:

I am noticing that my family is disturbed. I feel annoyed and disturbed. I start doing things to cheer them up. I feel worried about my family. Every person will feel depressed, not because of your condition, but because of your family, to leave the family. You will feel depressed if you are going to leave your family…

Similarly, Houda shared her worry about her children’s worry about her and said, “I do not want them (her children) to worry about me, they are still young. They think Mama will die. I do not like it. I wish they did not know about my condition. This is my nature.”
Likewise, Sonia said, “I do not want them (children) to feel afraid or worry that I am sick. I do not show anything, I do not show anything. As long as they are happy, I am happy...”

Unlike other participants, Amine did not mention anything about the worry of his family’s worry, but expressed very clearly his worries about his family, mainly his wife, after his death:

A person when he is hit by cancer. I mean I started to think of my family. My wife should have security; if something happens to me, I want her to be secure. I do not care about myself only. I do care about my family because, you know, happiness comes from inside your home. So if a person is happy, it is because his home environment is good. And if his home environment is not good, there is nothing good...

Also, being single did not prevent Samer from worrying about his mother and he said: “I am worried about my mother’s future. I wish I could do something to make her secure. She suffered a lot during our childhood to raise us. If my mother is secure, I would feel relaxed.”

Worrying about the family was a common feeling of all participants regardless of age or gender. Worrying about the family’s worries emphasized the state of worry that participants were experiencing towards their families and significant others. It is worth noting that all participants without exception expressed to the researcher that talking about these issues with her made them feel relaxed and relieved from a big burden. One participant in particular, Samer, said that what he shared with the researcher was impossible for him to share with family members or friends.
Theme Four: Relying on God and Divinity

The participants’ reliance and state of dependency on God were very clear in all interviews. All participants described themselves to be fully dependent on God, essentially to the same degree. All participants explained how the disease was created by God and He is the only one to have the power to stop it if He wants. They all had the “Why me?” in their relation with God, but then followed it directly by acceptance as they said “Let it be your will”. The participants’ relation with God was associated with great optimism and hopefulness.

Amine shared the following:

It means that we have a saying that says nothing will occur to you except by the will of your Father who is in the sky. I mean God, God gave and God can take, and who are we to resist the will of our God who is in the sky? If we do not help ourselves no one will help us. I mean I have something in my mind that says that even if you are cautious you cannot prevent your destiny. This is my destiny so I have to accept it; this flow, I have to go with it and if I resist, it will drown me. I mean a human being should accept his destiny…

Dima was also totally relying on God. She was ready to accept everything coming from Him. She was even grateful to Him and said:

As far as I am concerned, what comes from God, let it come, and you have to accept it. I have the feeling that I am grateful to God that the disease was discovered in due time. I rely on God. It means that nothing will happen to you except what God has written for you. If God wants to cure someone, He will cure him. And if He does not, he will not be cured. I feel that I will be better by God’s will.

Similarly, Tania said, “My soul is within God’s hands. I have cancer. Can
you remove it unless God makes a miracle?” And she added, “What comes from God is always good. I pray for God and the Virgin Mary, day and night. I feel relieved when I pray. Whenever I have five minutes, I sit and pray.”

All participants shared the same theme about God and divinity, though they did not have similar religious backgrounds. Ghandi stipulated, “At the end it is within God’s hands. Nobody knows what will happen. I keep on saying, ‘Thanks God. I am bearing the pain.’”

All participants had this full trust in God and His fair judgment. They all attributed the existence of the disease to God, but without doubting His will and decision. This positive relation with God gave participants the power to continue living, to accept their disease, and provided them with a source of emotional comfort when faced with a life-threatening situation.

**Theme Five: Dislike of the Hospital Stay: Feeling Trapped in Time, Place, and Disease**

The hospital experience elicited strong emotions in all participants. They all disliked the hospital stay because they perceived it as a signal of deterioration in their condition. They all perceived the hospital as a boring place where time passed very slowly. One participant even described it as a cemetery. Another compared it to a jail. All participants preferred to remain at home. The hospital was a reminder of progression of disease and the imminence of death. The feeling of being trapped in time, place, and in the disease process was instigated by the hospital environment.

Tania related the hospital to the end of life and she said:

When you tell me “hospital” as if you are mentioning a cemetery.. a cemetery. It is better to be buried than to go to the hospital. When I go to take the treatment, it’s as if I am going to hell. I have seen lots of people with this
disease. They go to the hospital at the end and they stay for one month at the hospital… then they die. I do not like the hospital.

For Tania, the hospital represented an entrapment in her disease, a place to die. While talking about the hospital stay Tania became agitated, started to play with her fingers and had tears in her eyes.

Houda described the hospital as a place full of bad memories; a reminder of her condition and her sufferings:

I do not like the hospital because I remember the first time I entered it when I was sick.. how I received the treatment with difficulty. I do not like the hospital; it makes me remember how I entered the first time. How I received the chemotherapy for the first time and how much a human being can suffer. I do not like the bed or the hospital. The hospital never, never… I do not like it…

Houda cried while talking about her hospital experience.

For Ghandi, the hospital was an entrapment in place as he stated, “I hate hospitals, and it is like a jail.” The word jail mentioned by Ghandi illustrates the idea of being trapped in a specific place or specific condition. While talking about his hospital experience, Ghandi had tears in his eyes and started to tear apart a tissue paper that was in his hands.

Similarly to Ghandi, Samer also compared the hospital to a jail and he mentioned:

I hate hospitals, they are like a jail, I do not like it, and I hate it. The reason is like this, I hate it. I do not like to enter a hospital. I feel if someone enters the hospital that’s it. He has to enter every time. I do not know, when I went out, I felt as if I was in a jail. I spent around one month and a half in the same room.
Every day I used to see the same walls, same people, nothing was changing, I felt as if I had a block pressing on my heart. I was bothered in the hospital.

When I went out, I felt relaxed… at home I am in my environment. I move freely, I go to the balcony, I receive people…

Anis also compared the hospital to a place in which he felt trapped in time and he said: “Every hour in the hospital is like a century. Every week is like a year. I feel time is passing very slowly. I feel bored.”

All participants shared the same feeling of dislike about the hospital experience. The hospital experience was illustrated as a place where they felt trapped in time, place, and disease.

**Theme Six: The Need to Be Productive**

Being productive constituted a pivotal point in the lives of the participants. Productivity, as explained by participants, was related to the feeling of still being needed by others. This feeling of being unproductive gave the participants a sense of powerlessness and a sense of not being needed anymore. The need for being productive was translated at two levels, the professional level and the personal level. Participants who used to work before getting cancer and reaching the palliative stage explained very clearly the difference in their lives before and after work. On the other hand, participants who were housewives illustrated productivity by being needed by family members and significant others. Participants divided their lives into two parts, productive and unproductive.

For Samer, going to work even as a visitor made him feel comfortable, relaxed and he mentioned:

I felt relaxed, and what made me more comfortable are the workers there, because they started to ask me questions. I felt psychologically very relaxed as
if I am back to work, although I did not touch anything with my hands. I felt very comfortable and it gave me courage to forget my condition, my disease, and to fight…

For Amine going to work had major implications for his morale. Going to work made him feel that he was still needed, still existing. It was very difficult for Amine to accept that he was not working anymore and he said:

At the beginning it was very difficult for me; then I got used to it. When I was working, I felt it was melting (the disease). I mean I kept myself busy in my shop. I used to go with my son. I used to help him open the shop and stay there from morning till evening. When I stopped working, I am not working part time even, I felt bothered. Because my happiness, my life, is my work. While being at work I feel that still I am important and needed…

Ghandi believed that work is equal to life itself. For him this sudden change in life pattern constituted a hole in his life. Being away from his job was compared to death and he stated:

Now, because I have closed my company and left my job, I feel that time is very long and I am not able to take advantage of it. With this disease you have to change your habits, you have to stop your work. I love my job; it is my preferred hobby in life. My works used to give satisfaction. I enjoy working, and it gives me pleasure to work. When you stop working there is a cut in the talent that you have acquired, so you feel like you are dying because you are away from your job.

As for Dima she mentioned the following:

I feel distressed because I am even unable to cook for my children. It is my mother who is 70 years who comes and cooks for us…. I used to fix my
children’s clothes myself. Yesterday my daughter asked me to fix her pants, but I told her go and take it to the seamstress I cannot do it anymore.…

While talking about these issues, Dima started to cry. When asked why she was crying, she said because she feels helpless. It is worth noting that all participants cried during the interview. However, when asked if they prefer to stop the interview, they all refused and insisted on talking.

All participants related the feeling of being productive to self satisfaction and to the sentiment of still feel needed by others. These feelings were perceived to create a sense of happiness and relaxation for the participants. Being productive was perceived as an important need for participants to still feel that they are alive.

Theme Seven: Fear of Pain and Suffering, Current and Future

Fear of the disease process emerged in all interviews. Participants expressed their worries about their inability to cope with certain cancer symptoms, mainly pain. The fear of pain was sometimes greater than the fear of death itself. The participants’ description of the physical symptoms emerged from their own experience and/or from witnessed experiences of family members or friends. Some even related the wish of having a hastened death to the degree of physical symptoms. They clearly mentioned that they preferred dying instead of suffering from pain. All participants, while discussing this idea, started to cry regardless of their gender. All participants stated that crying is not a shame and it is a way of expressing one’s feelings. They all mentioned that the worst aspects about their disease were the physical symptoms and mainly pain.

For Anis, pain was worse than cancer itself. A painful life did not mean a lot for him. He mentioned:
I want to be relieved by all means. I mean if it is killing (cancer), I want to finish and if it is not, I want to be relieved. About pain, I want to be relieved from pain. If it is a killing pain, I prefer to go to decrease my sufferings… Samer agreed with Anis about pain, and he said, “Pain makes me feel very disturbed. I do not like to say that I am in pain. Pain paralyses me, I cannot move anymore.”

For Dima the physical symptoms constituted a period of suffering that has no need. So the idea of hastened death surfaced because of physical symptoms:

Sometimes you have diarrhea and sometimes constipation. In general, I feel weak and exhausted. I like to go out but I feel too tired to go out. I mean it is not death that I am afraid of, but the period of sufferings that precedes death, this period has no need.

For Hind, the fear of suffering from physical symptoms brought back memories of uncontrolled pain in a loved one. Again, commonalities existed among participants regarding their perception of the impact of pain on their lives. Hind explained the following:

Death is a right. If I am going to die, I want to have an easy death. I do not want it to be difficult and be affected. My husband stayed in bed all the time. He was in pain and he was on morphine; this is it. It makes me feel afraid… every individual is afraid of it… aren’t you afraid yourself? Aren’t you afraid of staying in bed, taking morphine, urinating in bed, and people changing for you and you cannot move or stand and your body will be ulcerated? Aren’t you afraid of all these things? Is there a wise person who is not afraid?

The fear of pain was common to all participants and it was viewed as an unnecessary period in their life. They preferred to die earlier rather than suffer.
Theme Eight: The Impact of Communication, Verbal and Non Verbal

Participants highlighted the impact of words used by others on their morale and lives. Participants mentioned very explicitly that certain words or ideas communicated by others made them feel very sad or reminded them of their condition. On the other hand, open communication between the participant and family members or the participant and the treating physician was perceived to be very helpful and it relieved their anxiety and stress. Samer said, “The only time I felt relieved is when my sister told me that I have cancer. Deep in my heart, I knew it since the beginning…”

Houda mentioned very clearly her preference for truth telling and she said, “I felt very bothered at the beginning because my family lied to me about my disease. I prefer the truth; I am not a small child.” She added: “The physician does not say everything. This may be on purpose so that the patient’s psychology would not be affected. For me on the contrary, I prefer the truth from the beginning of the road. It is much better.”

Aniss described the relationship that should exist between the treating physician and the patients and said, “The physician should understand his patient. If the patient is ready to understand the truth, then he should talk to him. I prefer the truth.” He added:

Nurses and physicians have to come and talk with the patient, change the atmosphere for him; this will help him to decrease his loneliness. When people enter the room, even if they do not talk, you feel their presence. Your psychology will be relaxed. When I am alone, I stay asleep.

Likewise, Amine narrated a story to emphasize the importance of tactful communication and the choice of words in communicating and he said:
One day there was a king. One day a man came to him and he told him you are going to bury all your parents, so the king ordered his death. Then another man came to him and he told him you are going to survive all your parents, so he gave him lots of money. So the minister questioned his king, Sir, what did the first man tell you to order his death? And the king told him. Then he asked what did the second man tell you? And the king answered. So the minister asked him, “My king, what’s the difference between the two men?” The king told him the results are the same, but the way it was said made the difference. So a word can make the difference and this is how my physician deals with me. He tells me things bit by bit. This is important because I do not like rough words. I like the way he deals with me. He is very sensitive with me.

Ghandi highlighted the importance of open communication between family members and its impact on the individual:

There is lots of openness between my wife, my son and me. We talk about my condition … we talk like friends. It helps a lot. We joke together, we have fun so it strengthens the morale, and it makes me forget my disease…

On the other hand, at the time of the interview Hind was still upset from a conversation that she had two days prior to the interview with her brother-in-law and his wife. Though Hind perceived them as her support system and she highlighted their caring attitudes towards her, one remark from them regarding her condition made her feel upset. She said:

It hurt me because as a person who is 60 years old and receiving treatment, psychologically you feel wounded. You are under treatment and this might mean the end, this is what it means to you. He is not the first one. May be they are 15 for now who said “we were not born to stay”. Maybe they do not mean
it, but psychologically you feel wounded. He is not the only one that is talking like this, but around 20 individuals said so far, “Do not worry. We were not born to stay.”

The impact of communication on Hind was not always positive. Relatives, with their approach, made her feel frustrated because they reminded of her unstable health status.

Similarly, words used by Sonia’s friends made her feel upset. She said in this respect:

I mean I feel a bit hurt in my heart, I feel a bit disturbed. Because they [her friends] are talking about cancer and saying that she [Sonia] removed her breast and she might remove the other. Sometimes I feel disturbed…

Questions posed by others made Tania doubt her future and she started to anticipate the worst. She said:

They start to ask me about the treatment and whether I am feeling certain symptoms which I am not suffering from. So I start to think if I am going to reach that stage. Am I going to have all these symptoms that they are mentioning? I feel as if they know better than me about my disease.

Talking about death as a just end to life was perceived negatively by the participants of the study. The type of words and messages exchanged between physician, family members and participants seemed to have a big impact on the morale of the participants and on the way they perceived their future. Participants wanted to be told the truth and to discuss their condition; however, the thoughtful choice of words was accentuated as an important aspect of every communication.
Summary

The goal of this phenomenological study was to uncover the lived experience of Lebanese oncology patients receiving palliative care, and to obtain an increased understanding of the meaning of their experience. Phenomenological reduction and data analysis were performed on data collected through semi-structured in-depth interviews with ten individuals and field notes documenting the researcher’s observations. Eight themes were created from the data. The description of the lived experience of having cancer and receiving palliative care included excerpts from participants’ interviews. The descriptions allowed understanding of common dislikes, worries and constraints shared by the ten participants regarding their lived experience with cancer and palliative care.
CHAPTER V

DISCUSSION, SUMMARY, AND RECOMMENDATIONS

This chapter illustrates the phenomenological experiences of Lebanese adults with cancer receiving palliative care. It seeks to understand the meaning of those experiences that describe what life is like living with cancer and receiving palliative care. Findings of the study are presented according to themes and discussed in association to previous studies concerning the lived experience of cancer patients receiving palliative care and within the context of Lebanese culture. Recommendations for future research that will add to the breadth and depth of the science in the area of cancer palliative care, followed by implications for practice education, and policy finalize this chapter.

Discussion of Findings

Cancer diagnosis and treatment causes changes in patients’ personal paths of life, and in their daily activities, work, relationships, and family roles. Patient preferences with regard to treatment and care may vary from what health care professionals presume. Therefore, in order to meet patient needs, the hermeneutic phenomenology method was followed with the conviction that this approach supports the belief that the interpretation of the narratives provided by participants in relation to diverse contexts is foundational for a comprehensive understanding of the lived experience (Lopes & Willis, 2004).
**Theme One: Distressed from Being Dependent: Loss of Control, Disease Reminder, and Burden on Others**

One important theme that emerged throughout the data was related to the condition of feeling distressed from being dependent. The participants viewed the state of dependency caused by cancer as a signal of deterioration in their health status. This state of dependency was particularly problematic to the participants because it inspired in them the feelings of loss of control, being a burden on others, and it reminded them of their illness state. Participants expressed very clearly that they did not like the idea of being dependent; rather, they preferred to be needed by others, a condition that promoted their inner strength.

Results of this study concur with studies by Meier et al. (1998) and Sullivan, Hedberg and Fleming (2000) which indicated that becoming a burden on family members, increasing dependency, and fears about loss of personal dignity and control were the most cited concerns in terminally ill patients asking for an assistance for dying.

Kelly et al. (2002), in a study investigating factors associated with the wish to hasten death among a sample of terminally ill cancer patients in Queensland, reported that patients with a high wish to hasten death perceived themselves as being dependent and a burden on others. Study findings supported the results of this study which also related the feeling of being a burden on others to the state of dependency.

In a study by Vig and Pearlman (2003) conducted in Seattle Washington, aiming to characterize the experience of quality of life while dying from the perspective of terminally ill men, participants highly valued their independence. They expressed concerns about becoming dependent and burdening loved ones during the process of active dying and death. These findings are congruent with the findings of
this study. In Lebanon, the family system is patriarchal and the father is considered the head of the family. So, it was very difficult for the male participants to be dependent on others and it was obvious in their words. Amine said: “My God; please deliver me early because I do not want to be a burden on others.”

Also, in a study assessing the impact of hospice inpatient care on the quality of life of Chinese terminally ill patients with cancer, Yeung et al. (1999) reported that although dying patients are weak and sick, being independent was considered important to them. Again findings of this study are congruent with the Yeung et al. study.

Proot et al. (2004), in a grounded theory study conducted in the Netherlands describing the needs of terminally ill patients at home, also reported that patients wanted to direct one’s own life, health, and health care and directing things related to beloved others such as financial matters, insurance, and pension.

Liu, Mok and Wong (2005) in a study of Chinese cancer patients, revealed that patients did not want their close relatives to overprotect them because they hoped to try their best to go back to their previous life or to live with cancer instead of becoming dependent on others. It is worth noting that the Chinese and Lebanese cultures share some similarities with regards to the family’s role in the life of the sick person. In both cultures the family is a major element in the patient’s life with regards to decision making and presence in the hospital or at home (D’Avanzo & Geisseler, 2003).

Cancer and palliative management have a vast effect on a person’s capacity to complete activities essential to daily living. The majority of patients with terminal cancer have an impaired capability to achieve everyday functions during the diverse stages of the disease. In addition, it was noticed by the researcher, who is a member of
the Lebanese culture and understands this culture very well, that Lebanese society plays an important role in making the individual feel dependent. The composition of the family, which leans to the extended type, and the strong bonds among family members that favor the reciprocity in the relationship, might be the causes for dislike of this feeling of dependency. The Lebanese culture perceives the person who has cancer as an individual who is weak, who needs continuous protection, and meeting his needs is a kind of social and moral obligations on the family members. Findings interpreted within the Lebanese culture suggest that the emphasis on patient “performing” rather than “being performed for” can restore a patient’s self control and decrease the feeling of being a burden on others. Furthermore, this approach might help the individual to stop constantly remembering his illness. It is worth noting that the idea of being a burden on others and loss of control that emerged in this study were supported by previous studies in the literature. However, the concept of “Disease Reminder” was not mentioned in any of the reviewed studies. This concept emerged in this study may be because of the overprotective attitude exhibited by caregivers which kept on reminding participants of their disease. The theme Distressed from Being Dependent clashes with the traditions of the Lebanese culture. As a sick person being dependent is accepted by the society but refused by patients as highlighted in this study.

*Theme Two: Dislike for Pity: Threat to Self-Perception*

Participants in this study verbalized very clearly that being pitied by others initiated in them strong negative feelings about self. Pitied by others was noticed by the participants through the overprotective attitudes and certain terms used by family members or friends. This attitude exhibited by others evoked in the participants of this study the feelings of being “different from others, weak, not normal and it hurt their
dignity”. Being pitied by others was a threat to the participants’ self-perception. Participants explained that certain expressions or words used by friends or family members, such as “YA HARAM” (Poor person), made them feel hopeless. The use of the word “YA HARAM” is very common in the Lebanese culture. This word is used whenever a person is seen to be in trouble or is faced with a problem. It seems that this word had a very negative connotation to the participants of this study when used about them. In fact, studies have shown that the choice of words and attitudes exhibited towards sick individuals are very critical because negative responses by significant others or social ties may influence coping behaviour adversely by causing the person to appraise the situation as being more stressful, and cause the person to focus on negative aspects of the condition (Bertero, 2000; Landmark, Strandmark, & Wahl, 2002).

Liu et al. (2005), in a study assessing the perceptions of Chinese cancer patients of the favorable and unfavorable words conveyed by their social support providers, reported that favourable words and attitudes were those that inspired and reinforced patients’ hopes, while unfavourable words and attitudes were those that reduced their hopes and feelings of self-respect, such as looking pessimistic, depressed, and having tears in the eyes while communicating with patients. Indeed, the word “YA HARAM” when used in the Lebanese culture within the context of illness and specifically cancer, was perceived by the participants to hold in it a pessimistic meaning.

Asking personal questions about an individual’s health or exhibiting excessive helpful behaviors towards a sick person are considered part of the Lebanese culture caring attitudes towards sick individuals (D’Avanzo & Geissler, 2003). However, participants of this study seemed to perceive these attitudes as pity and they rejected
them. As a consequence, they were trying to hide their disease and sufferings in order
not to be pitied by others.

Wortmen and Lehman (1985) have acknowledged many forms of
unsupportive reactions, including well-intentioned efforts of problem minimization
and forced cheerfulness, as well as more negative reactions such as staying away from
the individual or avoiding talking about the troublesome event.

In a study describing living with untreated localized prostate cancer, Hedestig,
Sandman and Widmark (2003) reported that Swedish men preferred talking about
illness with other patients rather than family members or friends to avoid pity. In fact,
one participant of this study shared a similar idea with the researcher. He overtly said
that he felt very happy and relieved after the interview, because he believed that he
could not share his lived experience with cancer and palliative care with family or
friends as he did with the researcher who was a stranger to him. He did not want them
to pity him as he said.

Participants of this study referred to pity in relation to others exhibiting
overprotective attitudes, asking questions in which they compare participants’ current
health status to before getting cancer, and using certain terms as signs of pity. The
manner in which other people responded and reacted to their illness was critical in
promoting self-perception.

Theme Three: Worry for Family and the Worry about the Family’s Worry

Living in a paternalistic culture, the Lebanese people have very close family
ties. Usually children do not leave the paternal place of living until they are married.
It is not unusual to see married children living with their parents. This existing
relationship between parents and children is very strong and close most of the time. In
view of this tight and close relationship, participants, who were all parents except for
one, expressed worries about their family members. Even the participant who was a son expressed his worries about his mother. Participants did not want their family members to worry about them. They did not want the family to suffer for their sufferings. Participants also did not want to disrupt their family’s usual mode of living because of their illness. This attitude is typical of the Lebanese culture. This worry for the family is part of the Lebanese culture which worships family and family ties. Moreover, participants reported being worried about the family’s worry about them, which made them reluctant at times to share their own feelings with family members and friends. Participants were even at times hiding their real feelings in order to protect their family members from worrying about them.

Helseth and Ulfsaet (2005), in a study assessing the parenting experiences in Norway during cancer, stated that sick parents reported living in a state of emergency. Parents were putting the needs of the children first and were trying to maintain normal family life. Parents were protecting their children. These findings mirror the descriptions given by the participants of this study regarding protecting family members from worrying about them.

Studies by Billhut and Segesten (2003) and Shands, Lewis and Zahils (2000) reported that parents with cancer appear to place emphasis on keeping their children’s lives as habitual as possible and lessening disruptions. Barnes et al. (2000), in a qualitative interview study of communication between parents and children about maternal breast cancer, reported that some mothers talk with their children about the disease, while some intentionally hold back information. Mothers did what they thought was good for their children. It seemed that they tried to create a balance between telling children the truth and being open about the disease on one hand, and protecting the children from the truth to prevent them from becoming worried and
anxious on the other hand. This is actually what one participant of this study revealed; she wished to hide the truth from her children because she did not want them to worry about her.

Wheeler (2005), in her interviews in the US with three patients and their families during the course of cancer treatment, revealed that one patient did not want her family to experience any pain as a result of her pain. Therefore, she tried to hide pain, especially from her son, and this was also a source of emotional pain for her. Results of this previous study confirmed with the emerging theme in this current study regarding the worry about the family’s worry.

Proot et al. (2004), in a study on the needs of terminally ill cancer patients in the Netherlands, reported that participants of the study were worried about their beloved others after their death. Thus, they were trying to direct things related to their daily needs, personal relationship, and financial aspects.

It seems that participants of this study had the need to protect their family members and significant others from what they were experiencing. Therefore, they were trying to hide their own feelings and worries. Despite this need, they reported that sharing their experiences with the researcher was perceived as a relief to their worries.

**Theme Four: Relying on God and Divinity**

In general, Lebanon is known for its religious harmonious diversity. The two main dominant religions in the Lebanese culture are Christianity and Islam (D’Avanzo & Geissler, 2003). However, there are as many as 18 different sects. The term “God” is highly used in the Lebanese language. Whenever people want to mention something bad, they incorporate the word “God” in their sentences to protect them from the “evil eye”. While talking about something good, they mention God to
thank Him. The presence of the term God is very common in a Lebanese conversation. Most Lebanese, regardless of religion, consider God as powerful, capable, and the source of miracles. This positive relation with God and full reliance on Him gave all participants hope that God is in control.

Findings suggest that participants in this study attributed the occurrence or creation of their diseases to God. Some viewed their disease as a blessing from God and a means to examine their faith in Him. Others were waiting for a miracle from God to be cured. Participants relied on God throughout their disease, from diagnosis until death. Some even were talking to God, asking that He relieve them of their suffering. God was perceived as most powerful, compassionate and fair.

Results suggested that this belief in God helped participants to accept their diagnosis, live with their disease, and to bear willingly the consequences. This belief in relating to God evoked in the participants the feeling of hope that He might help them to be cured, or if not, at least to die without suffering. Participants were not afraid of death, which was a “right from God” as they stated; however, they were all afraid of the duration and intensity of suffering which precedes death.

All participants were either Christians or Muslims. The Christians believe in one physical life, with eternal life in heaven after physical death. Tests occur to shape character, and destiny is decreed by a God who loves his people. Muslims believe in a heaven and hell, and that Allah decrees destiny. Obedience to the will of Allah is an imperative exercise in faith. These two religions stress the power of God who directs the destiny of the believer (Ong, Back, Lu, Shakespeare & Wynne, 2002).

Research points out that a relation with God plays an important role in the coping process (Levin, 1999; Maynard, Gorsuch & Bjorck, 2001), especially if God is perceived to be nurturing, loving, comforting, protective and available. Moreover,
individuals who ascribe illness to a loving God are more likely to convey positive reinterpretations of their illness (Park & Cohen, 1993). However, this relationship with God seems to represent a complex process in that it does not exclude the experience of negative emotional states of disappointment, questioning, and doubt. Pargament (2003) discussed how spiritual struggles can be instigated by a painful event. Such struggles are in general revealed as anger, complaints, and hoping for a miracle in relation to God (Gall & Cornblat, 2002). In fact, Lebanese participants, while talking about God mentioned that by relying on God they hope to be cured; although they were fully aware of their real situation. None of the participants of the current study reported anger or complaints; on the contrary, some were grateful to God because they perceived their experience with cancer as a testing of their faith in Him.

Ryan (2005), in a phenomenological study of five older adults with advanced cancer, reported that reliance on God gave participants the needed strength to accept their condition and provided them with the required strength to decrease their worries. It can be seen that results of previous studies concur with the findings of this current study that cancer patients tend to have full trust in God and acceptance of His will.

Research has revealed that religiosity and spirituality significantly play a role in psychological adjustment to cancer and its treatment. Religion offers hope to those suffering from cancer, and it has been found to have a positive effect on the quality of life of cancer patients (Weaver & Flannelly, 2004). Spirituality refers to that part of being human that looks for meaningfulness through intra-, inter-, and trans-personal connection (Reed, 1992). Recognition of a patient’s spiritual needs is now being officially articulated through the Joint Commission on Accreditation for Health Care Organization (JCAHO, 2003). This is becoming particularly important in palliative
care settings, where the focus is on quality of life and responding to a person’s physical, social, emotional and spiritual needs (Kellehear, 2000).

It is worth noting that in spite of their large dependence on modern medicine, the Lebanese are superstitious and prefer to ensure additional “heavenly” assistance for their health problems. Lebanese Christians and many non-Christians visit shrines of the Virgin Mary and other saints and make vows to present alms or other gifts if they are cured (D’Avanzo & Geissler, 2003). Results of the current study suggest that religiosity and spirituality play a big role in the life of Lebanese individuals with cancer, which creates a big challenge for nurses working with cancer patients to assess the religious and spiritual needs of the patient and to incorporate those needs in the plan of care.

**Theme Five: Dislike of the Hospital Stay: Feeling Trapped in Time, Place and Disease.**

Participants of this study reported that their hospital experience constituted a “nightmare” for them. This thought was not related to the care delivered in the hospital, but to the connotations related to the hospital environment. They all viewed the hospital as a place to die, or as a symbol of disease progression. The hospital inspired in them feelings of hopelessness and that they were “finished”. All expressed their preferences to remain at their residence and to receive the care needed at home. Home represented a familiar environment in which the participant had the full freedom and control to do whatever he/she wanted; whereas, the hospital was perceived as a place controlled by constraints. The hospital was painted as entrapment in time, place, and disease.

The health care system in Lebanon lacks the existence of hospice care. Nursing homes exist, but in scarce numbers. Home care nursing agencies are starting
to infiltrate the health care arena. However, financial coverage from the insurance companies and the Lebanese Ministry of Health for patients admitted to nursing homes or using the home care agencies is unavailable. Therefore, usually patients who need palliative care are admitted to general hospitals. However, as revealed by the findings of this study, the hospital experience was negatively viewed by the participants, which suggests the need to explore other settings for palliative care delivery. Review of the literature on home and hospital palliative care revealed some contradictory results. For instance, the study by Appelin and Bertero (2004) on patients’ experiences of palliative care in their homes revealed that informants were satisfied to be in their own home. Personal experiences and physical comforts, such as common memories and photos, provided the informants a sense of community. Some informants revealed that the feeling of loneliness was not so noticeable when they could stay at home. Also, Rydahl- Hansen (2005) conducted a study on patients suffering from incurable cancer and reported that hospitalization prohibited patients from living their lives as they had until the hospitalization, in accordance with their roles, interests and values. Everything from smells, food, interior decoration, circadian rhythm, and language, to socializing with the professionals was alienating.

However, results of a study conducted by Harstad and Andershed (2004) showed that the majority of patients preferred to be cared for in a hospital rather than at home. The main reason for this was apparently that safety was perceived more readily at the hospital. In addition, most of the patients did not want their relatives to be burdened too much with their care. Results of this study have one similarity with the current study, which is the dislike of being a burden on others. The current study did not explore which of the themes was the most negative, being a burden or being in the hospital.
Participants of this current study did not compare the hospital experience to home care due to the lack of this later experience in Lebanon; but, they painted the hospital experience as an entrapment in time, place, and disease. The hospital environment was perceived to be a source of stress. They verbalized clearly their abhorrence to the hospital environment. Participants compared the hospital to a cemetery and a jail. Though participants of this study showed their detestation of the hospital experience, this does not mean that being in a hospital will not be a potential choice for receiving palliative care. Tang (2003), in a study assessing where terminally ill patients with cancer prefer to die and why, reported that quality of life consideration motivated participants to choose home as the preferred place of death; however the hospital was their final choice, because they did not only weighted personal values, but also took into consideration family caregivers burden, healthcare needs, and availability of health care resources to meet their needs at end of life.

In an exploratory and descriptive study conducted on 180 terminally ill patients with cancer Siew (2003) reported that participants of his study preferred to die at home. However, concerns regarding the vast difficulties related to providing care of a dying patient at home influenced several terminally ill patients to select a place other than the home to die. Therefore, a study assessing preferences of Lebanese cancer patients with respect to the place where they favor receiving palliative care becomes a necessity.

It is worth noting that the concept of feeling trapped in time, place, and disease in relation to the hospital experience as revealed by the participants of this study was not alluded to or mentioned in the literature in relation to oncology patients receiving palliative care. Therefore, a further investigation of this concept is highly suggested.
Theme Six: The Need to Be Productive

Among the many pressures confronted by individuals facing life-threatening illnesses are major changes in social roles, such as unemployment and becoming unproductive. Participants in this study highlighted the importance of this dimension in the course of their illness. The lack of employment or productivity was closely tied to the role change, which had an impact on the individual’s inner self. Participants of the study reported that being unable to work anymore caused them severe distress because they perceived lack of unemployment as a sign of their health’s deterioration. Going to work was a mean to feel that they are still “alive, functional, needed and important”. These results concur with a study conducted by Tierney and McKinley (2002), which revealed that the diagnosis of cancer and its treatment caused alteration in patients’ family roles, work, and was associated with a high level of patient psychological stress. In fact, one of the participants mentioned very clearly that when he stopped working he felt a cut in his life as if he had died.

In another study conducted by Appelin and Bertero (2004), falling ill altered everyday life and the changes entailed a great deal of distress in Swedish cancer patients receiving palliative care. This is actually what participants of this current study reported. They mentioned that cancer obliged them to change their everyday life.

Walsh, Manuel and Avis (2005) conducted a study to assess the impact of breast cancer on younger women’s relationships with their partners and children. Results revealed that the shifts in roles or family responsibility created some frustration among participants of the study. This frustration was related to the fact that they were unable to do as much for and with their children as they used to. This is what in fact one of the female participants of this study revealed in her interview.
Participants of this study reported that unproductivity and its implication on their life represented a source of stress.

Theme Seven: The Fear of Pain and Sufferings, Current and Future

Pain is a major symptom in the cancer population. It is estimated that 17% to 57% of patients in active treatment and 23% to 100% of patients with advanced or terminal disease suffer from pain (Miakowski, Clearly & Burney, 2005). Cancer pain has an intense effect on every facet of quality of life and is thus the leading cause of total distress of cancer patients (Kuppelomäki & Lauri, 1998). In fact, all participants in this current study expressed their fears and worry about the physical symptoms that accompany cancer, such as nausea, vomiting, weakness, fatigue and alopecia, but their primary concern was focused on experiencing pain. Participants were afraid of potential symptoms because they related the occurrence of those symptoms to the advancement and worsening of their condition. They associated physical symptoms with becoming dependent on others and with the feeling of being pitied. They all prayed to God to decrease their period of suffering as much as possible. Participants expressed very clearly their acceptance of death and their fears of suffering. So, all of them welcomed the idea of hastened death if symptoms worsened, mainly pain. One participant expressed that receiving pain medication was not welcomed because these medications would make her more dependent on others which she does not like.

Participants’ ideas about pain and death are in accordance with Henry Fielding (1707-1754), who wrote, “It is not death, but dying, that is terrible.” In fact, all participants mentioned that they were not afraid of death, but it is the pain period that they wanted to escape. Participants of this study were terrorized by the idea of being in pain. Often the manifestation of pain includes cultural dimensions or traditional perspectives. Because pain is frequently associated with serious chronic illness or terminal illness,
there is often a spoken or unspoken association of pain with death (Ferrell, 2005). Thus pain has been portrayed as a metaphor for death (Ferrell, Grant, Padilla, Vemuri, & Rhiner, 1991). A study assessing Lebanese patients’ perception about pain and death is highly encouraged.

Results of this current study regarding the perception of pain concur with previous studies (Bostrom et al., 2004; Grillo, 2002; Mystakidou, Parpa, Katsouda, Galanous and Vlahos, 2005; Tierney and Mckinley, 2002) reporting the ability to control pain, and the capacity to make decisions about pain management as being crucial to patients with cancer. As with current study participants, patients in these studies expressed a wish to be free of pain or attain as much relief as possible.

Clayton et al., (2005) after conducting focus groups and individual interviews with 19 palliative care patients, 24 caregivers and 22 palliative care health professionals in Sydney reported that patients emphasized the importance of reassurance that pain will be controlled when they die, that they would preserve their dignity and have plenty of support.

Coyle (2004) in a phenomenological study on pain conducted on seven cancer patients reported that pain had an impact on the will to live and hope. Loss of hope and desire for death followed episodes of severe unrelieved pain. Pain was the source of fear for the participants of the study because it indicated the progression of the disease. Relief of pain was crucial for them. It is worth noting that similar results were noted in the current study.

Cancer pain was perceived by Lebanese participants as an indicator of the worsening of their illness and it was related to feelings of hopelessness and desire for death. It is worth noting that pain reaction in Lebanon cannot be particularly characterized, although men may be less vocal then women (D’Avanzo & Geissler,
2003). However, participants of this study, regardless of gender, uniformly verbalized very clearly their fear of pain.

**Theme Eight: The Impact of Communication, Verbal and Non Verbal**

Communication in this study was reported to be an important element in participants’ disease trajectory. Participants mentioned very clearly that certain terminology related to their condition used by friends and family members was very disturbing to their morale and self-perception. Such words reflected pity or alluded to death as a natural ending of their condition. They indicated that certain verbal and nonverbal messages sent by others regarding their current illness and their potential death were badly perceived. On the other hand, open communication with family members and treating physicians was considered as an alleviating factor to their anxiety and stress and an important factor to help them accept their condition, which at the beginning was perceived as very difficult and as kind of a shock. Participants appreciated the openness of their treating physician; however, they requested to have more time allocated for discussion during their visits with the treating physician in order to be able to discuss their worries.

It is worth noting that there was a perception among Lebanese health care workers that Lebanese cancer patients are not ready or willing to discuss their condition or even to participate in a qualitative study. The fear was also that family members may constitute a barrier preventing patients from participating in an unattended, in depth interview (Adib & Hamadeh, 1999). But contrary to all perceptions, all participants without exception expressed gratitude to the researcher because she gave them the opportunity to discuss their condition, worries, and concerns related to their current condition. Family members did not object to the interview; on the contrary, they helped in providing the best environment. Some
participants even wanted the researcher to mention their real name in the study. The researcher explained to the participants the impossibility of doing it because of confidentiality issues.

Results reported in this current study related to communication concur with a study findings conducted by Halldorsdottir and Hamrin (1997) in Iceland, which revealed that patients with cancer perceive communication with health care professionals to be imperative in improving their quality of life. In fact, participants of this study perceived open communication and truth telling as a source of relief.

Kirk et al. (2004), in a qualitative study assessing what patients receiving palliative care for cancer in Canada and Australia want to be told, reported that open communication regarding all aspects of the illness was considered as desirable by almost all participants of their study. All patients said they wanted to know their diagnosis and prognosis. The timing, management, and delivery of information and perceived attitude of the practitioner were critical to the process. This is what the participants of the current study stressed while talking about communication. They reported that tactfulness in communication was an essential element of the process as a whole.

Clover et al., (2004) in a study exploring patients’ understanding of their discussion about end-of-life care with nurses in a palliative care setting in Australia, reported that palliative care patients often assumed passive roles and learned to not to engage in important decision-making.

In a study by Ryan (2005) caring communication was highlighted as a vital factor to the meaningful care of patients facing death. Actually, one participant of the current study compared untactful communication to a killing process.
Liu et al. (2005), in a study to describe the experience and expectations of Chinese cancer patients with regard to the favourable and unfavourable words conveyed by their social support providers, reported that patients expected to hear words that encourage them and boost their confidence. Patients often appreciated it when physicians gave them encouragement and consolation. Some patients mentioned that while others intended to give well intentional support by visiting, some of them might not know how to communicate their support, which had a negative effect, as the patient became sad after hearing such statements. Similar findings were depicted in the current study regarding the inability of some people to communicate properly their support to the participants. Participants highlighted that people asking too many questions about health, discussing potential symptoms with the cancer patient and referring to death as a conventional end to every person are considered improper communication techniques.

Summary

Cancer is not only a disease, but is also a sequence of experiences that intensely affect the person involved. Participants of this study highlighted eight themes affecting their physical, psychological and spiritual needs that are perceived important for them. Results of this phenomenological study are the first reported data on Lebanese cancer patients receiving palliative care. Findings of this study concur with international studies conducted on cancer patients receiving palliative care. However, the themes [Being Dependent perceived as Disease Reminder and Entrapment in Time, Place and Disease in relation to the hospital stay] were not encountered in any of the reviewed studies. Therefore, these findings are considered as an addition to this field of study, in need of further exploration.
Reflections on the Study

The purpose of this study was to describe and understand the lived experience of cancer patients receiving palliative care. Review of the literature, which revealed a paucity of phenomenological studies on cancer palliative care and no studies conducted on Lebanese cancer patients receiving palliative care, justified the need for this study and the method followed.

The study followed the hermeneutic phenomenological approach. Phenomenological research is a principal method with which to begin when investigating a new topic, or a topic that has been studied but for which a new perspective is needed, as is the case for this current study (Cohen et al., 2000). Hermeneutic phenomenology is the method to follow when the aim is to understand the way people interpret their world.

Hermeneutic phenomenology situates the body and mind as inseparable, and starts by placing the person in the life world of experience. Van Manen (1990) instructs that lived experience is essential to the phenomenological view of a person, acknowledging that the background of socio-cultural practices and languages aids to mould perceptions and responses to life: life’s encounter and experiences. Experience is a mixture of receptive and spontaneous processes that are interpreted by the person. However, it is only on reflection that a person attributes meaning to an experience.

Cancer as a disease does not affect only the body, but the entire life of the affected individual. As one looks beyond the diagnosis and thinks about the lived experience, one gets a clearer portrait of the whole person and the meaning that this experience had for the participants of the study. Van Manen (1990) suggested four
fundamental life world themes that are helpful guides for reflection. Lived time or temporality: these are links created by the commonalities shared by living during a certain period in time. Lived human relationships or relationality: those are relationships with others that connect humans in important and valued ways. The communities (lived space or spatiality) and the roles humans have in these spaces relate the people in distinctive ways to their environment. Corporeality (lived body) relates to the changes in physical body. While these four themes can be identified, they can not be separated in the lived world of experience. However, often health care professionals tend to respond to the corporeal changes caused by the disease, and to overlook the considerations of the mind and spirit as they are incorporated in the world.

The participants of this study were all oncology patients receiving palliative care. Each interview provided a personal presentation of the participant’s experiences of the lived experience of receiving cancer palliative care. Undoubtedly, participants of this study shared similarities and differences in their experiences. Admitting that individuals bring distinctive perspectives to their lived experience, data analysis revealed common themes that portrayed this experience. Awareness and acknowledgment of these data can enhance the lives of persons living with cancer and receiving palliative care. Major themes revealed the meaning of the lived experience of receiving cancer palliative care.

In view of the eight emerging themes, participants of this study portrayed their lived experience with cancer and palliative care as an alteration in their corporeality, temporality, relationality, and spatiality. Alteration in corporeality was translated by the participants’ fears regarding physical symptoms, mainly pain. Variation in temporality was explained by the participants’ dislike of the hospital stay. The change
in relationality was highlighted by the participants dislike for pity, their worries about others and their relation with God. Alteration in spatiality was portrayed by the participants’ needs to be productive, to have a better communication with others, and the distress of being dependent on others. This change in the life world themes was reflected in the participants’ physical, psychological, and spiritual needs as revealed by the emerging themes from the interviews.

Illuminating the meaning of the lived experience of cancer patients receiving palliative care improves nurses’ understanding, an understanding that can permit nurses to move beyond assumptions toward understanding. The knowledge of what is significant and helpful for individuals receiving cancer palliative care can guide effective interventions to enhance current practices. This knowledge can provide the core for comprehensive palliative care programs; improve the overall quality of life while living with an incurable illness, and permit health care professionals to act more thoughtfully in the care of cancer patients receiving palliative care. Such knowledge also can help patients to have a more meaningful life rather than just a bearable one. Amelioration in the area of cancer palliative care has the promise to induce a societal sigh of relief over the concerns about suffering as a result of cancer.

Limitations of the Study

Before the results of this study can be fully applied, the study’s limitations need to be acknowledged. As with all qualitative research, the sample cannot be considered representative of the population or sub-set of population receiving cancer palliative care. Only individuals knowing about their condition and willing to discuss it were asked to participate in the study. Individuals with cancer and receiving
palliative care who are unaware of their diagnosis and prognosis might have different needs or concerns.

Purposeful sampling of participants is a typical qualitative method and is effective when greater depth of information is required. Consequently, the intentional selection of participants for this study is accepted.

The extent to which results of this study can be generalized to Lebanese cancer patients receiving palliative care is unknown; however, generalizability is not a goal of phenomenology. Guba and Lincoln (1981) imply that the findings of a qualitative study should be considered in terms of transferability. One person’s experience cannot directly become another person’s experience. Nevertheless, what can be transferred from one person to another is not the experience as experienced, but its meaning. The experience stays private, but its connotation and significance become public (Ricoeur, 1976).

The “nuance” meaning may be missed in translating participants’ interviews from one language to another. However, the researcher is fluent in both languages and attempted to capture as many nuances as possible. As mentioned in Chapter 3, measures were taken during the translation process to ensure accuracy of the interviews.

Regardless of these limitations, the method followed in this study entails that the results should be seen as a contribution to an ongoing effort to comprehend the lived experience of Lebanese cancer patients receiving palliative care.
Recommendations

Because this research was the first phenomenological study conducted with Lebanese cancer patients receiving palliative care, its findings have a distinctive significance for the research endeavor in the area of palliative care. Recommendations for future research and implications for nursing education, clinical practice, and policy related to the care of Lebanese cancer patients emerged from participants’ lived experience.

Recommendations for Research

It is imperative to stress that one single study, irrespective of its qualitative or quantitative design, cannot investigate any phenomenon to its full extent. The themes highlighted in this study offer opportunities for additional qualitative and quantitative research in the field of palliative care. The findings of this study must be supplemented by further specific studies, such as exploring the concept of disease disclosure and truth telling in Lebanese cancer patients, family members and health care workers; a study investigating the hospital experience as lived by cancer patients is recommended. A study exploring the idea of hastened death in relation to pain from the patients’ perspective is also suggested. While visiting participants at home, care givers expressed the need to talk about their own experience. Since this was not the aim of the study, the researcher did not elaborate on the topic; therefore, a study about the lived experience of care givers of cancer patients is highly valued. The theme of being trapped in, time, place, and disease and disease reminder deserve further investigation.

Implications for Nursing Education

In view of this study’s results, courses concentrating on palliative care should be offered and emphasized in nursing curricula. Malloy, et al. (2006) reported data
from the one year follow-up in the US of the three conferences targeted toward
continuing education providers and staff development educators and reviews the train-
the-trainer model used in disseminating the End-of-Life Nursing Education
Consortium (ELNEC). Data suggested that nurses were very responsive to End-Of-
Life (EOL) education and were positive in the implementation of the course goals and
objectives. Educators have expressed that they are more efficient in teaching EOL
care because of the ELNEC curriculum and its influence on better quality care of the
dying and their families.

Results of this study may be incorporated into nursing curricula when
addressing cancer in Lebanon. Training and continuing professional development in
the area of communication should be available for all disciplines working in cancer
palliative care.

*Implications for Nursing Practice*

Nurses have a distinctive opportunity of interacting with the patients and their
families because of their professional role. Nurses need to explore patients’ ideas,
beliefs and experiences regarding pain and analgesics treatments. Early educational
interventions about pain and treatment should occur immediately after diagnosis, and
pain should be recognized and treated promptly.

Health professionals need to recognize that people are experts about their own
lives. Therefore, it is vital to encourage cancer patients’ participation through proper
communication in order to have their care preferences used as a basis of care. The
initiation of an open communication with patients is essential for proper assessment of
patients dislikes regarding the hospital stay.
Implications for Policy

The Lebanese medical services are among the most sophisticated and up-to-date in the Arab speaking countries of the Eastern Mediterranean area. But unfortunately, national strategy for health care is decided upon exclusively by policy makers without taking into account the beneficiaries’ perceptions of the care needed. Results of this study emphasize the importance of initiating national strategies for cancer palliative care that meet the needs of Lebanese cancer patients.
Appendix A

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE: The Lived Experience of Lebanese Oncology Patients Receiving Palliative Care

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ADVISOR: Joan Such Lockhart, PhD, RN, CORLN, AOCN,
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Duquesne University, School of Nursing
412-396-6540

SOURCE OF SUPPORT: This study is being performed as partial fulfillment of the requirements for the doctoral degree in nursing at Duquesne University.

PURPOSE: You are being asked to participate in a research project that seeks to investigate the lived experience of Lebanese oncology patients receiving palliative care. The anticipated number of participants in this study is around 10 to 12. For this project, you will be interviewed twice. These sessions will be conducted in Arabic, audiotaped and transcribed. The purpose of the second interview is to make sure that analysis of data from the first interview reflects your views. It is anticipated that each interview will take between 45 to 90 minutes. The time lapse between the first and second interview may be around 1 to 2 weeks. These sessions will be taped and transcribed. Your treating physician will be informed of the study and your participation. These are the only requests that will be made of you.
RISKS AND BENEFITS: You may feel uncomfortable discussing this sensitive topic. You may stop and rest at any time. Be assured that in case you feel distressed the interviewer will not leave you and will do her best to relief you. And, if need be your treating physician will be contacted for help. There are no benefits to participating in this study, other than the knowledge that you may someday be helping others in the same situation as you. Results of the study may have constructive impact on patient care and nursing education.

COMPENSATION: You will not be compensated for participating in this study, but a small token of appreciation will be offered to you at the end of the first interview as a thank you for your cooperation. On the other hand, participation in the project will require no monetary cost to you.

CONFIDENTIALITY: Your name will never appear on any survey or research instruments. No identity will be made in the data analysis. All written materials and consent forms will be stored in a locked file in the researcher's office. Data will be maintained until the study is completed and all manuscripts, presentations are done. Your response(s) will only appear in summaries. Audiotaped recordings made during interviews will be destroyed after transcription. The transcriptionist hired to assist in data transcription will sign a confidentiality form in which she agrees to keep confidential all the transcribed material and to submit all the copies of the transcribed material to the primary investigator.

RIGHT TO WITHDRAW: You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time. The withdrawal from the study will not affect your relationship or treatment with the hospital or health care team.

SUMMARY OF RESULTS: A summary of the results of this research will be supplied to you, at no cost, upon request.
VOLUNTARY CONSENT: I have read/listened to the above statements and understand what is being requested of me. I understand that if I don’t feel comfortable signing this consent form, I may substitute my signature with a mark that is meaningful to me. This mark will indicate my willingness and consent to participate in the study. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reasons. On these terms, I certify that I am willing to participate in this research project. I understand that should I have any further questions about my participation in this study, I may call Myrna Doumit, RN, BSN MPH, (01 3850000 ext 5968); or The Institutional Review Board for Human Subjects Research at the American University of Beirut (01 350000 ext 4911) or Dr Paul Richer, Chair of the Duquesne University Institutional Review Board (412-396-6326) Office of Research, 424 Rangos Building, Duquesne University, Pittsburgh, 15282, USA. E-mail: richer@duq.edu Fax: 412-396-5176

------------------------------------------------------------
Participant's Signature........................................Date

------------------------------------------------------------
Researcher's Signature........................................Date

------------------------------------------------------------
Witness' Signature.............................................Date

Education for the Mind, the Heart, and the Soul
الموافقة على المشاركة في دراسة بحث

الخريطة الفعلية الحية للمريض اللبناني الذين يعانون من مرض سرطاني ويتلقون العناية

المتعلقة.

عنوان:

اسم الباحثة:

الأستاذ المشرف:

جوان سوكهار، PhD، RN، CORLN، AOCN، FAAN

جامعة دوكيك كلية التمريض. 412-396-6540

هدف:

الهدف من هذا البحث هو وصف فرص الخريطة الفعلية للمريض اللبناني الذين يعانون

مقدم من خلال وصفهم لحياتهم اليومية.

العدد المقدر للمشاركين يتراوح بين العشرة والعشرين. عدد المقابلات التي

سوف تقام هوหنان لكل مقالبة سوف تستغرق من 45 إلى 90 دقيقة. الوقت المقدر بين

المقالبة الأولى والثانية هو حوالي أسبوع أو أثنتين. الهدف من المقابلة الثانية هو التأكد

أن تحليل المقابلة الأولى يعكس وجهة نظرك الفعلية. خلال هذه المقابلات سوف نسألون

عن كيفية رؤيتك للحياة التي تعيشونها في الوقت الحالي وكيفية معايشتك للحالة التي

تمرون بها.

جميع المقابلات سوف تكون باللغة العربية وسيتم تسجيل على أشرطة سمعية. طبيبك

سوف يكون على علم بالاشتراكات وأجباتك.

الإخطار والفوائد:

من الممكن أن يكون نوع من التأثير على نفسك من جراء المقابلة. إذا شعرت باي

نظام من الممكن التوقف عن المقابلة و من ثم استئنافها في وقت لاحق. في حالة أنك تشعر

بتعب. لا يوجد أي فائدة شخصية من مشاركتك في المعلومات التي ستعطيها ممكن أن تحدث تغيرات في

طريقة الاعتناء بالمرضى والدراسات التمريضية عند انتهاء البحث.

تعويضات:

ن تعطي تعويضا مقابل الاشتراك في هذا البحث كما ان الاشتراك في هذا البحث لن

كلفك مالا أيضا. عند الأنتهاك من المقابلة الأولى سوف تحصل على هدية رمزية

كموريد شكر على الاشتراك في هذا البحث.

سرية المعلومات:

لن يظهر اسمك في أي إحصائيات أو أدوات البحث. لن تذكر شخصيتك في التحليلات.
كل المواضيع الخفية سوف تخزى في خزينة مفتوحة في مكتب البحث.

إجوبتك سوف تظهر فقط في الموقعة من دون أي ذكر للأسئلة. جميع الأسئلة السمعية والمعلومات سوف تختلف بعد الانتهاء منها. المستند الذي يوجد فيه المستند المستند للمساعدة في استخراج الأسئلة السمعية سوف توفر عريضة ثقة واحتراز السرية المستنسلة وتتعهد بتسليم كل النسخ للمادة المستنسلة للباحثة الأولى.

لك الحق أن ترفض الاشتراك في هذا البحث. يمكنك أن تسحب فوائد الاشتراك في هذا البحث في أي وقت دون أن يكون لذلك أي تأثير على العناية الطبية المقدمة لك(إ).

موجز النتائج: موافقة الباحث:

لقد شرحت بالتفصيل للمشترك في البحث الطبي ل(اسم المشترك او ممثله القانوني أو وليه الجرسي أو وصي إذا كان المشترك قاصرًا أو غير قادر على التوقيع) طبيعته ومجرياته وتأثيراته السلبية. ولقد أثبت على كل أسلحته بوضوح على خبر ما تستطيع. وسوف أعلم المشترك بأي تغييرات في مجريات هذا البحث أو تأثيراته السلبية أو فوائدها في حال حصولها أثناء البحث.

توقيع الباحث أو الشخص المسؤول
الحصول على موافقة المشترك

Education for the Mind, the Heart, and the Soul
موافقة المشترك:

قرأت استمارة القبول هذه وفهمت مضمونها. تمت الأجابة على أسئلتي جميعها. وبناء عليه فأنني، حراً مختاراً، أُجيبُ إجراء هذا البحث وآملاً، وأوافق على الاشتراك فيه، وأدى أعلان الباحثة ميرناً الوضوء ونظملاها ومعاونيها أو مساعديها سيكونون مستعدين للإجابة على أسئلتي، وأنه ضامنًا للإتصال بهم على الهاتف 35000000/10 المقسم 8698. وإذا شعرت لاحقًا أن الأجهزة تحتاج إلى مزيد من الإيضاح فسوف أتواصل بأي إغلاق لجنة الأخلاق. (013-0000 المقسم 119) أو بالدكتور بول ريتشارد رئيس لجنة الأخلاق في جامعة دوكين على الرقم (412-4396-326), رقم الا بحث , 424, جامعة رانغوس, جامعة دوكين, richer@duq.edu.

في تشرير 2015, الولايات المتحدة. البريد الإلكتروني. البريد الإلكتروني. Email: richer@duq.edu.

كما أعرف تمام المعرفة باتني حر في الإنسحاب من هذا البحث حتى بعد التوقيع على الموافقة دون ان يؤدي ذلك على العناية الطبية المقدمة لي. أعلم أنني سوف أحصل على نسخة طبقة الأصل عن هذه الموافقة.

بناء عليه فأنني أصرح طالما مختاراً بقبول ما ورد في هذه الموافقة.

 توقيع المشارك: --------------------------------- التاريخ: ----
 توقيع الباحثة: --------------------------------- التاريخ: ----
 توقيع المشاهد: --------------------------------- التاريخ: ----

Education for the Mind, the Heart, and the Soul
Appendix B

The interview will start by social greetings, and then the primary investigator will ask some demographics questions. This technique will help in breaking the ice before the actual in-depth interview begins. It is understood that the researcher will help participants describe their lived experience without leading the discussion.

The in-depth interview will start with a global interview question.

Can you tell me how you are experiencing your illness? Please share your thoughts and feelings about the experience that you can remember. If you feel tired just let me know to stop the interview. Open-ended interviewing permits researchers to pursue participants’ lead, to pose clarifying questions, and to smooth the expression of participants’ lived experience.

Other questions prepared for the interview guide:

Where should I begin?

Pick a typical day and talk about it

Pick an unusual day and talk about it.
During the interview, the PI will help the participant explain ideas in more details by using probing techniques such as:

Please tell more about it.

What does that mean to you?

Is it possible to give an example?

Describe to me what that was like for you.
Appendix C

Demographic data

Gender:

Age:

Marital Status:

Area of living:

Occupation: Past----------    Current---------

Educational background: Illiterate----------
Primary----------
Intermediate------
Secondary--------
University-------
Others

Time since initial diagnosis with cancer

Cancer Site

Current treatment
Appendix D

Consent to Confidentiality

I, -------------------------------, agree to translate/ type the contents of audio cassettes transcripts given to me by Mrs. Myrna A.A. Doumit for the study entitled “the Lived Experience of Lebanese Oncology Patient Receiving Palliative Care” and promise to keep confidential all information I gain access to through my translation/ typing service. I will give back all documentation and audiotapes to Mrs. Myrna A.A. Doumit and erase the original transcription from the hard drive of my computer whenever she instructs me to do so.

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

Witness: ---------------------------                                                        Date ----------------

Education for the Mind, the Heart, and the Soul
REFERENCES


Dawson, R., Sellers, D. E., Spross, J., Jablonski, E., Hoyer, D. R., & Solomon,


