

The Needs of Young Adults with Cancer: Their Own Perspectives

by

Jennifer Parkins
BScN, University of Ottawa, 1996

A Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of

MASTER OF NURSING

in the Faculty of Human and Social Development

© Jennifer Parkins 2008
University of Victoria

All rights reserved. This thesis may not be reproduced in whole or in part, by photocopy or other means, without the permission of the author.

SUPERVISORY COMMITTEE

The Needs of Young Adults with Cancer: Their Own Perspectives

by

Jennifer Parkins
BScN, University of Ottawa, 1996

Supervisory Committee

Virginia Hayes, RN, MN, PhD, Supervisor
(School of Nursing)

James Ronan RN, MN, PhD, Departmental Member
(School of Nursing)

Kelli Stajduhar RN, MScN, PhD, Departmental Member
(School of Nursing)

Esther Devolin RN, BScN, MSc, Additional Member

Supervisory Committee

Virginia Hayes, RN, MN, PhD, Supervisor
(School of Nursing)

James Ronan RN, MN, PhD, Departmental Member
(School of Nursing)

Kelli Stajduhar RN, MScN, PhD, Departmental Member
(School of Nursing)

Esther Devolin RN, BScN, MSc, Additional Member

ABSTRACT

The purpose of this research was to learn about the needs of young adults living with newly diagnosed cancer and undergoing chemotherapy and/or radiation treatment in order to enhance oncology care providers' understanding of these needs. This was a qualitative investigation of the perspectives of young adults with cancer using interpretation description methodology (Thorne, 2008). Semi-structured interviews were conducted with seven individuals to gain a deeper insight into the subjective experience of being a young adult with cancer with consideration of quality of life issues. Eight interpretive themes were revealed from the data: *It Is Hard Being a Parent with Cancer, Symptom Management Is a Challenge, Social Support is Imperative, Information Access is Essential, Fear of Recurrence and Mortality, Trusting Relationships with Health Care Professionals Make a Difference, Financial Worries, and Follow Up Care*. These concepts represent a critical analysis which can serve to guide oncology care and oncology nursing practice.

TABLE OF CONTENTS

SUPERVISORY COMMITTEE	ii
ABSTRACT	iii
TABLE OF CONTENTS	iv
LIST OF TABLES	vi
ACKNOWLEDGEMENTS	vii
DEDICATION	ix
CHAPTER ONE: INTRODUCTION AND BACKGROUND	1
Statement of the Problem	4
Purpose	6
Research Question	6
Forestructure: Personal	7
Forestructure: Theoretical	10
CHAPTER TWO: LITERATURE REVIEW	13
Physical Well-Being in Young Adults with Cancer	13
Psychological Well-Being in Young Adults with Cancer	23
Social Well-Being in Young Adults with Cancer	31
Spiritual Well-Being in Young Adults with Cancer	36
State of the Knowledge	40
CHAPTER THREE: METHODOLOGY	43
Design	44
Sample/Sampling	45
Setting	46
Data Collection and Procedures	46
Reflexivity	47
Analysis	49
Trustworthiness	52

Ethical Considerations.....	56
Summary of Methods.....	56
CHAPTER FOUR: I’VE GOT CANCER, <i>OH NO!</i>	58
Introduction to the Participant.....	59
Interpretive Description as Themes.....	67
It Is Hard Being a Parent with Cancer.....	68
Symptom Management Is a Challenge.....	71
Social Support is Imperative.....	73
Information Access is Essential.....	76
Fear of Recurrence and Mortality.....	80
Trusting Relationships with Health Care Professionals Make a Difference.....	83
Financial Worries.....	87
Follow Up Care.....	90
Summary of the Findings.....	93
CHAPTER FIVE: DISCUSSION.....	98
Significance of this Research.....	98
Limitations.....	99
Synthesis of the Findings and Related Literature.....	101
Nursing Implications.....	110
Six Suggestions for Oncology Nurses.....	111
Other Implications.....	118
Conclusion.....	120
REFERENCES.....	122
APPENDIX A: RECRUITMENT POSTER.....	133
APPENDIX B: SEMI-STRUCTURED INTERVIEW PROMPT.....	135
APPENDIX C: CONTRACT FOR TRANSCRIPTIONIST.....	136
APPENDIX D: WRITTEN CONSENT FORM.....	138

LIST OF TABLES

Table 1- Profile of Participants.....	59
Table 2- Summary of Interpretive Themes, Sub-Themes, and Participant Identified Needs.....	94
Table 3-Nursing Care Implications.....	114

ACKNOWLEDGEMENTS

The evolution of this thesis has been a personal quest for greater knowledge and articulation of the nursing contribution to the caring sciences. I acknowledge that there are many individuals who have been on this quest with me and who have supported me and made this thesis possible. First and foremost, I would like to extend my utmost appreciation to the seven individuals with cancer who volunteered their precious time to participate in this study. I am grateful that each of you shared so eloquently with me your cancer journey and allowed me to learn from your personal struggles and tribulations. This thesis would not have been possible without your generous sharing.

I would like to thank my thesis supervisor Dr. Virginia Hayes. Thank you for believing in my work and for encouraging me to push ahead. Thank you for supporting my ideas and for guiding me to excellence! Thank you to my committee members Dr. Kelli Stajduhar, Dr. James Ronan, and Esther Devolin, Oncology Nurse Expert. It is through your work I have been inspired and motivated to continue in my pursuit of a Masters in Nursing. Thank you for answering my questions and critiquing my work.

This thesis was supported by financial contributions from the following: Canadian Cancer Society/Cancer Care Ontario Nursing Scholarship Fund and the Canadian Nurses Foundation Scholarship Fund Aplastic Anemia/ Myelodysplasia Association Award. I am very grateful to Cancer Care Ontario, the Canadian Cancer Society, and the Aplastic Anemia/Myelodysplasia Association of Canada for supporting nursing research and recognizing its importance. Without this financial support completing this work would not have been possible.

I wish to thank my extended family for supporting me through my academic years as a Masters student. Thank you Mom, for assisting me with my children and for believing in my ability to complete this thesis. Your self sacrifices have enabled me to achieve higher education. Thank you Dad, for contributing financial support so I could buy a new computer to complete this program and for always believing I can chase my dreams. I still remember, when I told you I wanted to be a nurse and you replied, “Well then I think you better spend some time with some nurses taking care of people”. The concept of care is one that I have come to value and embrace as an oncology nurse. Thank you to my in-laws Tony and Mary Parkins for supporting me each step of the way and understanding the commitment I needed to make the past five years. Also thank you for being such loving grand-parents to our children.

Lastly, thank you Wayne, my partner, my encourager, the person beyond all others who has always believed in my work and supported my pursue of the human sciences. Without your support this thesis would not have been possible.

DEDICATION

This thesis is dedicated to

my children

Kara and Owen Parkins

you are the future, always remember a life led serving others will bring you much richness and fulfillment, thank you for sharing your mommy so that others can learn from this important work.

THE NEEDS OF YOUNG ADULTS WITH CANCER: THEIR OWN PERSPECTIVES

CHAPTER ONE: INTRODUCTION AND BACKGROUND

Cancer care and supportive care for young adults facing a cancer diagnosis are major health issues for our society. The diagnosis of cancer and complex treatments affect every element of an individual's life (Howell, Fitch, & Caldwell, 2002). Recently, Canadian researchers formed a working group to examine cancer patterns in young adults. According to the group's final report entitled "Cancer in Young Adults in Canada" (Cancer Care Ontario [CCO], 2006), approximately 10,000 Canadians aged 20 to 44 were expected to be diagnosed with cancer in 2005, and 2,000 were expected to die from it. For the purpose of this research, a young adult is defined as an individual aged 20 to 44 years (CCO, 2006).

The CCO report indicated that the types of cancer that occur most often in young adults are distinct from those of children and older adults. The three most common cancers in young men are testicular, non-Hodgkin's lymphoma, and melanoma. In comparison, the three most common cancers in young women are breast cancer, cervical cancer, and thyroid cancer (CCO, 2006). Over the last 30 years, there has been an increase in the incidence of specific cancers for this age group; for example, thyroid cancer and non-Hodgkin's lymphoma have increased in young people of both genders and lung cancer has increased in women (National Cancer Institute of Canada [NCIC], 2003). Cancer in individuals aged 20 to 44 occurs twice as often in women as in men (NCIC, 2003). Treatments modalities for young adults range the same as for other adults, to include surgery, radiation therapy, chemotherapy, hormone therapy, biotherapy, bone

marrow transplant, rehabilitation therapy, and complementary therapy (Canadian Association of Nurses in Oncology [CANO], 2001). Young adults require specialized nursing care throughout their treatments. There is a need for oncology care providers to have a greater understanding of what the care needs of this group are. This thesis research was a qualitative inquiry into the needs of young adults with cancer as described by them.

Quality of life (QOL) is described as encompassing physical, psychological, social, and spiritual well-being by the City of Hope National Medical Center QOL model (Ferrell, Hassey Dow, Leigh, Ly, & Gulasekaram, 1995; King, 2006). According to this model, physical well-being throughout the cancer experience will be influenced by symptoms related to the disease and the treatment, nutrition, functional activities, and issues of infertility (Ashbury, Findlay, McKerracher, & Reynolds, 1998; King, 2006). Common symptom related side effects include fatigue, pain, nausea, vomiting, weight loss, dyspnea, constipation, and problems concentrating (Ashbury et al., 1998). Psychological well-being will be influenced by feelings of anxiety and/or depression, coping abilities, changing priorities and fear of recurrence (Powel, 1993; King, 2006). Social well-being will be influenced by self-esteem, roles and relationships, financial burden, family distress, and sexuality (King, 2006; Woodgate, 2006). Spiritual well-being will be influenced by feelings of hope and/or despair, spiritual meaning, religious and/or cultural beliefs (Brunas-Wagstaff, Griffiths, Norton, & Wagstaff, 2002; King, 2006). Further, this model directs oncology care providers to strive to provide care that addresses the complex medical and supportive care needs of individuals with cancer. Supportive care has been defined as “the provision of necessary services for those living

with cancer to meet their physical, psychological, practical, informational, and spiritual needs across the continuum of the cancer experience” (Crooks et al., 2004, p. 19).

Young adulthood is a time of personal growth when individuals are faced with many social challenges. When a young adult has cancer, he/she must attempt to balance peer and family relationships, and to pursue academic and/or occupational endeavors while managing a life threatening illness and complicated side effects. Young adults with cancer seek support of their health care team to gain knowledge of the disease and the proposed treatments, to mobilize effective coping strategies to normalize their lives, and to teach them strategies in relation to energy maintenance (Kyngas et al., 2001). Thus, QOL within the domains of physical, psychological, social, and spiritual well-being is a significant concern for young adults with cancer and their families (Ferrell et al., 1995; King, 2006).

Oncology nurses are in pivotal positions to positively impact the delivery of care to this unique group of individuals and their families. They engage in transpersonal caring relationships with individuals with cancer—relationships which according to nurse theorist Jean Watson (2005), involve the concern of another’s holistic condition. Such relationships promote knowledge, control, and healing for young adults at various points in the cancer trajectory (Watson, 2005). There is increased demand for oncology nurses to deliver complex interventions to prevent illness, to promote adaptation to illness, to teach treatment protocols, to alleviate symptoms, to support rehabilitation from chronic illness, to assist individuals with transitions in care, and to create support networks for cancer survivors (CANO, 2001). Oncology nurses with a deeper understanding of the needs of the young adult population can significantly influence QOL of this group.

Statement of the Problem

There is a vast amount of literature examining the supportive care needs of individuals with cancer. Greater research is called for, into the distinct supportive care needs of young adults with cancer.

A need is a complex term to define in relation to health care context. A sociological understanding of need can be explained in terms of what an individual perceives, feels, expresses and desires to achieve health and well-being (Bradshaw, 1972). For oncology care providers to provide high-quality care as defined by young adults living with cancer, they require better understanding of the illness experience. What is it like to be a young adult filled with hopes and dreams for the future, only to come face to face with the possibility of his/her own life altering health concerns and premature mortality? What is it like to experience a cancer journey as a young adult? Are issues for young adults with cancer individualized or specific to the kinds of cancer they develop? When we study the human experience, we are better able to understand the necessities that people desire to achieve health and well-being. This research was a qualitative investigation into the needs of young adults with cancer in order to gain greater insight as to what it is like to be a young adult with cancer. Interpretations were derived through thematic analysis and formulated to guide nursing practice (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). Interpretive description methodology is outlined extensively in the methods section of this thesis as supported by Thorne (2008).

Some authors who engaged in research with young adults with cancer have identified concerns of this population and areas for improvement of their health care. Kyngas and colleagues (2001) studied young adults with cancer, summarizing how

cancer brings about permanent changes in an individual's life requiring strong support systems for effective coping. Similarly, Woodgate (2006) studied adolescents with cancer, recognizing social support as a critical component of their overall well-being during the cancer experience. Haase and Phillips (2004) studied young adults' experiences with cancer, and highlight that this population has unique physical, emotional, and social concerns that are difficult for health care providers to address. In a published editorial, Stevens (2005) described the young adult population in oncology care as "a group of patients whose needs are squeezed between, and insufficiently addressed by, the achievements of the paediatric oncology world on the one hand and the weight of cancer burden on adult cancer services on the other" (p. 280).

I believe that more research is needed to more accurately conceptualize the described needs of young adults with cancer and the nursing interventions to support such needs (Thorne, Reimer-Kirkham, & MacDonald-Emes, 1997). My research sought to address this inquiry.

Young (2002) discusses a transformative approach to health promotion as a process of collaboration between clients as individuals, patients, families, communities and populations with health care professionals to improve health through the joined effort of both parties in understanding the social, organizational, political and personal patterns that influence health. Similarly, Thorne (2002) notes that individuals with chronic illnesses are experts in their own health and as health care consumers can identify flaws in the delivery of the health care system to bring about positive change. Within the young adult population, there are many disease types and treatment protocol-related needs. This thesis evolves around the general experience of having cancer as a young adult

irrespective of the type of cancer with which they had been diagnosed. This is known as a non-categorical approach and has been used in the past by researchers to study children with chronic illnesses. Specifically, Jones Jessop and Stein (1982) introduced the importance of taking non-categorical approach to identify the common life experiences and problems of a group of individuals with chronic medical conditions without disease classification. Geist, Grdisa, and Otley (2003) discussed the non-categorical approach as a means of understanding important factors that contribute generally to the impact of chronic illness, such as the nature of the onset, the potential for fatality, and the risk of incapacitation. Young adults with cancer have many multifaceted, unique needs associated with their cancer journey.

Purpose

The purposes of this study were to:

- Learn about the needs of young adults aged 20 to 44 living with newly diagnosed cancer and currently undergoing chemotherapy and/or radiation treatment;
- Enhance oncology care providers understanding of the needs of young adults aged 20 to 44 and their families living with cancer, and;
- Identify nursing interventions that support the needs of young adults aged 20 to 44 and their families living with cancer.

Research Question

The research question that directed this study was “How do young adults, aged 20 to 44 who are diagnosed with cancer and undergoing chemotherapy and/or radiation treatment, describe their needs?”

Forestructure

Personal

In my current position as a Specialized Oncology Nurse with a diagnostic assessment unit at an integrated Cancer Centre, I work in collaboration with individuals and their families during the pre-diagnosis and diagnostic phase of their illness. Hence, I have gained a deep understanding of the heightened anxiety and distress with which individuals present at the time of a cancer diagnosis. During my career in oncology nursing I have been privileged to engage with individuals and their families at all phases of the illness trajectory, including pre-diagnosis, diagnosis, chemotherapy treatment, radiation treatment, community care, and palliative care. In my previous role as a Supportive Care Nurse, I worked closely with individuals with cancer and their families to alleviate pain and suffering associated with living with cancer. When a young adult has cancer, health care providers struggle to provide the best symptom management and supportive care. In my experience, there is a tendency on the part of young adults, their families, and health care providers to try to normalize the illness experience to optimize every day life. Normalization is a key theme identified by pediatric researchers in which the families of the children with chronic illness maintain their day to day lives with a behavioural strategy to live as normal as possible to manage the child's condition (Rehm & Franck, 2000). In other words, families that normalize childhood chronic illness, recognize the seriousness of the illness but also the importance of viewing their child and their family as unchanged to cope with the illness in ways that draw on their usual patterns of family functioning. This theme is challenged by other researchers who argue that a patient and his/her family's view of illness may change over time (Knafl &

Deatrick, 2002). Thus, health care professionals might consider the psychosocial context in which an illness is experienced before a full understanding of the illness impact can be actualized (Thorne & Paterson, 2000). My understanding of the theme of normalization may have influenced my interpretation of the data as I tend to align myself with Knafl & Deatrick (2002) and I feel that young adults have different perspectives on coping with cancer. I do, however, think there are common patterns amongst their differences from which myself and my oncology colleagues can learn. I attempted to approach the research open mindedly, in an attempt to let the participants guide my understanding of the coping process and whether or not the theme of normalization exists for the young adults in the study.

I have learned from my interactions with young adults with cancer that quality of life is a very personal, unique phenomenon. My past experience working as a pediatric bone marrow transplant Registered Nurse sparked my interest in nursing interventions to support adolescents with cancer. I reflect often on the young adults and the adolescents with whom I have worked in pediatric and adult oncology and I am moved by their displays of resilience and courage during their periods of challenge.

In addition, I am within the 20 to 44 age group. From my own life experience as a young adult, I have preconceived thoughts of some of the challenges young adults will face at the time of diagnosis in relation to career development, relationship commitments, and family planning. While I have not faced a cancer diagnosis personally, I have a life experience of my aunt dying from metastatic breast cancer when my cousins were young teenagers. Also, I have supported my 32 year old sister in-law facing the uncertainty of a diagnosis of malignant melanoma. After two pathology reviews, she did not have a

definitive diagnosis. I shared in her worries, fears, and anger as she proceeded with another surgery and a sentinel lymph node biopsy. I supported her as she expressed discontent with changes in her body after surgery and an overwhelming need to gather as much information as possible in regards to her future health. She discussed with me her greatest fear that she may have to face an aggressive cancer. Throughout all this, I tried to be the oncology expert at the same time as being the comforting big sister. Recently, she has been informed that her sentinel lymph node biopsy was negative for malignant melanoma. Despite my knowledge of the realities of cancer, I was in a state of disbelief when she informed me what was unfolding in her life. I expected to hear that she and my brother would be having a baby some time in the next year. Thus, I am cognizant of how deeply embedded our social, cultural, and psychological influences are on what we expect as societal norms for young adults.

My being a specialized oncology nurse and having had experiences in therapeutic relationships with young adults with cancer have naturally influenced my interpretation of the data. I have therefore attempted to be cognizant that such life experiences may have contributed to my impressions of what some of the issues for young adults with cancer might have been (Wolf, 2007). I attempted to truly engage in each individual interview establishing rapport with each of the participants. I have also attempted to abstract relevant themes from the collected data in a manner with attention to the subjective experiences of the participants (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). However, my experience as an oncology nurse caring for young adults will cancer did inevitably influence; what I observed in the field, what I saw when I made the observations, and how I made sense of the observations (Thorne, 2008). This nursing

experience brings strength to my credibility as a researcher in the topic of interest and my analysis of the findings. Ultimately, the cancer experience as described by the young adults in this study has illuminated the findings of this research. The rigour of the research has been validated by my thesis supervisor Dr. Virginia Hayes. The criteria of rigour will be outlined using Sandelowski's points (1986) points, and will be discussed more fully in Chapter Three: Methodology: Trustworthiness, p. 51.

My past occupational endeavors have influenced my interest to learn what it is like to be a young adult with cancer and how as a future Oncology Advanced Practice Nurse, I can improve the delivery of quality supportive care to this population.

Theoretical

Quality of life (QOL) is an essential component of understanding the needs of young adults with cancer. The theoretical orientation of this research was based on the "Quality of Life in Long Term Cancer Survivors" (1995) model that was developed at the City of Hope National Medical Center (Ferrell et al., 1995; King, 2006) and is built on four domains of well-being: physical, psychological, social, and spiritual. It is important to recognize, however, that QOL is difficult to measure because every individual has her/his own perspective on what gives his/her life fulfillment and quality (George & Bearon, 1980; Ferrans & Powers, 1985). There is debate concerning how to achieve the most accurate and rigorous measure of QOL. Ferrans and Powers (1985) emphasize that life satisfaction is one the most important elements of quality of life. In contrast, King and her colleagues (2002) state that "Nurses recognize that their most valid measure of QOL is what the individual believes it to be; this belief could differ from what others (including health care professionals and family members) believe and could vary by

situation” (King, Hinds, Dow, Schum, & Lee, 2002, p. E123). I felt, therefore, that it was important to talk to young adults with cancer to gain a deeper understanding of their individualized experience of living with cancer and how the experience had impacted their QOL. In turn, I anticipated this understanding would provide a preliminary basis for viewing their supportive care needs.

Researchers have studied a unique oncology nursing role known as the Interlink Community Cancer Nurse, in which expert oncology nurses build strong therapeutic relationships with individuals with cancer and their families to directly improve their quality of life (Howell, Fitch, & Caldwell, 2002). The Interlink Community Cancer Nurses (ICCN) is a non-profit, community-based oncology nursing program founded in 1988. The program is partially funded through the provincial cancer organization and private donations, and operates independently from public homecare. ICCNs improve patients’ overall coping with a cancer diagnosis through sharing expert knowledge, caring interactions, active listening, resource mobilization, teaching in regards to bothersome symptoms, and assisting with navigating the complex health care system (Howell et al., 2002; King, 2006). I began to study this unique nursing role during my experience as a pediatric bone marrow transplant nurse and often referred my patients and their families to this program after they completed their hospitalization for a bone marrow transplant. This program is offered to adult patients with cancer in large metropolitan cities and to pediatric patients and their families throughout the Province of Ontario. My understanding of the ICCN role influences my understanding of the critical role oncology nurses have in supporting individuals with cancer as they transition between care teams and throughout the hospital and community setting.

Thorne's (2008) qualitative research methodology of interpretive description underpins the theoretical forestructure of my research. Interpretive description is a good fit with my inquiry into the needs of young adults with cancer, as it encompasses the knowledge nurses bring to an inquiry and how nurses study the illness experience from the patient perspective to better guide their practice. The goal of interpretive description is to illuminate themes that represent the phenomenon of interest and to apply those themes to nursing practice. It challenges the researcher to think beyond the original forestructure of experience and literature to create an interpretation that is supported by the individuals living with the experience. The end product is a conceptualization that is useful to nurses working with those individuals (Thorne, et al, 2004).

Generally speaking, as a specialized oncology nurse I have a strong understanding of the QOL model, the role of the Interlink Community Cancer Nurse, and the theoretical foundations of interpretive description. These may have influenced, knowingly or unknowingly, my assumed knowledge of the potential needs of young adults with cancer before I engaged in participant interviews and the perspectives I brought to data collection and analysis. These constitute the "forestructure" (Addison & Packer, 1989) of ideas I brought to conceiving the research and interpreting the participants' input. Thus, the shared experiences of young adults with cancer led to the generation of interpretive descriptions and the development of clinical interventions for this unique group (Thorne, et al., 2004).

CHAPTER TWO: LITERATURE REVIEW

This literature review covers the theoretical and research literature about the young adult cancer experience with the different cancer types identified in the introduction. The literature is discussed within the context of the domains of the City of Hope National Medical Center QOL model; physical well-being, psychological well-being, social well-being, and spiritual well-being (Ferrell et al., 1995). In keeping with the non-categorical approach, I focus on key issues for increased psychosocial support for this unique population (Geist, et al., 2003). This review makes it evident that research is needed to examine the needs of young adults with cancer and to identify the role of the oncology care team in supporting such needs.

Physical Well-Being in Young Adults with Cancer

Physical well-being encompasses issues of infertility, functional activities, symptom management, and late effects of treatment (Ferrell et al., 1995; King, 2006). Whether a young adult is struggling with anticipatory nausea or decisions in regards to fertility planning, the direct effects of cancer and subsequent treatments on the human body will have a great impact on an individual's personhood. Personhood is care that looks beyond the disease to the person within (Touhy, 2004). This is an area in which oncology nurses can positively promote health and well-being through educational strategies and counseling to facilitate various coping mechanisms. Within this domain of QOL there is theoretical and scientific research literature to support the need for increased investigation into the described needs of young adults with cancer.

In their review of the data from the National Cancer's Institute's Surveillance, Epidemiology, and End Results program and the United Kingdom (UK) registry.

Pentheroudakis and Pavlidis (2005) identify adolescents and young adults aged 15 to 30 as a unique group for consideration by oncology care providers. The authors describe qualities of diagnosed tumors, etiologic associates, management, outcomes, and late toxic effects of the cohort under study. Issues associated with physical well-being are divided into early and late effects. Early physical effects include mutilating surgery, alopecia, acne, weight gain, and disruption of sexual functioning at a time when individuals are just starting to accept their self-image. Late physical effects include loss of fertility, peripheral neuropathy, ototoxicity, anthracycline induced cardiotoxicity, neurocognitive defects, bladder constriction, hepatotoxicity, skin reactions, and femoral head necrosis. The authors report that loss of fertility was dependent on frequency, degree, duration, dose and type of chemotherapy. They further note that testicular, ovarian, and hypothalamic-pituitary irradiations contributed to sterility. The authors conclude that young adults with cancer are a specialized population requiring coordinated interdisciplinary care to meet their needs similar to pediatric and geriatric populations.

Nurse researchers Tucker and Rahr (1990) used a case study approach to discuss the nursing care of a patient with non-Hodgkin's lymphoma. Although this article was written 18 years ago, the authors emphasize important QOL issues that have been consistently identified by other researchers (Ferrell, et. al., 1995). The paper identifies a variety of cancers that are more common in young adults, including lymphomas, leukemias, and first site cancers of the bone, brain, testes, cervix, and ovaries. Tucker and Rahr also note that the cancers associated with young adulthood have improved cure rates due to the introduction of new innovative treatments, but at the same time they also have greater potential life-threatening long term side effects. Similarly, CCO's (2006) report

“Cancer in Young Adults in Canada” states that the non-Hodgkin’s lymphoma rate has been increasing over the last 30 years especially in males, while the mortality rate for individuals with the disease has remained stable. It is therefore important to consider how the long term side effects of treatment will affect young adults as they survive the cancer experience. Tucker and Rahr present many issues related to physical well-being, such as the risk of infection related to having periods of myelosuppression during treatment, the challenges of nutrition and hydration associated with treatment-related nausea, vomiting, and diarrhea, body image disturbances associated with hair loss, and fertility concerns related to the risk of sterility with specific chemotherapy protocols (Tucker & Rahr, 1990). They emphasize the important role nurses play as educators in relation to the disease process, diagnostic procedures, complex medications, and self-care protocols for centrally inserted venous catheters. Because Tucker and Rahr’s findings are limited to a single case study, the degree to which it can be generalized to an entire population is uncertain (Polit & Hungler, 1991; Myers, 2000). However, their work did provide an important focus on the role of nurses in supporting young adults with cancer, which is of particular relevance to my study.

A study by Lock and Willson (2002) conducted at Princess Margaret Hospital in Toronto, Ontario, examined the informational needs of cancer patients receiving chemotherapy in an ambulatory care setting through a descriptive analysis of a 17 item questionnaire. The study consisted of a convenience sample of 101 individuals, although, only 26 individuals were within the 20 to 49 year old age range. The authors identified the need for greater support within three areas: side effects; drug information; and coping strategies. Over half of the study participants stated they had access to a computer and

on-line learning recognized by the authors as an appropriate educational tool for people with cancer receiving chemotherapy treatment. Generalization of these findings is partially limited by language and literacy barriers, because all interested participants were required to read and write English to complete the questionnaire. In addition, there may have been selection bias and ethical concerns related to the investigator approaching potential study participants directly.

In comparison, Lindop and Cannon (2001) investigated the self-assessed support needs of women with breast cancer at various points in their illness trajectories through qualitative semi-structured interviews. The authors approached women within a wide age range who had variable times since their diagnosis and treatment. The study included a purposive sample of 12 women with breast cancer between the ages of 26 to 58. The interviews were analyzed using the computer software system QSR-NUDIST. Following this content analysis, a questionnaire was formulated which divided statements into seven categories diagnosis, treatment, support, femininity and body image, family and friends, information, and after care to be rated on a Likert scale ranging from 'of no importance' to 'extremely important'. Data from the questionnaires were analyzed by means of a one-way analysis of variance (for three independent variables) or t-test for two independent variables. The authors concluded that the highest needs were within the 46 to 53 age group; however, the 20 to 45 age group did have higher perceived needs than the age 54 and over group. These higher needs occurred within the areas of femininity, body image, information, and after care follow-up. One of the strengths of this study was that it achieved triangulation with the use of mixed methods. However the potential issue of

selection bias resulting from the authors inviting pre-selected individuals to participate in the investigation is a limitation of this study.

An Australian study by Thewes, Meiser, Taylor, Phillips, Pendlebury, Capp, et al. (2005) examined the fertility and menopause-related information needs of younger women with a diagnosis of early breast cancer. The authors used a quantitative design involving a self-report questionnaire on fertility and menopause-related items and standardized measures of hospital anxiety and depression, state anxiety, climacteric symptoms, and breast cancer-specific quality of life functioning. Thewes and colleagues point out that in general, more women were delaying childbearing for personal, educational, and professional reasons and the number of women who are childless at time of diagnosis of breast cancer is increasing. One of the strengths of the study was that it numerous assessment tools were used to cross validate findings related to the participants' fertility and menopause-related needs (Polit & Beck, 2004). The study was, however, very complex; analyses included eight demographic variables, six treatment and health-related variables, and four paper and pencil measures. The description of the analyses and findings is overly brief and difficult to interpret, making it's application a challenge for nurses in their every day interactions with young women with breast cancer.

Thewes et al. (2005) analyzed their data using descriptive statistics, several non-parametric comparison tests, and an ordinal logistic regression. Two separate bivariate tests were used to test the differences and relationships between variables. These variables included age, time since diagnosis, menopausal symptoms, quality of life, measures of distress, information preference style, stage, nodal status, type of adjuvant therapy, attitudes towards childbearing, number of children at diagnosis, and educational

level. The authors reported that “younger women want to be well informed about the impact of adjuvant therapy on fertility and menopausal status” (p. 10). Receiving menopause-related information was rated as significantly more important than receiving fertility-related information during adjuvant treatment, at completion of adjuvant treatment, and during follow-up. Receiving fertility-related information was more important at time of decision making compared with time of diagnosis, during treatment, and at the end of treatment. There were no significant differences between perceived importance ratings for fertility related information at time of treatment decision making and follow-up. According to the authors, fertility-related information should be introduced at the time of treatment decision making but revisited during follow-up as well. They further conclude that informational support and innovative ways to deliver this support should be considered by the oncology care community. My study expands on this research by encouraging young adults with cancer to voice their perspectives on the timing of informational support and whether or not, they view fertility as an unaddressed need.

Sarna, Brown, Cooley, Williams, Chernecky, Padilla et al. (2005) examined quality of life and meaning of illness in women with lung cancer, and reported important results within the domain of physical well-being. The sample included 217 women with non-small cell lung cancer six months to five years since diagnosis within the age range of 33 to 89 years. The study utilized a descriptive, cross-sectional design with several quantitative assessment tools including a Short Form-36 QOL instrument (Hays & Morales, 2001), the Charlson Comorbidity Index for health status (Charlson, Pompei, Ales, & MacKenzie, 1987); the Center for Epidemiologic Studies-Depression (CES-D)

Scale (Radloff, 1977; Radloff & Terri, 1986), the Lung and Health Survey (Ferris, 1978), the CAGE questionnaire for alcohol use (Mayfield, McLeod, & Hall, 1974), and demographic and clinical variables. While the combination of multiple assessment tools provided once again the advantage in assessing QOL issues, the exclusion of the participants' subjective voices on living the cancer experience and QOL was a drawback of this study. The researchers found that younger age was related to lower overall QOL within the physical, psychological, and social domains. The participants indicated fatigue and pain were the most prevalent symptoms, a finding supported by previous research with women with lung cancer and disease-free survivors (Sarna, 1993; Sarna et al., 2002). More research is needed to investigate physical well-being in young adults undergoing chemotherapy and radiation for their cancer.

Trask, Paterson, Fardig, and Smith (2003) investigated distress and QOL in individuals with testicular cancer. Testicular cancer is the most common cancer in white males between the ages of 15 and 45, and it is noted that there is a 90 to 100% -five year survival rates for Stages I and II seminomatous and nonseminomatous, while individuals with metastatic disease have survival rates greater than 80% (Heidenreich & Hofmann, 1999, as cited in Trask et al., 2003). Previous research identified variable physical side effects associated with treatment for testicular cancer such as nausea and/or vomiting, alopecia, fatigue, anorexia, mouth and gastric ulceration, diarrhea, neuropathy, and sexual problems (Golden, Horwich, & Lockrich, 1980; Penman et al., 1984). Trask and colleagues used the following three questionnaires to assess distress and QOL 16 individuals undergoing chemotherapy for testicular cancer the Brief Symptom Inventory (BSI) (Derogatis, & Melisaratos, 1983; Derogatis, 1992), the Functional Assessment of

Cancer Treatment (Cella et al., 1993; Cella, 1994), and the Symptom Distress Scale (McCorkle & Young, 1978). These instruments were completed pre-treatment, on the first day of each of the three cycles of chemotherapy (over nine weeks), and at the three month and eight month follow-up appointments. Within the physical well-being domain there were statistically low levels of reported symptom distress, such as feeling sick, poor appetite, pain, appearance, fatigue, and sleep. The most bothersome symptoms occurred during the second cycle of chemotherapy and then improved with the third cycle of chemotherapy; these were fatigue, sleep, mood, and appetite. The authors postulated that this could have been related to improvement in the decreased use of highly toxic levels of chemotherapy and innovations in new antiemetic medications. From a nursing perspective, it would have been interesting to examine the nursing interventions for symptom management between the second and third cycle of chemotherapy. It is surprising that this study did not discuss the physical side effects of retrograde ejaculation, decreased sexual desire, and sterility as being important to the well-being of young men with testicular cancer. One might consider that had open ended questions been utilized, more fertility related issues might have been identified by participants. Overall, however, Trask et al. provide a clear study that will assist other researchers using a longitudinal design to investigate QOL.

Huang, Lee, Chien, Liu, and Tai (2004) investigated QOL among individuals with thyroid cancer in Taiwan. The sample included 146 participants over the age of 18 with a mean age of 47.95 years. The researchers conducted telephone interviews and reviewed medical records with the participants' consent. The interviews utilized Wang, Ku, Lin, & Wei's (1998) Likert type scale for rating social support and the Chinese version of the

QOL Index. The data were analyzed statistically using multivariate methods to identify variables associated with QOL. The results showed that symptoms such as fatigue and chills related to unstable thyroid hormone levels contribute to an overall decrease in QOL. Huang and colleagues suggest that nurses could improve QOL for patients by educating them in self-management of uncomfortable symptoms, although a direct correlation for this conclusion is not present in the study's findings. The authors also observed that individuals of Chinese descent generally prefer not to reveal psychological distress, and this may have contributed to an increase in the reporting of physical discomfort, this in turn may decrease the study's applicability to North American patients. In general, however, Huang and colleagues' study identifies management of physical symptoms as an unmet need for individuals with thyroid cancer. My research further examines this unmet need within the physical well-being domain for young adults with cancer.

Persson, Larsson, Ohlsson, and Hallberg (2001) investigated QOL for individuals with acute leukemia or highly malignant lymphoma. This was an extensive study that used both quantitative and qualitative methods which allowed the researchers to make credible conclusions based on the internal and external validation for this population of individuals living with malignant disease. The study involved 16 individuals, grouped in ages 20 to 50 years, 51 to 64 years, and 65 years and older. The study participants were followed from the start of their chemotherapy through the following two years. Four individuals died before the completion of the study. Open-ended questions, a QOL questionnaire (QLQ-C30) (Anderson, Aaronson, & Wilkin, 1993; Ringdahl & Ringdahl, 1993), the Life Satisfaction Index A (Neugarten, Havighurst, & Tobin, 1961), and the

sense of coherence scale (Antonovsky, 1993) were used at the start of an individual's treatment and again at 4, 8, 16, and 20 months after the initiation of treatment. Ten of the 16 interviews corresponded with the QOL questionnaire (QLQ-C30) and six did not. Overall, QOL from the start of treatment was decreased for the reported symptoms of fatigue, dyspnea, and sleep disturbances. Younger participants had higher complaints of dyspnea. This is an interesting finding, as much research has been carried out by Corner and colleagues (1999) to articulate dyspnea as a symptom with physical and psychological aspects. One might question whether the higher complaints of dyspnea were related to an anxiety component of being a young adult undergoing treatment for a potentially life threatening disease. The interviews revealed that voiced symptoms related to physical well-being were not captured in the QOL questionnaire. These symptoms included losing one's hair, dry and irritated eyes, weight loss, being intensely cold, itching, blisters hands and feet, dry mouth, swollen tongue, pain and blisters in the mouth, dental problems, taste alterations, pins/needles sensations in extremities, weakness in hands and feet, and seeing double. This study reinforced my decision to conduct my research using semi-structured interviews to learn more about the subjective concerns of young adults with cancer with respect to their physical well-being and symptom management.

In general, there has been significant theoretical and research based investigation of the identification of physical well-being as an important element of QOL for young adults with cancer. My research contributes to a deeper understanding of this issue, with particular reference to the needs and concerns of young adults undergoing chemotherapy

and radiation treatment as they describe their symptoms and their priorities for nursing care.

Psychological Well-Being in Young Adults with Cancer

Psychological well-being encompasses issues of anxiety, depression, fear of recurrence, changing priorities, and coping with survival (Ferrell et al., 1995; King, 2006). Young adults are at a stage in their lives when traditionally they should be planning for their future. A young adult with cancer is faced with uncertainty regarding morbidity and mortality of his/her illness and associated treatments. Oncology nurses respond to psychosocial distress in these young adults through the development of strong therapeutic relationships in which mutually agreed upon goals and expectations are achieved. A number of the previously cited articles within the physical well-being domain are presented again in relation to psychological well-being and its impact on young adults with cancer.

Alfano and Rowland (2006) examined issues of cancer survivorship in a critical review of existing literature with a practical assessment of some of the common symptoms and events that disrupt the psychosocial aspects of adult life with cancer. The authors determined that the period after completion of treatment is a time of persistent challenges for individuals with cancer. Issues such as pain syndromes, fatigue, changes in body image, worry about cancer's late effects, risk of cardiovascular disease, risk of second cancers, and infertility were identified as important to individuals as they completed their active treatment for cancer. The fear of recurrence was a universal theme for cancer survivors across disease sites. Young adults with breast, ovarian and gynecologic type cancers voiced fear of recurrence and fear of risk for other family

members as high priority concerns. Alfano and Rowland describe the fear of recurrence as variable, depending on situational circumstance such as clinic appointments, unexplained symptoms, cancer in the media, and death of a fellow survivor. From my past experience working as a Supportive Care Nurse, I can relate to these situational circumstances, as I have seen firsthand how they impact individuals undergoing chemotherapy and radiation treatments. Alfano and Rowland state that fear of recurrence is comparable to the fear and worry that has been described at the time of diagnosis for individuals with cancer. In my opinion, this is a crucial period of time in which health care providers can consider how they can best deliver care to individuals who are experiencing periods of intense stress and worry. Further, Alfano and Rowland highlight that a fear of recurrence can lead individuals to heightened body monitoring and constant preoccupation with an uncertain future. They also point out that there is little research examining the use of intervention programs to support reducing the fear of recurrence.

Kyngas and colleagues (2000) investigated coping with the onset of cancer among young adults in Finland. The study was conducted with a sample of 14 individuals between the ages of 16 and 22 who had been diagnosed with cancer for more than two months and were undergoing chemotherapy and/or radiation treatment. A “qualitative study” that utilized semi-structured interviews and content analysis, this work highlighted a variety of interesting findings in relation to coping with the cancer experience and specific needs for young adults. Participants indicated that the most problematic time for them was when the initial cancer diagnosis was made, as they experienced feelings of apprehension while waiting for appointments and initiation of treatment. Once treatment was initiated, participants suggested that the shared professional knowledge of their

primary physician and nurse team provided significant comfort. The participants' three major themes with respect to coping with the cancer experience were: social support, belief in recovery, and getting back to normal life as soon as possible. While the rigour of the study could have been enhanced by validating these themes with the study participants, it remains an informative study specific to the cancer experiences of adolescents and young adults. It provided further impetus for me to pursue an investigation into the subjective experience of young adults with cancer as it was evident there is much to learn about the psychosocial and coping needs of this population.

A study by Roberts, Piper, Denny, and Cuddeback (1997) used quantitative evaluation research to assess an innovative support group that was established to facilitate young adults' adjustment to cancer. The support group evolved out of previous research by Roberts and colleagues with young adult cancer survivors that identified six key areas of concern following diagnosis and treatment. These areas included anxiety about health, loss of physical well-being, worry about children, relationship problems, financial and vocational concerns, and feelings of unattractiveness. A six week social worker led support group intervention was designed to address the areas of concern. The support group was evaluated by pretest and posttest measures with the following assessment tools: the Profile of Mood States (POMS) (McNair, Lorr, & Droppleman, 1971), the Cancer Rehabilitation Evaluation System (CARES) (Schag, & Heinrich, 1988), and the Ways of Coping Checklist (Revised) (WCCL-R) developed by Folkman and Lazarus (1980) to assess the use of different coping strategies in response to stressors. The sample consisted of two support groups, each with seven participants were involved in the support group meetings. These authors cited difficulties in attendance related to the busy

treatment schedules of patients, distance to travel for the support group, and multiple family and occupational stressors. They suggest this difficulty was due to the six week commitment, despite the fact that participants were reimbursed \$30 for travel and parking expenses. Attendance is an important issue for consideration when planning an investigation of the young adult population. In planning for my study, I decided to give the study participants a choice of interview setting, such as their homes or a quiet room in the Cancer Centre.

Roberts and her colleagues (1997) concluded that the sample size of their study was too small to obtain statistical significance at the 0.05 level and used an adjusted statistical score of .10 instead. Based on the results of the POMS tool, the intervention support group improved symptoms of fatigue, confusion, and total mood disturbance, while the CARES tool revealed improvements in medical interactions and psychological well-being in pre-test and post-test scores. In contrast, the WCCL-R tool did not reveal improved coping mechanisms following the support group. The research team summarized the importance of combining the quantitative measures with qualitative observations such as participants' feedback. Overall, the study participants commented that the support group was a positive experience that provided enhanced psychological support. Specifically, they talked about the value in sharing with others their concerns about fertility, relationships, finances, vocational worries, and feelings of unattractiveness.

Roberts and her colleagues' study was an exemplary project designed to meet the needs of young adults with cancer. One limitation of the research was that it lacked qualitative research techniques to supply the voices or opinions of the young adults with

cancer. The research team also identified limitations of single group threat to internal validity. In quantitative research, a random sample is often used. However, a small sample size limits the generalization of the study's findings. In contrast, qualitative research uses a selective sample with in-depth analysis of the subjects and can lead to substantial information on the subjective experience of a phenomenon. Lincoln and Guba (1981) recommend fittingness as the criterion for the applicability of qualitative research; that is, a study can fit into contexts outside the investigation when the participants view the findings as meaningful and applicable in terms of their own experiences. Thus, the gaps in the work of Roberts et al. supported my decision to pursue a qualitative investigation for my study.

Siegel, Gluhoski, and Gorey (1999) conducted a thematic analysis to investigate age-related distress among young women with breast cancer. Their sample consisted of 34 women between age 22 and 35 who had completed their treatment for breast cancer and who believed they could get pregnant. The methods included a session with an interviewer to obtain informed consent, administer a questionnaire of relevant socio-demographic information, and participate in an in-depth interview with a series of open-ended questions. The data were audiotaped and transcribed utilizing ZY-index, a text based software program for qualitative analysis which allowed the authors to pull relevant information and analyzed content. The participants discussed the unique issues about being a young woman with breast cancer. Six predominant stressors were identified: coping with the untimeliness of the diagnosis, concerns about the impact of the illness on their husbands, sadness about lost opportunities for childbearing, a feeling of being different and isolated, uncertainty about their future, and concerns about their

children. One limitation of the study was that the researchers did not disclose if study participants were approached for validation of identified themes. Despite this, the work of Siegel et al. provides an in-depth exploration into issues that are important for young women faced with a cancer diagnosis. The themes extrapolated from the study participants' interviews and completed questionnaires represent significant issues for oncology care providers to be aware of as they interact with young women with breast cancer and plan for quality care.

As previously discussed in the physical well-being section of this review, Sarna and her colleagues (2005) studied QOL and meaning of illness of women with lung cancer. Such research is relevant when considering future investigation into the psychological well-being of young adults with cancer. Specifically, at least half of the 217 participants rated seven items in the psychological QOL subscale of the QOL Scale-Patient Version as the most distressing. The seven items included distress over diagnosis, fear of metastasis, fear of diagnostic tests, distress over treatment, fear of recurrence, anxiety, and fear of a second cancer. Depressed mood was identified as an explanation of poorer psychological well-being. Accordingly, negative meaning of illness and younger age were significant factors related to poorer QOL.

Trask, Paterson, Fardig, and Smith (2003) also investigated distress and QOL as issues of psychological well-being in individuals with testicular cancer. Study participants did not report distress levels higher than that of a healthy population (Derogatis, 1992). Thirty percent of the 16 participants reported increased distress at pre-treatment baseline with increased levels of anxiety that decreased over the course of chemotherapy. The researchers concluded that anticipatory anxiety is associated with fear

of chemotherapy. The psychological impact of receiving chemotherapy as a young adult is a thought provoking need for health care professionals to consider during treatment sessions with these individuals. The findings of this study bring forth issues that oncology care providers might consider when contemplating the best way to deliver informational support to alleviate anxiety and fear throughout the course of chemotherapy. My study expands this research by exploring the myriad of feelings young adults with cancer experience when they are undergoing chemotherapy and/or radiation and asks the participants to consider supportive gestures they received from oncology nurses.

Persson, Larsson, Ohlsson, and Hallberg's (2001) study investigated QOL in individuals with acute leukemia and highly malignant lymphoma. The study revealed important considerations with respect to psychological well-being. Participants reported decreased QOL at the start of treatment and men were significantly more emotionally affected than women. In addition, individuals who had experienced one or more relapses were more affected with respect to their social, cognitive, and emotional functioning throughout the study period. The authors also assessed participant's sense of coherence as defined by Antonovsky (1979) as a stable, long lasting way of looking at the world. Also, they reported decreased functioning and symptoms among those in their sample, although these were not correlated with decreased sense of coherence. A previous study by Langius, Bjorvell, & Antonovsky (1992) described how a low score on sense of coherence to be related to greater displayed anger and hostility. Persson and her colleagues (2001) suggested that coping strategies when evaluating coping strategies in individuals with cancer may be dependent on an individual's personality and they challenge readers to consider components of ego functions, defences, experiences,

personality, and self-perception when evaluating coping strategies in individuals with cancer. Persson and her colleagues (2001) discussed psychological well-being during recovery and report increased problems for those who relapse during treatment. In interviews, study participants brought forth consistent themes of problems with decreased psychological and sexual energy, existential problems, and sensitivity to infections.

Overall the research literature supports issues of anxiety, depression, fear of recurrence, changing priorities, and coping with survival as critical issues affecting the psychological well-being of young adults with cancer. My research is intended to provide a greater understanding of these and other psychological considerations in young adults with cancer from their own perspectives. A diagnosis of cancer can have life-altering consequences for a young adult. There will be a greater risk of treatment related side effects and risk of a second malignancy for the young adult population in the future (CCO, 2006). How do health care professionals, families, and friends support this group of individuals as they embark on a journey filled with emotional turmoil and uncertainty for their future? As a specialized oncology nurse, I believe we need to address the compelling needs of young adults with cancer now, to assist with national health care planning in the future. My study provides critical information on the needs of young adults with cancer from the individuals who are experts on their own health care experience. This in turn will inform young adults with cancer and the oncology community on gaps in service and opportunities for improvement in care delivery. It is important that young adults with cancer are aware of their needs to support their empowerment and participation in future health care planning.

Social Well-Being in Young Adults with Cancer

Social well-being encompasses issues of appearance, financial burden, leisure activities, roles and relationships, family distress, and occupational/academic endeavors (Ferrell et al., 1995; King, 2006). Young adults are establishing social networks and many are seeking life long partners. A young adult diagnosed with cancer will experience changing dynamics in his/her relationships with others and have difficulty maintaining his/her normal roles and responsibilities. Oncology nurses engage with young adults at many points throughout their cancer journey. On-going assessment of the social supports and family needs of young adults with cancer is an important role for the oncology nurse. Within the social well-being domain of QOL literature, I review theoretical and research-based articles which encompass social concerns for young adults with cancer, including some previously mentioned articles already mentioned in the preceding sections of this review.

As previously discussed, Alfano and Rowland's (2006) article also emphasized the importance of social well-being for young individuals surviving a cancer experience. The authors presented some of the difficulties family members have in adapting to a cancer experience, such as role changes, economic shifts, ongoing care needs, lingering effects of the illness, and uncertainty about the future. Alfano and Rowland identified two factors consistent with positive adaptation to having a family member living with cancer: perceived social support from a spouse/partner and positive coping style. According to the authors, the literature supports the argument that individuals who undergo an intervention, such as a support group, will improve their individual well-being and alleviate distress associated with the cancer experience. The most helpful sources of

support identified in the literature were support groups, internet support, and physical activity interventions.

As introduced in the physical well-being section of this review, Tucker and Rahr (1990) presented a case study involving a 25 year old individual who underwent treatment for non-Hodgkin's lymphoma. They utilized Levinson's (1978) developmental theory to describe the age period of 22 to 29 years as a time of transitioning to adulthood. The authors discussed important issues to improve social well-being during this time frame, such as establishing a home away from one's childhood family, beginning a career, developing a strong sense of connectedness to persons outside the family through significant relationships, close friendships, and community ties. Further, Tucker and Rahr highlighted the process of normalization as an attempt for individuals to live as normal as possible despite long-term illness. Because there is a higher cure rate for cancers in young adults, dealing with long term side effects and adapting to life as a survivor of cancer become part of the normalization process.

Lynam (1995) investigated the nature of family work when a young adult has cancer through "a qualitative study with young adults with cancer that examined social relationships in order to understand the nature of interactions perceived as supportive and the context within which they occurred" (p. 116). She noted that support is based on family interactions in various situations, and that young adults are at a time in their lives when they are making difficult decisions about; leaving the family home, getting married, living with a partner in an intimate relationship, raising a family, and establishing a career. Her study involved 12 participants, eight women and four men between the ages of 19 and 30 who had completed the initial treatment phase of their illness. Participants

completed one to three semi-structured interviews which were transcribed and analyzed by content analysis. Truth value was enhanced by re-approaching the participants for a second interview to ensure the interpretation of the data was consistent with the views of the participants (Sandelowski, 1986). The data revealed five themes relevant to family work when a young adult is faced with a cancer diagnosis: establishing caring partnerships, acknowledging the possibility of death, putting illness in its place, looking towards the future, and recognizing the roles of others in supporting the young adult. Lynam emphasized that families are often overlooked as the informal support for individuals coping with cancer and that illness affects one's ability to fulfill roles and responsibilities within and outside of the family. She concluded that nurses have a role to play in working with young adults to establish how to communicate information about the illness and treatment to their families. Her paper further discussed continuity of nursing care as an aspect of care for young adults.

The Lynam article presents many key concerns for the social well-being of young adults with cancer. In current practice, oncology nurses conduct assessments of all aspects of an individual's being beyond the domains of traditional medicine. Specifically, oncology nurses assess who a person is and how the illness experience will affect the individual and their family in relation to family dynamics, community support and financial resources (CANO, 2001). This thesis study demonstrates how to empower young adults to speak about their cancer experience. In turn, it serves to educate oncology care professionals on the importance of individualized care based on various unique socioeconomic variables. Further, my study expands on Lynam's work.

Kritcharoen, Suwan, and Jirojwong (2005) investigated the perceptions of gender roles, gender power relationships, and sexuality in Thai women following the diagnosis and treatment of cervical cancer. The study involved 97 women aged 30 to 65 years and their partners one year after completion of treatment. The authors brought forth that study participants may have felt obligated to participate in the study due to the differences in social position between themselves and members of the researchers, creating an ethical issue for the study. The methods included structured interviews with a questionnaire which consisting of three components: demographics, gender roles and gender power relations, and sexuality. The demographic data were analyzed with descriptive statistics, and the interviews were recorded and transcribed, and the content was analyzed. As described by Polit and Beck (2004), increased validity can be achieved by utilizing mixed methodology for data analysis. The results indicated that there was an increase in the percentage of partners who undertook the woman's gender role-specific activities after she underwent treatment. These activities included doing laundry, looking after the family's financial situation, and earning a family income. The study found few reported changes in gender power relationships. Of interest, both women and men reported decreased importance of sexual intercourse to their married life after treatment. The researchers conclude that nurses have pivotal roles to play in assessing couples for potential gender role and sexuality problems and to develop interventions to counsel women and their partners on the proposed cancer treatments and possible side effects.

Previously discussed in the physical well-being section of this review, Huang and colleagues (2004) investigation of QOL for individuals with thyroid cancer also revealed important considerations within the domain of social well-being. The researchers

conclude that “social support from families and friends explained about one-third of the variance in quality of life among patients with thyroid cancer” (p. 495). Social support from family and friends is an essential component of quality of life in the young adult population. Thus, the researchers encourage oncology care providers to gain a deeper understanding of individuals’ family and friends when developing support networks and providing resources.

Also previously discussed, Lindop and Cannon’s (2001) study of the needs of women with breast cancer articulated thought provoking information within the domain of social well-being. It is emphasized in this report that support encompasses the care for and the value of the individual (Bloom & Spiegel, 1984). Lindop and Cannon contend further that provision of support to a woman with breast cancer may have a positive effect on her reaction to illness and may prolong survival (Greer, 1989; Spiegel, 1992). The results of the study, which involved semi-structured interviews followed by a questionnaire, identified greater expressed need in the family and friends category for women aged 20 to 45. This category included perceived needs such as practical support on the domestic front, acceptance and emotional support from a husband and/or partner, having open and honest communication, and having family presence. It is noteworthy that the women with partners did express increased worry and concern over their partner’s coping in relation to the illness.

Similarly, as I discussed in the psychological well-being section, Siegel and colleagues’ (1999) article revealed that women with breast cancer reported excellent emotional and practical support from their partners. However, the women also expressed feelings of guilt over how the illness changed their marriages. The women in the study

discussed feeling different from other women because of their cancer experiences; some women disclosed that they felt isolated because they did not know any other women in their age group who were experiencing the same illness. The authors' findings support the idea that relationship strain and isolations are relevant social themes for young adults with cancer.

This thesis research investigated the perceived social needs of young adults with cancer, with the goals of building on the existing literature and to abstracting new meanings about the social needs for this population and health care professionals providing care for them (Thorne and colleagues, 1997). My research design is presented in the Methods: Chapter Three of this report, following the literature review.

Spiritual Well-Being in Young Adults with Cancer

The final segment of the literature to be reviewed with respect to QOL for young adults with cancer is within the domain of spiritual well-being. This area encompasses issues of hope, despair, religion, strength beliefs, and the meaning of illness (Ferrell et al., 1995; King, 2006). Being a young adult is characterized by the developmental milestones associated with planning for one's future adult life. Often a young adult with cancer is faced with a difficult reality of living with both hope for a cure and fear of mortality. As a result, spiritual affiliations, faith communities, and one's personal beliefs about illness, and death and dying are of paramount importance. Oncology nurses include spiritual assessments and hope-promoting strategies in their every day practice with young adults. Here I review one article specific to the topic of hope and several other articles previously discussed articles in this literature review with an emphasis on important spiritual concerns for young adults with cancer.

Ceronsky and colleagues (1996) investigated individuals' own meanings of hope and strategies to sustain hope while facing cancer. The study compared the relationship of hope to spiritual beliefs, sense of coherence, and QOL. The sample included 32 men and women undergoing active supportive and/or palliative treatment for their cancer and included seven individuals 35 years old and under, 13 between the ages of 36 to 50, nine between the ages of 51 to 65, and three who were 66 or older. The researchers utilized a mixed methodology of semi-structured interviews for content analysis and self-report questionnaires. The latter included the Herth Hope Scale (Herth, 1991); a research team developed, six-item Spirituality Index; Antonovsky's sense of coherence scale (1979); and a QOL tool designed by the Dartmouth Primary Care Cooperative Information Project (Nelson et al., 1987). Rigour of the content analysis was achieved by using ten investigators and two consultants to analyze the data from the interviews. Correlation analyses were performed on quantitative data from the questionnaire, in order to measure the influence of demographic and disease indicators on individual outcome variables. The researchers concluded that a sense of hope was universal to all of the study participants. While all the participants identified with common themes of hope, some participants relied more on inner resources and strength. Others derived hope from the people in their lives, and some from their belief in God. Overall, this was an extensive study using many different data collection tools to capture the ever-changing theme of hope for individuals with cancer.

Similarly, Ebright and Lyon (2002) investigated the theme of hope and factors that enhance hope in women with breast cancer. The sample consisted of 73 women between the ages of 20 and 73 with a first time diagnosis of breast cancer. The

methodology included surveying with the Lazarus Appraisal Components and Themes scale (Smith, Haynes, Lazarus, & Pope, 1993), the Herth Hope Index (Herth, 1992), Rosenberg's Self-Esteem scale (1979), Personal Resource Scale 85-Part 2 (Weinert, 1987), Helpfulness of Religious Beliefs Scale (Brandt, 1987), and a demographics questionnaire. The surveys were mailed to participants three and 12 months after surgery. Descriptive statistics were used to summarize each of the surveys. Unexpectedly, the study's findings revealed hope scores for women with breast cancer were higher than those previously reported scores of people with chronic illness. Overall, the participants' thoughts about the breast cancer experience were reported more as hope/challenge than anxiety/fear. Self-esteem was found to contribute to internal personal control and potential for coping. Potential for coping, self-esteem, and social support contributed the variance in hope. Religious beliefs accounted for variation in potential for coping/influence. Individual strength and problem solving appeared to contribute to hope. Although the global applicability of the study is questionable (the sample was limited to married, Caucasian women with a least a high school education and above average incomes), and it is difficult to interpret how the reported results might apply to every day nursing interactions with women with breast cancer, the study highlighted that hope is a complex phenomenon that should be included in any quality of life consideration of those with cancer. Religious beliefs accounted for variation in potential for coping/influence.

As previously discussed in the physical and psychological well-being sections of this review, Sarna and her colleagues' (2005) work on QOL and meaning of illness for women with lung cancer, they used the Meaning of Illness Tool developed by Degner, Hack, O'Neil, and Kristjanson (2003). Participants described the meaning of their illness

in relation to positive, negative, or other meanings. The majority of the participants described a positive meaning, indicating that illness as a challenge was the best description for their cancer experience. The authors concluded that health care professionals should assess individuals with lung cancer for negative meanings of illness and possible perceived blames and stigmas towards the illness that may be present.

Further, Kyngas and colleagues' (2000) previously cited research involving a qualitative analysis of interviews with young adults aged 16 to 22 with cancer emphasized the essential elements of spiritual well-being. Specifically, the young adults identified several spiritual resources for dealing with cancer, including positive life attitude, belief in one's resources, belief in God, earlier life experiences, and willingness to fight against the disease.

Also, Siegel and colleagues (1999) previously cited research, which investigated age-related distress among young women with breast cancer, revealed six prominent themes for consideration. One of the themes, uncertainty about the future, is strongly associated with the domain of spiritual well-being. Women in the study talked about how the cancer experience altered their worldview and vision for the future. The women talked about complex challenges associated with living with cancer, such as changing family and career goals to meet more realistic expectations based on the possibility of early menopause, extreme fatigue, sadness about lost opportunities for childbearing, and anger at having to confront issues of mortality and disability at a young age.

In addition, as previously discussed in the social well-being section of this review, Lynam's (1995) article on the factors influencing social relationships for young adults with cancer identified five themes for consideration. One of the themes, acknowledging

the possibility of death, is associated with the domain of spiritual well-being. Participants in the study spoke of an awareness of high cure rates for most cancers affecting young adults, but always living with the possibility of one's mortality. They also spoke of the importance of talking about the possibility of death with families and friends. In turn, acknowledging that mixed emotions and feelings of sadness were congruent with better adaptation to illness, some participants indicated that if they did not talk about the possibility of death, they were living a charade with family and friends (Lynam, 1995). Overall, the work of Lynam and other researchers reveals many significant considerations for the spiritual well-being of young adults with cancer.

State of the Knowledge

In summary, a review of the published literature reveals a vast array of theoretical, quantitative, and qualitative investigations into the concerns of young adults with cancer. It demonstrates that young adults with different types of cancer undergoing various treatment modalities have identifiable significant quality of life issues. The quality of life issues were reviewed within the domains of physical well-being, psychological well-being, social well-being, and spiritual well-being (Ferrell et al., 1995). These issues include body image disturbances, fertility concerns, informational support needs, symptom management strategies, altered coping mechanisms, fear of recurrence, concern with genetic susceptibility, relationship changes, financial concerns, uncertain future, child rearing difficulties, career challenges, maintaining hope, "illness as a challenge" and risk of mortality. These are all relevant issues for oncology nurses to address in providing care.

One strength of the existing literature is that there are many rigorous, triangulated studies that use valid quantitative assessment tools to support the multifaceted needs of young adults with cancer. However, the reviewed research reveals a lack of Canadian studies and much of the research has focused on the needs associated with specific disease types, rather than on young adults with cancer. “The Cancer in Young Adults in Canada” document (CCO, 2006) presents incidence patterns and critical issues surrounding late effects of cancer for this population. The oncology community might consider greater use of interpretive paradigm qualitative research for young adults with cancer in a Canadian setting. The “Cancer in Young Adults in Canada” report states there is an urgent need for research about the effects of a diagnosis of cancer and its treatment on people in this age group (CCO, 2006, p. 86).

My thesis investigation supports the argument that there is a need to listen to the stories of young adults with cancer to better understand how oncology care can be delivered in the future. CANO (2001) emphasized the nursing role in caring for individuals with cancer in Standard 6, “Individuals with cancer and their family are entitled to a supportive, knowledgeable, caring and therapeutic relationship with care providers throughout their cancer experience,” (p. 31) and Standard 7, “Care delivered to individuals with cancer and their families is based on theory, science (physiologic and psychosocial sciences), and incorporates principles of evidence-based practice, best practice or available evidence,” (p. 31). Clearly, the diverse needs of young adults with cancer are personalized and health care professionals are challenged to meet those needs in a timely, effective manner (Crooks et al., 2004).

The literature review is part of my theoretical forestructure and provided an understanding of the components of QOL for young adults with cancer which I took into the design and completion of this research. My study serves to generate knowledge to improve supportive care for young adults with cancer and their families in Canadian settings. Quantitative research methodologies are used to test theories from existing knowledge and investigate variables with data analysis through numbers. In comparison, qualitative research methodology is a systematic process that investigates the human experience as described by the humans experiencing it (Carr, 1994). For purposes of this investigation, a qualitative research method, interpretive description (Thorne, 2008) was judged to be the most appropriate methodology to study young adults with cancer as it empowered this population to educate others about their needs and concerns.

Young adulthood is a time of intense change and planning for one's future; a cancer diagnosis brings with it a risk of life altering side effects, altered social change, and the possibility of mortality (Thomas, 2007). As a specialized oncology nurse, I believe we need to address the compelling needs of young adults with cancer now, in order to assist with national health care planning in the future. My study is intended to build on existing knowledge and provide critical information on the needs of young adults with cancer from the individuals who are experts on their own health care experience. This in turn, will inform young adults with cancer and the oncology community of gaps in service and opportunities for improvement in care delivery.

CHAPTER THREE: METHODOLOGY

Design

I conducted an interpretive descriptive (Thorne, 2008) research study to investigate the perceived needs of young adults aged 20 to 44 diagnosed with cancer and undergoing chemotherapy and/or radiation treatment at a small urban Cancer Centre in South Western Ontario. Interpretive description is a qualitative approach to nursing research developed by Thorne and colleagues (1997; 2004; 2008). It is a means of gaining an in-depth understanding of the subjective experiences of members of a given population. The purpose of this type of research is to analyze themes and patterns to generate an interpretation that will inform clinical understanding (Thorne et al., 2004). Interpretive description is a process of discovering distinctive elements of a common issue, such as cancer in young adults (Thorne, 2008). It serves to bring forth the value of individual perceptions to gain an understanding of intricate patterns within common experience, behaviour or consciousness. Interpretive description is most appropriate for questions that can be answered by exploring the specific observations and building towards general patterns to describe a phenomenon (Patton, 2002; Thorne, 2008). The term description is used to provide a foundation for studies with the purpose of categorizing what has been observed (Sandelowski, 2000; Thorne, 2008). Description is a mechanism for increasing awareness of health and illness phenomena for health care professionals. Interpretation situates health and illness phenomena within the philosophical stance that reality does not exist objectively; instead it is better understood as it is socially constructed by the person who experiences it (Mottier, 2005; Thorne, 2008). Research that is built on interpretive description is based on the subjective

experience and the social and cultural factors that have shaped that perspective. The role of the researcher is to account for what is already known and to critically reflect on the interactions with the participants to analysis themes that can inform nursing practice. This approach serves as a significant contribution to changing the delivery of future health care with attention to “real lives” of young adults with cancer (Thorne, 2008). This method was the best approach for my research because I wanted to learn directly from the experiences of young adults with cancer to enhance oncology nursing practice. Nurses can apply this expanded knowledge to improving the quality of life for young adults with cancer as a specialized group.

External validity is the degree to which the study’s findings can be applied to other settings and samples (Polit & Beck, 2004). Interpretive description research is the smaller scale qualitative investigation of a clinical phenomenon of interest to the nursing discipline based on the premise that nursing knowledge is built from research and clinical interpretation (Thorne et al., 2004). The theoretical and research based knowledge about the needs of young adults with cancer formed the foundation for conducting a non-categorical needs assessment of representatives of this population. “Interpretive description in nursing requires that nurse researchers come to know individual cases intimately, abstract relevant common themes from within these individual cases, and produce a species of knowledge that will itself be applied back to individual cases” (Thorne et al., 1997, p. 175). Previous knowledge is accounted for and new knowledge is generated by the perceived needs of our patients to guide how we deliver care in the future. In turn, the original clinical and research knowledge transforms into deeper meanings and interpretations relevant to the caring sciences (Thorne et al., 2004). Nurses

use critical reflection to guide clinical reasoning, and as such, conducting interpretive description research sheds light on clinical questions with thoughtful analyses that nurses go on to use in their every day practice (Thorne, 2008). This method is therefore a good choice for this study of an important “clinical population, young adults with cancer, with potentially important application to the improvement of their oncology care.

Sample/Sampling

Recruitment consisted of a purposive sample of interested young adults aged 20 to 44 with cancer who were receiving treatment at the integrated Cancer Centre. Purposive sampling is when certain individuals within specific settings are recruited based on their experience or characteristics (Thorne, 2008), these guide the researcher and the audience to better understand the phenomenon of study. Young adults with cancer, who were undergoing chemotherapy and/or radiation, were invited to participate as their similar experiences serve to provide a greater understanding of the major needs that affect them as individuals living with cancer. After receiving ethics approval from the Cancer Centre Ethics Review Board and the University of Victoria Human Research Ethics Review Board, recruitment posters were put up in the waiting areas at the Cancer Centre and at a local cancer support centre (Appendix A). I e-mailed all the staff at the integrated Cancer Centre to communicate the purpose of the study and the methods to be utilized. Oncology nurses were encouraged to refer individuals who might be interested in participating.

I made a plan to sample until no new information occurred and no new categories emerged as described by Morse (2007). Lincoln and Guba (1985) suggest that sampling is terminated when no new information is emerging from the newly sampled units and redundancy is present, that is, until data saturation occurs. Over a period of five months,

11 individuals expressed interest in participating in the study. But all those who expressed interest did not participate as some were feeling unwell and experiencing symptom related side effects of their treatment when it was time to schedule the first interview, and decided against it. Seven individuals participated in one on one interviews. A description of the participants is presented at the beginning of the next chapter.

Setting

The setting for data collection was the participants' preference of either a designated quiet, private room at the Cancer Centre or in the participant's home. All seven participants preferred to meet with me at the Cancer Centre in a quiet room. The rooms used were private with comfortable chairs for sitting and signs on the closed door to assist in avoiding unnecessary interruptions.

Data Collection and Procedures

As previously stated, study participants were recruited by poster advertising in the waiting rooms at the Cancer Centre and on the information board at a local cancer support centre. Poster recruitment and the e-mail to colleagues included contact information such as my telephone voicemail and an e-mail address. Once potentially interested candidates had made initial contact to express interest in study participation or expressed interest to their primary nurse or physician team, I contacted them in person or by telephone. I explained the study purpose again (it was in the poster and my telephone voicemail) and the expected time commitments for study participation, and I answered any specific questions they had. Thereafter, I set up a one-on-one meeting time with each interested participant to review the informed consent form for study participation and to conduct the first semi-structured interview designed to elicit information specific to the

research question. Written consent was signed during the initial meeting with each participant, and he/she was assured that he/she could request that the tape be stopped at any point during the interaction and also that he/she could withdraw at any point during study participation (Appendix D). Informed, written consent was obtained at this initial meeting and a verbal consent affirmed consent at subsequent meetings with two participants. All were assured that their participation was voluntary and they were assured of confidentiality both during data collection and reporting of results.

I conducted semi-structured interviews with all the study participants using audio tape recorded conversations that were subsequently transcribed verbatim, and a reflective journal of my own. Thorne and colleagues (1997) cite May (1989):

An analytic framework constructed on the basis of critical analysis of the existing knowledge represents an appropriate platform on which to build a qualitative design. Such a framework orients the inquiry, provides a rationale for its anticipated boundaries, and makes explicit the theoretical assumptions, biases, and preconceptions that will drive the design decisions. (p. 173)

As such, I planned my interview approach and prompts prior to entering the field (Appendix B). The semi-structured interview prompts guided me, as a novice researcher, in my interactions with the study participants. Also, the prompts served to encourage the participants to discuss various aspects of their experience. These prompts were based on a published study by Houldin and Lewis (2006) and on Ferrell and colleagues' (1995) Quality of Life (QOL) model for cancer survivors and hence reflect aspects of the forestructure I brought to the research.

Reflexivity

Reflective journaling, as suggested by Thorne and colleagues (1997; 2008), served to account for and document my reflexivity of the research process. Reflexivity is

recognized as a process by which researchers understand their awareness of the interpretation of the data (Wolf, 2007). I wrote my thoughts, questions, and ideas in a journal prior to each visit. I recorded my internal reflections on audio tape immediately after each interaction with participants. The journal recorded my reactions in the interpretive process and served to recognize my interpretation of the data as an oncology nurse. The reflections were transcribed verbatim with the interview data and included in the data analysis. I recorded my preconceived notions, my rapport with participants, my thoughts on the themes of the conversation and unexpected events that occurred during the interactions. As such, I was aware of my communication and my evolving relationships with participants and how such interactions influenced the generation of knowledge for the study. I attempted to use this personal writing to reflect on how my clinical experience as an oncology nurse could influence the interactions, and how I was influenced by them. I tried to enter each interview open minded, so I would enter the participant's world through an interpretive eye (Thorne, 2008).

I spot-checked the tape-recorded transcribed verbatim conversations for quality after initial transcripts were received. I analyzed the data with the assistance of my thesis supervisor, Dr. Virginia Hayes, when interpreting themes, patterns, and descriptions. Thorne and her colleagues (2004) state that, "the best interpretive descriptions will pass what has been referred to as the "thoughtful clinician test", in which those who have expert knowledge of the phenomenon in a particular way find that the claims are plausible and confirmatory of "clinical hunches" at the same time as they illuminate new relationships and understandings" (p.17). The emergent findings were shared with Dr. Hayes and an expert oncology nurse. Also, I presented the preliminary findings of this

research at the CANO's annual conference in the fall of 2008. I received feedback from several oncology nurses working in various roles who stated that they recognized the emergent themes from their own nursing practice. In addition, they stated that the reported sample seemed diverse enough to have generated themes applicable to their practice with young adults with cancer.

Finally, I had an 'in person' interview with one of the participants and a telephone interview with another participant to challenge the initial conceptualizations of the data collection and analysis. These assisted me to refine the emergent themes and are part a process referred to as member checking (Thorne et al., 1997). Lincoln and Guba (1985) refer to member checking as a process in which the analytic categories and interpretations are tested with those with whom the data were originally collected as it serves to establish credibility.

Analysis

The data were transcribed verbatim into a Microsoft Word word processing electronic file by a contracted professional transcriptionist hired to the study. A signed contract was negotiated with the transcriptionist to assure confidentiality for all participants (Appendix C). I checked the transcripts to clarify integrity and accurate representation of the interview conversations, by performing spot-checks on the transcribed data with the audio tape. Also, I filled in any missing words on the transcript by re-listening to the tape to clarify what was said. I compared my written journal notes to the transcribed data to capture the non-verbal points of intense emotion and areas of emphasis. I corrected punctuation to reflect the two way dialogue of the conversations. Subsequently, segments of the data that are quoted in the following Findings chapter

were punctuated by a professional editor who had no personal context for individual comments. Data from the interviews were analyzed by me with the assistance from my thesis Supervisor.

Analytic induction was used for data processing:

This strategy involves scanning the data for categories of phenomena and for relationships among such categories, developing working typologies and hypotheses upon an examination of initial cases, then modifying and refining them on the basis of subsequent cases....Negative instances, or phenomena that do not fit the initial function, are consciously sought to expand, adapt, or restrict the original construct. In its most extreme application, analytic induction is intended to provide universal rather than probabilistic explanation; that is, all cases are to be explained, not merely some distribution of cases. (Goetz & LeCompte, 1981, p. 57)

Analytic induction involves the examination of single cases based on a preformulated hypothesis that is ever-changing; therefore, if patterns and themes do not fit with the initial hypothesis then new knowledge is generated (Vidich & Lyman, 2000; Patton, 2002). According to Thorne and colleagues (1997), it is recommended that researchers engaging in interpretive description follow the analytic techniques of Giorgi (1985), Knafl and Webster (1988), or Lincoln and Guba (1985). Each of these reflect repeated immersion in the data prior to beginning coding, classifying, and creating linkages. The data analysis process of Lincoln and Guba (1985) was used for this study.

The data were analyzed through two processes, unitizing and categorizing. Lincoln and Guba (1985) discussed units with two characteristics, specifically, understanding the action the inquirer needs to have and analyzing the smallest information about something that can stand by itself. They may be sentences, comments, phrases, and/or paragraphs from the observational, interview notes, and non-verbal cues (Lincoln & Guba, 1985). Units were pulled from the transcribed interview data and my

reflective journal and entered into a Microsoft Excel spreadsheet system for further data reflection and analysis. Each was coded with the source, the type of respondent, and the data collection episode. Lincoln and Guba (1985) state that “categorizing is a process whereby previously unitized data are organized into categories that provide descriptive or inferential information about the context or setting from which the units were derived” (p. 203).

The first unit represents the first category and each unit was compared to the first to determine whether it fits in the provisional category or it represents a new category. After categories were established, rules for category inclusion were determined. Fifteen emergent themes were identified. Next, the entire category sub-set was reviewed and the categories were reviewed for overlap. I was consistently reviewing the data and asking myself, What am I learning here? Have I generated new knowledge? Further, the set of categories was examined for relationships between categories. Categories were pursued in subsequent data collection through the extension of existing knowledge, the bridging of earlier knowledge, and the verification of new knowledge gleaned in the analysis. The four criteria to stop data collection and processing were used: exhaustion of sources, saturation of categories, emergence of regularities, and overextension (Lincoln & Guba, 1985). Thorne and her colleagues (2004) state, “The product of an interpretive description, or the object of the exercise, is a coherent conceptual description that taps thematic patterns and commonalities believed to characterize the phenomenon that is being studied and also accounts for the inevitable individual variations within them” (p. 7). Constant re-examination and reflection of initial conceptualizations occurred throughout the analytic process. Thematic analysis is the complex analytic process of

identifying and articulating commonalities that are present in the interviews (Morse and Field, 1995). Thus, in this research there are eight emergent themes to illustrate the most important ideas as described by young with cancer undergoing chemotherapy and/or radiation treatments. Integration and expansion of the literature was conducted to further illuminate the needs of young adults with cancer and will be represented in the Discussion Chapter of this thesis.

Trustworthiness

Qualitative research is “the investigation of phenomena, typically in an in-depth and holistic fashion, through the collection of rich narrative materials using a flexible research design” (Polit & Beck, 2004, p. 729). Sandelowski (1986) cites Lincoln and Guba (1981) which discuss four factors relating to tests of rigour in traditional scientific research and naturalistic inquiry that are useful when examining the similarities and the differences in qualitative and quantitative approaches: truth value, applicability, consistency, and neutrality. **Truth value** of a qualitative investigation is in the “discovery of human phenomena or experiences as they are lived and perceived by subjects, rather than in the verification of a priori conceptions of those experiences. Significantly, truth is subject-oriented rather than research defined” (Sandelowski, p. 30). My experience as a specialized oncology nurse gave me credibility going into this research. The truth of the study was enhanced by recognizing the forestructure (Chapter One, p. 6) that I brought to the research. Further, I demonstrated self awareness in the data analysis of this research with the use of a reflective journal. The truth value was represented by using a qualitative approach to gain the insights of young adults with cancer from their own perspectives.

Applicability of a qualitative study is often discussed by examining external validity and fittingness. As previously stated, Sandelowski (1986) brought forth that there are fewer threats to external validity in qualitative research than quantitative. She highlights the importance of studying phenomena in its natural setting without controlling variables. In my study, I gave the participants a setting of choice as their home or the Cancer Centre to support the natural setting. I attempted to develop a rapport with the participants as I encouraged them to share their experiences and I actively listened to their concerns. The details of our discussions were accurately documented and thoroughly analyzed. Throughout the data collection and analysis, I was consistently attempting to explore what was being said and to question what I was learning. Further, Sandelowski states, “sample sizes in qualitative research are typically small because of the large volume of verbal data that must be analyzed and because qualitative research tends to emphasize intensive and prolonged contacts with subjects” (Sandelowski, 1986, p. 31). My sample size of seven participants was small. However, it represented individuals from various socioeconomic backgrounds with different cancer types and treatment protocols for young adults with cancer. In-depth interviews provided extensive data that was rich in detail about the phenomenon of interest which was the needs of young adults with cancer.

A qualitative study is credible when it presents descriptions and interpretations of a human experience that the people having that experience would immediately recognize it and other researchers can recognize the experience when confronted with it after having only read about it in a study (Sandelowski, 1986, p. 31). My study was applicable and credible as two of the young adults that were involved in the interviews recognized and

supported the preliminary observations in terms of their own experiences. Further, an expert oncology nurse and oncology nurses at a national cancer nursing conference supported the findings as useful and relevant to their interactions with young adults with cancer.

Consistency of qualitative research is demonstrated by Lincoln and Guba's (1981) term *auditability* or when the study and its findings can be clearly followed by another researcher and another researcher could arrive at comparable conclusions based on the data collection. Another researcher could follow the progression of events in this study by reviewing my documentation in the research process. All transcripts have been checked for quality and my initial reactions have been kept with a personal journal. My initial observations and emerging themes were analyzed exhaustively and documented clearly in excel spreadsheets and word documents.

Neutrality refers to "the freedom from bias in the research process and product" (Sandelowski, 1986, p. 33) and Lincoln and Guba (1981) recommend that "confirmability be the criterion of neutrality in qualitative research. Confirmability is achieved when auditability, truth value, and applicability have been established" (Sandelowski, 1986, p. 33). Neutrality was demonstrated in this study through the disclosure of the elements of forestructure I brought to this research (Chapter One, p. 6), reflexivity (Chapter Three, p. 47), and accurate documentation of the research process. Also, I attempted to learn about the needs of young adults with cancer by empowering the participants to tell me about their cancer experience and their concerns. I asked the participants, questions about living with cancer (Appendix B), I listened to their concerns and documented them, and I sought out clarification with paraphrasing and probing questions periodically during our

interactions. In other words, in qualitative research there is an emphasis on the subjective rather than the objective experience and subjective reality of the findings support the neutrality of the study rather than the researcher's subjective or objective stance (Sandelowski, 1986).

There are philosophical stances that form the fundamentals of naturalistic inquiry according to Lincoln and Guba (1985), and such philosophical underpinnings guided this research study. They are:

1. There are multiple constructed realities that can be studied only holistically; inquiry into these multiple realities will inevitably diverge (each inquiry raises more questions than it answers) so that prediction and control are unlikely outcomes although some level of understanding (*verstehen*) can be achieved. (p. 37)
2. The inquirer and the "object" of inquiry interact to influence one another; knower and known are inseparable. (p. 37)
3. The naturalist prefers inductive (to deductive) data analysis because that process is more likely to identify the multiple realities to be found in those data. (p. 40)
4. The naturalist elects to allow the research design to emerge (flow, cascade, unfold) rather than to construct it preordinately (*a priori*) because it is inconceivable that enough could be known ahead of time about the many multiply realities to devise the design adequately; because what emerges as a function of the interaction between the inquirer and phenomenon is largely unpredictable in advance; because the inquirer cannot know sufficiently well the patterns of mutual shaping that are likely to exist; and because the various value systems involved (including the inquirer's own) interact in unpredictable ways to influence the outcome (p. 41).

Those who engage in interpretive description research share the above stated view and distinguish that *a priori* theory can not encompass these multiple realities.

Interpretive description researchers aim to derive theory that emerges from the clinical phenomenon of interest.

Ethical Considerations

The study met the approval of the University of Victoria's Human Research Ethics Board and the Cancer Centre Ethics Review Board. As an MN student principal investigator, I completed the ethics applications for review and finalization and submission by my thesis Supervisor, Dr. Virginia Hayes.

The recruitment process has been outlined in the sample/sampling section of this thesis. All participants were assured that their participation was voluntary and they were ensured of confidentiality both during data collection and reporting of results. An audio tape recorder was used. All data were stored on tapes and transcribed on a private lap top computer with security code password for access. The tape recorder and audiotapes were transported in a locked box. The data have been kept in a cabinet in a locked room when not being used. Demographic data about participants' ages, addresses, genders, occupations, cancer types, months since diagnosis, and types of treatment were obtained from each of the participants after the process of informed consent for study participation had occurred, and were kept separately from the data in a locked drawer in a private, locked office. This information was stored in the transported locked box for transport and in a cabinet in a locked room when not being used.

All data will be kept for five years after completion of the study and will then be destroyed in the confidential waste at the Cancer Centre. All audiotapes will be erased by me at the five year time point.

Summary of Methods

This chapter reviewed the design, sample, setting, data collection procedures, analysis, trustworthiness, and ethical considerations of the research into the needs of

young adults with cancer. Interpretive description was the most appropriate methodology to approach the subjective needs of young adults with cancer because it serves to advance nursing knowledge about a group of patients who have developmental supportive care concerns which have not been fully explored by nurses in the past. This study demonstrates **truth value, applicability, consistency, and neutrality**. The philosophical tenets of interpretive description led to the conceptualization that follows in the Findings Chapter.

CHAPTER FOUR:

I'VE GOT CANCER, *OH NO!*

The seven participants spoke intimately about their trials, challenges, and vulnerabilities of being young adults with cancer. They also shared their suggestions for how oncology care for young adults could be improved in the future. Using the process of interpretive description, I analyzed the participants' responses to answer the research question, "How do young adults aged 20 to 44 who are diagnosed with cancer and undergoing chemotherapy and/or radiation describe their needs?"

In this first section of this chapter, I introduce the participants and describe their ages, sexes, and current treatments. I also articulate the unique needs that each person identified. In the second section, I identify and discuss eight interpretive themes that arose from the data. Each of the themes highlights the multidimensional quality of life issues of young adults with cancer and provides critical insight into the needs of this group of individuals and their families.

Verbatim quotations from the interviews are used to illustrate and support each theme. Certain elements have been omitted to protect the participant's confidentiality, such as locations, names, genders, exact diagnoses, treatment regimens, and exact protocols. Names of the family members and health care providers have also been removed. All such omissions are denoted by square brackets. Some quotations have been edited slightly to ensure readability (e.g. excessive "ums", "likes", and other hesitations were removed) while preserving the participants' original meaning; editorial deletions are denoted by "...". Break-off dashes "—" are used when there was a pause between

thoughts. Italics are used to accentuate words that were emphasized by the participants, and [I] for Investigator.

Introduction to the Participants

Participants ranged in age from 23 to 43 years old and were living with various cancer diagnoses. The participants came from different families and social backgrounds. While the diagnosis of each specific participant has not been disclosed to help protect his/her privacy, they include Hodgkin's disease, melanoma, and testicular cancer. Each participant was undergoing treatment at the time of our interaction. Treatment regimens ranged from induction therapy to combination chemotherapy/radiation treatment to palliative chemotherapy. A profile of the participants is summarized below in Table 1.

Table 1

Profile of Participants

Participant	Age	Sex	Treatment at Time of Interview
#1	30	Female	Chemotherapy
#2	43	Female	Radiation
#3	36	Male	Radiation
#4	23	Male	Chemotherapy
#5	29	Male	Chemotherapy
#6	39	Female	Chemotherapy
#7	43	Male	Combination Chemotherapy/Radiation

Participant # 1 is a 30 year old female, who was undergoing chemotherapy treatment at the time of the interview, was passionate and energetic in sharing her story. She expressed her belief that a study about the needs of young adults with cancer is an important topic for investigation. This participant came to the interview in a wheelchair assisted by a family member and sat in a comfortable position on a couch with her legs stretched out on the couch, using her hands occasionally. She described the time of cancer diagnosis:

Basically I went from feeling tired to being on chemo and [laugh] half dead. They said it usually takes six to eight weeks to run its course and I had been *feeling bad* for about four weeks already so I was *really* close. If I hadn't caught it then, I might have been in some more trouble.

She became tearful at times and took short breaks at various times of the interview to use a tissue and to take sips of water. This participant shared with me the challenges of being a young adult with a rare cancer and her fear of facing a potentially life threatening illness. She discussed managing the many roles in her life such as being a mother, a wife, and a daughter. She spoke of the shock of the initial diagnosis, prolonged hospitalizations, loss of mobility, risk of her own death, concern for the adjustment and well-being of her children, concern for maintaining her relationship with her partner, financial pressures, the need for strong family support, the caring presence of nurses, and the trusting reciprocal relationship she shares with her primary care physician. A second interview was conducted with this participant to clarify and validate the emerging interpretive themes gleaned from the first interview.

Participant # 2 is 43 year old female who was undergoing radiation treatment at the time of the interview. She sat upright in a chair across from me. She had just come from one of her radiation treatments and required frequent sips of water to moisten her

mouth during the interview and her voice had low volume. She used her hands to emphasize topics of importance and she readily made eye contact with me. She initiated our conversation with the following statement:

I think for me, the emotional part is *quite challenging*....and also...
I find you are immersed in the treatment, you [are] kind of...holding on
your life...It's very *hard* to be that way and...also, one day I find that if
anyone tries to help us, *I feel isolated*.

[I]: Isolated, yeah.

And that could be...I think, could be looked at. And I could...feel like...a
small, small object.

Feelings of social isolation and the need for practical support with issues of daily life such as meal preparation and transportation for children in post-secondary education were revealed. Also, she talked about coping with cancer as a single parent and being a great distance from her immediate family. She shared her experience as a parent and how she decided to take a break from her career to complete her treatment. This participant experienced difficulties with peripheral intravenous access and tolerating chemotherapy agents. Also, she expressed great concern for the survivorship period following completion of active treatment for her disease. The risk of death and her views on euthanasia and being supported in her treatment decisions by the health care team were key issues as well. As such, she detailed concerns about dealing with a potentially life threatening illness and spoke at length about strong trusting relationships with health care providers as well as disappointing relationships in which she did not feel her individualized concerns were addressed. She was very forthright and talked about her cancer experience with openness and honesty, saying that it was her hope others might learn from her journey. A second interview by telephone with this participant was

conducted to clarify the themes that were described in the first interview and the participant concurred with the interpretive themes that emerged from the first interview.

Participant #3 is a 36 year old male, who was receiving radiation treatment at the time of the interview. This participant spoke with ease and sat upright in a chair during the interview, using hand gestures when appropriate to emphasize issues of importance to him. He demonstrated confidence in the way he entered the room and how he remained engaged in the conversation throughout the interview. He described what it was like to be told he had cancer:

Well, being told you got cancer really...*,bothers you, basically.*
Because...as a normal person that doesn't have any medical background, *cancer is cancer.* It's death, right? So, you know, when they told me I had that and I had to have [treatment], it was just like *go, go, go.* And there was no real communicating. They didn't tell me...at first they didn't tell me it was *bad.* *They didn't.* It took them so long to come back with the biopsy and tell me if I had it or if I didn't and what to expect further down, if it's going to come back or anything like that or...what I'm looking at.

This participant came to the interview with an eagerness to share his cancer experience. He expressed some of the positive aspects of the care he had received as well as articulating some areas for improvement in the pre-diagnostic aspect of his cancer illness. He spoke about how he lived through serious complications and common side effects of treatment. Fatigue was a focus for him and how it had impacted his daily life, and he articulated concerns for the well-being and adjustment of his children, his financial worries, and his need for support during the survivorship period. He also shared his thoughts about the important role of nurses in addressing concerns about symptoms and as educators about treatment follow-up care. This participant also expressed an interest in getting involved and leading peer support groups for young adults with cancers if they were initiated.

Participant # 4 is a 23 year old male, who came to the interview and sat upright in a chair as he shared his cancer experience with me. He appeared comfortable talking with me and occasionally crossed his foot on his planted leg. I noted that he was sweating intermittently during our interaction. He used a handkerchief to wipe his brow throughout the interaction. This participant made eye contact with me and demonstrated animation (such as with facial expression and, hand gestures) to emphasize important issues. He was tearful at times, would break for short periods and then continue to describe his needs. He was undergoing chemotherapy treatment at the time of the interview and he shared his experience of being diagnosed with cancer:

Being told you have *cancer* at the age of 22...it's kind of...I think [a] blow to you...You know me and my wife had just been married a year, *just over a year*, at that point. So...it was all these kind of shocks coming at you...I mean I had no indication or anything else that it was coming. The only thing that was happening was it was a Sunday night...I was supposed to start work at 9 o'clock the next morning. And we were watching a movie and I got a pain in my left hip and kind of thought it was...you know, just a muscle or something. It got *worse and worse. Excruciating pain*. I went to [name of hospital] and...10 hours later they told me that, you know, they either thought I had...a severe infection or cancer...[names his cancer diagnosis]. But... he believed that it was [name of diagnosis] because there wasn't other...things to show that it was just an infection, *you know*. So I mean it [was] just,...a matter of hours.... I mean, it's a weekend...Sunday night, enjoying a movie and then a pain in your hip and *that's it*.

This participant discussed all aspects of his life since the cancer diagnosis openly with me. Worries for the future and his challenges with pain, nausea, and loss of mobility during the treatment phase of his illness were revealed. Key concerns included a need for greater informational support for rare types of cancer, feelings of social isolation, a challenging emotional response to the illness with decreased self-esteem, and feelings of sadness. Difficulty coping with altered role functioning, and financial concerns as he

experienced them were brought forth, and he emphasized a need for strong spousal support. He identified his strong faith as a support system for him during his cancer experience. He further spoke about the importance of having a trusting relationship with one's primary care physician and the significance of receiving timely medical care. We talked about nursing, and in his opinion, nurses can make a difference in an individual's cancer journey by being present and answering questions with up-to-date, relevant information pertaining to the disease process and treatment options. He indicated that he would be interested in starting a support group for young adults specific to the cancer with which he was diagnosed.

Participant #5 is a 29 year old male, who was undergoing chemotherapy treatment at the time of the interview. He came to the interview with his mother and requested that she remain present, suggesting that she could contribute significantly to what I wanted to know. I agreed. He sat upright across from me on the couch during our interview and he appeared tense. He displayed a resting hand tremor at times and often avoided eye contact with me. This participant did express that he was interested in contributing to the research as he felt the needs of young adults with cancer was an important topic for discussion. His mother sat comfortably beside him and spoke frequently, using hand gestures to accentuate points of interest. She appeared more relaxed than her son during the interview and leaned towards me during the conversation. She engaged in the conversation and shared her feelings on issues faced by young adults with cancer with an emphasis on the unique circumstances surrounding her son's illness. She would pause and look attentively at her son when he spoke, often nodding her head in agreement. He talked about his cancer diagnosis:

At first it was kind of *hard*, and then [I] kind of accepted eventually, and then...I don't know. At the beginning it was hard and then [it] kind of gets easier with family. Later on it gets a bit easier because you kind of accept it. There's *nothing* you can really change about it.

The difficult circumstances he faced with a cancer diagnosis as well as a pre-existing mental health concern were revealed. He disclosed the difficulties of being a young adult with cancer, namely trying to establish an independent life, an occupation, and leisure interests. Financial concerns and how he would not be able to pay his bills and buy food without government social assistance and family support were brought forth. The debilitating side effects of the disease and treatment, including fatigue and breathlessness and how they impacted his life were concerns for him. Also, this participant discussed being aware that his illness had caused much worry for his family members and expressed his feelings of social isolation and need for greater peer support. The importance of continuity of care and the integration of personalized care plans for young adults facing complex issues at the time of a cancer diagnosis was important to him. Also, he described how nurses had made a difference in his cancer experience by treating him as a person and addressing his unique health issues.

Participant #6 is a 39 year old woman, who expressed a keen interest in sharing her cancer experience, and voiced her support for the notion that greater research is needed to examine the needs of young adults with cancer. She sat upright across from me in a living room style environment and spoke confidentially using hand gestures. The interview began with her sharing pictures of her family with me. She appeared comfortable and at ease with our interactions. She told the story of her diagnosis in a family context and described how she lost her business clients at the time of her cancer diagnosis:

The day before we were leaving for [vacation destination]...that's when they told us...that it was [disease] and it was pretty severe because they feel that it had already spread through the body and they don't know to what extent and *so on and so on*. So my husband and I, we didn't tell anyone when we went to [vacation destination] and it was the best trip we [ever] had...I knew this was going to be worse than we were thinking...We came back from [destination] and they cancelled [my services] so I knew that...this was going to be worse than we...had anticipated.

Participant # 6 spoke of her altered roles in her life since her diagnosis of cancer. She verbalized a strong need for child care support and assistance with domestic duties. She talked about the side effects of treatment, such as fatigue, fever, nausea, and vomiting. She shared her feelings of anxiety and worry about the possibility of her death and how her partner would manage being a single parent and the primary breadwinner. She discussed her inner strength and membership in a faith community, both of which have helped her to cope with cancer as a young adult. She stated it was important to her to have continuity of care and a team of expert professionals to consult. She also highlighted the importance of the humanistic element of nursing and how she valued being treated with dignity and respect. She is eager to learn the outcomes of my research and her belief that she felt it would be a huge challenge for me to conceptualize the many issues faced by young adults with cancer.

Participant # 7 is a 43 year old male, who was undergoing chemotherapy and radiation at the time of the interview. He came to the interview with his partner and asked that she be able to participate when possible since she is one of his main sources of support. The couple sat in a comfortable upright position beside each other on the couch, across from me. He described his diagnosis as, "Devastating, that's for sure, it was very devastating. It was just...a chapter you never want to refer to....Very emotional for

myself.” He went on to describe the uncertainty that he lives with each day and his fears that he might die. He said he was worried that he might not be alive to see important milestones in his children’s lives. He expressed appreciation for the caring relationships he has established with members of health care team.

The participant spoke about how important it was for him to have information about his disease, such as the treatment expectations and the goals of his treatment. He talked about the idea of hope as a theme that assisted him and his family coping with the diagnosis of cancer. He reviewed how his social and occupational relationships with colleagues had changed and how it was difficult to talk to his peers about his diagnosis. He described difficulty expressing his emotions openly, due to a societal norm that men be stoic and not to share their feelings. He also talked about delays in securing government support when he was too sick to continue working. There were periods during the interaction when he cried and we needed to stop the conversation before continuing. Throughout the conversation, he was supported verbally by me and by caring hand holding and expressed empathy by his wife.

Interpretive Description as Themes

All of the participants were open and willing to talk about what it is like to be a young adult with cancer, and how being in the age 20 to 44 age group brings added socioeconomic challenges. Each participant’s background, social status, and personal struggle influenced his/her cancer experience in a unique way. However, all expressed similar feelings of shock, disbelief and unfairness, as well as altered coping styles. Analysis of the interview data revealed a number of common patterns and eight interpretive themes: (i) *It Is Hard Being a Parent with Cancer*; (ii) *Symptom*

Management Is a Challenge; (iii) Social Support is Imperative; (iv) Information Access is Essential; (v) Fear of Recurrence and Mortality; (vi) Trusting Relationships with Health Care Professionals Make a Difference; (vii) Financial Worries, and (viii) Follow-Up Care. The eight interpretive themes are presented in the balance of this chapter. Each one encompassed sub-themes which represent common characteristics and contextual meanings with the theme but have distinctive features that bring them within the named theme or a sub-grouping (Lincoln & Guba, 1985).

(i) *It Is Hard Being a Parent with Cancer*

Five of the seven participants are parents of children ages 1 to 22 and spoke at length about a need for greater support for children at the time their parents are diagnosed with cancer. The participants talked about being ill-equipped to discuss the meaning of the cancer diagnosis with their children and difficulty in arranging childcare so they could adhere to their treatment regimens. They expressed concerns for their own future well-being and who would take care of their children if they died. Sub-themes of altered adjustment for children, issues of child care, changing roles and responsibilities within the family, risk of genetic predisposition to the cancer, and difficulties in family planning are part of this theme. One participant stated:

My daughter was, *just* turned one on [birthdate] so she wasn't even walking yet. She was a baby...[laugh] but she wasn't even walking yet and I don't think to this day she remembers me being healthy. I think her only memory of me is being like this. So, whereas my son, he notices... "*Oh mommy your hair is starting to come back,*" or he notices little changes in me, which is really good so...And now that we have the consistency of my parents basically living with us during the week so that my husband can work and she can look after the kids...Now that we have that in place, my son has gone back to normal [laugh]. I think he's gone back to normal.

This statement represents the feelings of guilt that a young mother lives with as she interacts with her children and realizes that they do not know her as healthy and energetic like she was prior to her illness. It is about being different and how her children have had to adjust to their mother's illness. Her concerns in relation to not having the strength and the endurance to keep up with her children were brought forth along with her need for child care and her family solution of having extended family live with her to assist with her decreased ability to perform parenting responsibilities during the treatment phase of her illness. She disclosed that there were changes in her children's behaviour and that the impact of cancer is difficult for them. She suggested that the role of community volunteers is an essential component to maintaining the children's routines. She went on to describe a dedicated reliable volunteer who is considered a part of her family and comes to the home once a week to play with her son and provide caregiver support for this participant and her mother. She expressed how she felt this was a valuable component to her son's growth and development and someone he looked forward to spending time with each week.

Another participant spoke at length about sharing her parenting role with others in her support community. She articulated the importance of involving young children in the caregiving when a parent has cancer and answering their questions and concerns about the illness. She shared her concerns for future generations of children in regards to the risk of cancer due to environmental exposures. She spoke about the importance of health promotion to teach children about cancer prevention and screening. Further, she had learned to delegate and to coordinate care for the safety and well-being of her children.

Keeping their children safe and secure was a theme that was discussed by many of the participants. Another parent expressed his concern for his children in the following way:

You know, I got two young kids at home... and I'm the one that's leading them on their way. And I know *if I'm gone*....That was *my main concern, my kids*....I don't really care about myself, I care about being healthy for my kids.

This individual is speaking about his love for his children and his concern for their well-being if he were to die. He also discussed changing responsibilities in his home, and his children taking on greater responsibilities with the management of the household during his illness. Although child care was not a significant issue for him due to the age of his children, he felt it would be relevant for many young adults.

Another participant also did not identify child care as a predominant issue, most likely related to her children being teenagers. Instead, she talked about wanting to maintain a level of normalcy in the home and to have her children perceive her as healthy. She expressed concern for her future in the event that she would get sick and be incapacitated in some way. She spoke about protecting her children from her illness and the potential that she might get sicker one day; specifically, she disclosed not wanting her care requirements to be a burden to her children. This view was shared by another participant with teenage children, who talked about how he wished that there was greater support in place for school-age and teenage children who want to know as much as they can about their parents' illnesses. He said his children wanted concrete examples of how they could help during the illness, and what to expect.

In comparison, another participant, who was not a parent at the time of interview, expressed concern about the genetic risk of passing on a malignancy if he were to have

children. He had a strong desire to have children but was worried about being able to provide for them financially, emotionally, and socially:

I think that's one of the scary things with the medication...having the children, you know. Because we've been told that we can...probably [have children]...But then there's also fear of: well, am I going to pass it onto my child, you know? Are they going to end up being sick?...or is the [treatment] or the whole...all the medications that I'm on....Is one of those medications going to do something to my child?

Thus, the interpretive theme *It Is Hard Being a Parent with Cancer* arose from data from six of the seven participants. Each expressed issues unique to the developmental stage of his/her family and specific individualized concerns are grouped according to the following sub-themes: altered adjustment for school age children, issues of child care, changing roles and responsibilities within the family, the risk of genetic predisposition for cancer among offspring and difficulties in future family planning.

(ii) *Symptom Management Is a Challenge*

All of the participants spoke at length about the changes they had experienced in their bodies since the time of their cancer diagnoses. They discussed the physical signs of the cancer and the symptoms related to complex chemotherapy and/or radiation treatments. They also spoke about how physical signs and symptoms directly impacted their daily living and how they have learned to cope with the changes in their bodies. Sub-groupings of this theme included the difficulties of managing pain, breathlessness, mucositis, nausea/vomiting, weight loss, fatigue, alopecia, risk of infection, loss of mobility, the use of exercise as rehabilitation and changes in sexual desire. One participant stated:

The [treatment] was *heavy* to begin with, the first round of chemo. And that was about a month and a half in the hospital and then I kept having complications, different infections and rashes and things like that. So I

ended up actually being in the hospital for three months where I lost basically most of my mobility. I'm still in a wheelchair for long distances. I can walk...I can get around my house and stuff like that and can walk short distances, but not long distances, so that's been difficult.

This participant was explaining the challenge of feeling physically unwell and how her decreased energy levels from both the cancer and the treatment impacted her ability to spend time with her family. She detailed the specific side effects associated with her cancer treatments including pain, mouth sores, weight loss, hair loss, infection, and loss of mobility. She sought ways to cope with these side effects by means such as collaborating with her physician to change her medication regimen and changing her diet to accommodate the mouth sores. It was evident through our discussion that she believed that exercise was important as rehabilitation for those that experienced weakness from prolonged hospitalizations. She also talked about cancer rehabilitation and a need to educate health care professionals about the long term prognosis of young adults with cancer.

Another participant also experienced fatigue and decreased energy levels during the treatment period for her cancer. She spoke about a personal responsibility to eat well, rest, and exercise. She recounted difficult times in the treatment phase of her illness in relation to difficult intravenous access and administration of chemotherapy.

A third participant had experienced difficulties with bleeding complications. He spoke about pain, fatigue, and changes in activity levels:

I'm tired some days. I have to have naps. I feel like an old man or a young kid again. I have my afternoon nap. So I have to work on that and...get my endurance built up because I've got to go back to work in a week.

He indicated that keeping active and maintaining a positive outlook were positive coping strategies that worked for him.

Three other participants discussed the symptoms of breathlessness, pain, fatigue, risk of infection, and decreased mobility and the impact of these symptoms on their daily activities. In expanding on these, the data reveals participants' coping strategies of activity pacing, rest, and small amounts of exercise. One of the three participants indicated his body image had altered since his cancer diagnosis. He highlighted the importance of exercise as rehabilitation. He had feelings of the decreased self esteem that were associated with the use of his walker. One unique element of this individual's discussion pertained to the effect of his decreased energy levels on his interest in sexual activity and intimacy:

The other thing is...being well enough or...feeling well enough...You know, you would try to be intimate...you know, because when you're sick and things like that...you just...you really don't want to be intimate with your partner.

The theme *Symptom Management is a Challenge* is about physical well-being and treatment related symptoms and it was supported in some way by every single informant in this study. Individual concerns associated with this theme are represented by sub-themes of pain, breathlessness, mucositis, nausea/vomiting, weight loss, fatigue, alopecia, risk of infection, loss of mobility, using exercise as rehabilitation, and changes in sexual desire.

(iii) *Social Support is Imperative*

All seven participants discussed the importance of the family and social support that they received during their cancer journeys. They spoke about spousal and parental support, and how their friends and members of their faith communities offered assistance with the practical issues of daily living. Participants recalled being so involved with their treatment regimens that they did not have time to socialize and to maintain their pre-

existing friendships. Sub-groupings of parental assistance, spousal support, changes in social relationships and feelings of isolation are part of this theme.

One participant said that she had benefited from having her parents move in with her family to assist with child care and transportation to appointments. Another woman also spoke about social support in relation to household management and child care. A few participants indicated that their relationships with their significant others changed once they were diagnosed with cancer. Social activities such as entertaining and going out were considered difficult. One participant said:

Oh my gosh, I have *no social life* [laugh]. At least, not much of one...because I can't go out. Basically, if I want to visit with my friends, they have to come over to my place because it's just that much easier for something like that.

It is critically important for young adults to maintain relationships with friends when they are faced with life-threatening illnesses. This participant went on to discuss with me her need to connect with other young adults facing cancer. Although another participant described himself to be a private person who did not want to share his health concerns with his social supports, once his friends became aware that he had cancer, he realized that they were able to assist him with child care and offer emotional support. He stated:

Well once...it had leaked out...Basically, people found out, they were calling and...brought people closer and that. I'm a quiet bird, I keep things to myself, you know. I'm stubborn so I like to do things myself and I don't like hand outs. A lot of my friends, close friends, they came close.

He discussed feeling alone, particularly during periods of intense treatment. Another participant explained that it was difficult to know what to say to friends and employers at the time of a cancer diagnosis. This individual suggested that practical advice from health care providers about how to talk to one's friends about cancer would be beneficial. Such

support could be offered by an oncology nurse through counseling or the development of an information booklet or internet based web-page on “How to talk to others about cancer”.

In comparison, another individual spoke about being a single parent and not having close family in Canada to support her through her cancer experience. She identified work colleagues as her support system. She emphasized the importance of being offered their assistance, such as grocery coupons and help with transportation. She indicated it would be helpful to connect with others in a similar situation as her own:

In this case maybe because I have not much family here, for me it's more than that.

[I: Ummhmm.]

I think we should have *group therapy*...we go through cancer...even cancer of a certain type.

[I: Ummhmm.]

Because...I think you learn more from other people who have already had it.

Another participant explored how the illness impacted his entire family and also indicated that he would value being involved with a group of peers who had lived with a cancer diagnosis:

It's good to...have someone that you can relate to, that *you know* they're going through the same thing, and then you know you can talk and...*it makes you feel better as well, right?*

This participant also spoke of his feelings of social isolation. Another participant described an incident in which he was socially stigmatized when he was out in public:

I went to [store name] and I had to use the washroom. And as I was going to the washroom there was these two guys coming out. They were probably in their mid twenties and *they pointed and laughed at me*...I couldn't hear what they were saying but I could see them they were pointing and laughing at me and looking back and laughing and things like that.

Feelings of being different and experiencing more than one should have to at a young age came up in the data. Many of the participants felt that there was a need to educate the public better about cancer. They felt this would foster transitions back into everyday life after treatment. Another individual lived at a distance from his immediate family. He noted how significant his relationship with his partner is and how it helped him cope through his cancer journey. He stated, “For me and my wife, it brought us very close together, you know.... It’s one of those things I think that will make you or break you”. Most of the participants articulated the need to surround themselves with people who cared and respected them for overcoming huge challenges of the cancer journey to be satisfied with their lives.

Two of the participants talked about their involvement in strong faith communities as a sense of social support that facilitated effective coping. Inner strength, belief in God, and devoted support of their community are sources of enhanced coping. It is evident that social support will be unique to the individual. However, some degree of social support is necessary to foster adjustment to cancer illness. More specific sub-themes that arose as part of this theme include parental assistance, spousal support, changes in social relationships, and feelings of isolation.

(iv) Information Access is Essential

Participants verbalized a keen interest in learning more about their diseases, the physiologic processes of cancer, proposed treatments, chance of cure, and anticipated side effects. As previously highlighted, some of the participants indicated that it would have been helpful to connect with others who have lived through the same diseases and treatment protocols. I have named the

sub-themes of this theme: lack of relevant information related to specific diseases, the importance of knowledge as power, a need for individualized education, how celebrity status promotes certain diseases, and the need to increase public awareness of specific cancers.

One participant talked about the consequences of not having access to relevant, up-to-date information to prepare for the side effects of treatment:

I know for breast cancer there is a ton of stuff out there, a ton of stuff, and there is absolutely nothing for [disease] and I was...*Actually*, I found with [my disease]...on a website, and what, maybe a month ago...*A pamphlet, a booklet, whatever, you know: what to expect with this treatment protocol...*What to expect. Because I didn't know what to expect. I thought, you know, most people that have cancer come in once every three weeks or six weeks to get chemo, as far as I know, and they get chemo every three weeks and that's it. *Well*, I didn't know that I was going to be needing chemo every single day and heavy chemo at that, while I was in the hospital to bring down my neutrophils to wipe out my white count and then have to get so sick after...I knew that, but I mean it would have been just nice to know.

The participant emphasized the need to have information specific to one's disease in order to "arm herself", to assist with coping . Many also felt that information should be customized to the needs of young adults as a specialized population such as: family centered approaches to treatment discussions; including children in play therapy to understand a parent's diagnosis; relevant computer accessible information about the disease and treatment; and peer support of others living with cancer. Indeed, one participant said that access to reputable information at the time of diagnosis is essential to plan one's life. He also articulated a need for greater public awareness about the many different forms of cancer that can occur in young adults. He pointed out that when a celebrity is diagnosed with a cancer, that particular cancer gains public awareness and support:

Another big thing... just an awareness of, you know, the different types of cancer and things.... We had never heard of [my disease]... I've had even people... say... "Oh there's no such thing as [names of disease]". So they'll argue with me that I didn't have this... disease... when we knew we had it. One thing that's really frustrating to ... me and my wife, and we've noticed since I've gotten sick, is that... the two big cancers... [that] are always supported and mentioned is breast cancer and prostate cancer and... *It's not that I'm trying to... demean those things* or anything, but it's frustrating.... Because everything is, "Support breast cancer, support breast cancer" or... Gillette has support[ed] prostate cancer. When it comes to other things it's.... What about the support the funding or, you know, the backing for these other types of things?... Having cancer and seeing these things, it's like, oh wow, I guess my type of cancer is not that important...., Then again, you know, it's probably just a small thing, but you know when you're sick and stuff and you're seeing these things, it's always... *breast cancer, breast cancer, breast cancer*. It's kind of like, you know, I guess mine's not that big or... that I'm not that important type thing.

Frustration with a lack of information and public awareness of his exact diagnosis were apparent. Further discussion revolved around the participant's needs for himself and other young adults to have a better understanding the disease process, the expected side effects of treatment, and the follow-up care for their specific cancers. This individual recognized how increased knowledge can empower one to face the unexpected trials of the illness.

Another participant was frustrated with the lack of informational support he received at the time of his diagnosis. He experienced anxiety and fear when he did not know the type of cancer he was facing and the possibilities for treatment. He suggested that the young adults would prefer Internet based and written information to take away from appointments for future reference.

In comparison, another participant described the positive impact of having received pertinent information prior to her treatment. She stressed the importance of truth telling by health care professionals and voiced a need to know the expectations within the course of her treatment regimen.

I went to a workshop....

[I: Yes.]

And the lady who did the workshop was...actually professional and *also competent...*, so *she knew what she was talking about*. So when I went to hospital and I went to treatment I knew what to expect. And for me, I need to know—Some people they don't need to know, and I need to know.

But I do think they should give concrete answers all the time. They do not need to go into the details, but I think of myself, and so I [knew] there was something wrong with my body.

[I: Yes.]

But...I think of this—you know what I mean.

[I: Yeah.]

Of course, I do not know exactly what the physicians talk [about], but I know they talk me through it.

[I: Yes, yes.]

Kind of have a roadmap. But we don't need to somehow... Maybe it's my age, I don't know, because *maybe when you are older you don't want to know...* When I got diagnosed I already knew... I want to know how many chances I have to make it.

She brought forth relevant ideas about education for young adults with cancer. Oncology care providers to might ponder the topic of patient navigation with a goal of improving support for the patient on the next steps in his/her cancer journey.

A family member of another participant spoke about the importance of setting up meetings with the primary care team to review disease progression, life expectancy, and further treatment options. She felt that it was beneficial to have someone else present when medical information is given, because this provides an extra pair of ears when treatment options are presented. It is important for oncology care providers to consider how to facilitate the best presentation of information to guide informed decision-making in young adults with cancer.

In contrast to the other participants, one individual did not speak directly about a need for greater access to information at the time of her diagnosis. Rather, she felt there

was a need for increased knowledge and public awareness of cancer prevention and early detection. This encompasses information access for the public. Thus, the theme Information Access is Essential incorporates the importance of finding the right time to exchange knowledge for young adults so they can better understand the specific cancer they are living with through communication, education, and accessibility of resources.

(v) *Fear of Recurrence and Mortality*

All of the participants expressed worry and concern about their own future well-being. Each participant revealed that his/her life had been changed forever since the diagnosis of cancer and that he/she experienced constant preoccupation with the notion that the cancer could lead to death. Sub-themes of this theme include the intense emotional response to dealing with a cancer diagnosis at a young age, the fear of recurrence and dealing with one's possible mortality, inner resilience as a coping strategy, and the need to maintain hope. The emotional and physical suffering at the time of the cancer diagnosis, including at least one of the feelings of denial, anger, despair, sadness and anxiety about their illnesses and the concern that they might die was shared by all. One participant stated:

So there's a big fear of...how long do I have?...How long do I have to spend with my [partner]? How long do I have to spend with my family? And things like that...And that fear...creates a whole new way of life. [It] just, it changes how you think about things, how you do things, you know.

I mentioned before...depression and stuff. I went into...crying every night... You're just so...feeling sorry for yourself. But it's also...your whole world's changed...and we're creatures of habit, we don't want to change.

Another participant spoke about his fear of dying and what that would mean for his children:

I just didn't want to die, right?...[I] had friends that died from cancer and it's brutal....So you don't know until they...tell you. Like it's curable, this and that. They give you hope right, but before that... you go, "I've got cancer, oh no!"...I didn't mind [operation], that's no problem. I've got my two kids....But it's just too young to die, basically.

All of the participants who were parents were concerned about the well-being of their children should they die. There is an overlap of some of the interpretive themes in relation the data about parenting, social support, and the uncertainty of one's existence. Many of the participants mentioned that young adults with cancer often have children who are still totally dependent on them. As a result, young parents with cancer are suddenly faced with the question: Who do I want to take care of my children if I am unable? One young woman strongly desired to have a back-up plan for a nanny to assist her family in the event she was incapacitated. Another participant recalled the time of initial diagnosis and his belief that he would never get to see important milestones in his children's lives, such as obtaining their drivers licenses', graduations, and marriages.

Many of the participants expressed concerns surrounding the risk of recurrent disease. Living with the worry of the disease returning and incapacitation from advanced illness was a pre-occupation that prevailed in the thoughts shared by the participants. One individual eloquently stated, "Cancer is—... I don't think there will be an end of the story somehow." Some of the participants talked about their world views with concerns that their time to live might be limited. Coping with uncertainty to the best of their abilities was verbalized throughout all of the interactions.

Six of the seven participants spoke of having inner resilience and deep inner strength to fight their cancer. One participant stated:

Uncertainty—I just do [laugh]. I mean, what can I do? I mean, my life is in the hands of my doctors. They're doing a great job. So far I've been in

remission almost a year now. So...I can't complain about anything they've done, by any means....You just do. You do what you have to.

Another young woman disclosed her high chance of cure from her disease. She went on to state, however, that uncertainty always underlies a cancer diagnosis and how inner strength is important. She said, "It doesn't change the fact that you choose how you react sometimes." Exploring inner strength and resilience will bring greater understanding to how clinicians can use such sub-themes to gain a better understanding of the illness experience for patients and their families. Resilience of a person is defined as, "being able to withstand or recover quickly from difficult conditions" (Soanes & Stevenson, 2005). Resilience was identified as a coping mechanism for dealing with the fear of recurrence and mortality by all of the participants.

A number of participants shared their thoughts about hope, some through a discussion of their faith affiliations. Others shared the importance of being future oriented in their personal belief system as a means of fostering their goals to beat their cancers. One participant and his wife recalled how they waited each time they met with his health care team to hear pertinent information that would provide them with hope that the cancer could be cured: "It would be nice to know...a little bit of hope. Right from the get-go because right away you hear cancer, that's it, right?"

With each participant discussing his/her concern about cancer recurrence, *Fear of Recurrence and Mortality* constitutes an important need for young adults with cancer. The sub-groupings of this theme include the intense emotional response to dealing with a cancer diagnosis at a young age, the fear of recurrence and dealing with one's own possible mortality, inner resilience as coping strategy, and the need to maintain hope.

(vi) *Trusting Relationships with Health Care Professionals Make a Difference*

This interpretive theme was an instrumental aspect of the cancer journey as described by these young adults with cancer. Individual participants reported positive interactions that occurred with oncology care providers that promoted their healing processes. Some participants also identified gaps in the delivery of care and ideas for improvement to care delivery. Sub-themes include the need to be supported in one's decisions in relation to treatment and end of life issues, the significance of continuity of care, and a need for an oncology nurse to provide personalized care within a complex health care system.

All of the participants remarked on how they appreciated continuity of care and the opportunity to build trusting relationships with the members of the health care team. One participant has a trusting relationship with her primary care professional and was able to make necessary changes to her treatment plan when she experienced debilitating side effects with her initial treatments:

It makes a *big difference*. I think if I had a doctor that wasn't as nice as mine, it would make it a lot harder on me. She's very supportive and would listen to what I would tell her and how I'm feeling. We've switched medications around and she actually listens to me when I was telling her that...this medication is making me feel like crap [laugh].

Similarly, other participants expressed the benefits of having health care professionals who listened and supported them in the treatment decisions they made. Participants discussed being faced with many difficult decisions and advanced care planning. Numerous examples of the importance of humanistic care by health care professionals appear in these data. One participant stated, "Sometimes you want the right to live with dignity." This type of statement was also articulated by other participants

who shared their views about how individuals with cancer want to be treated as people, not as diseases. One of the participants contrasted his experience interacting with professionals at two different oncology centers. He recognized how his social needs were better addressed at one centre in comparison to the other. He preferred to be treated like a human being with important social concerns, not like a number.

Another participant identified a gap in service related to access to specialist care during the pre-diagnostic phase of his illness. All of the participants emphasized how essential it is that young adults with cancer have prompt medical care by a team of experts. This care should be coordinated and consistent. Participants talked about how when a young adult is sick, there is a sense of urgency to fix their illness by many people in society. This sense of urgency was discussed by all of the participants with an emphasis that health care providers need to act promptly to offer the best possible chance at prolonged life and cure from the disease.

Accordingly, the role of oncology nurses as navigators and clinical experts was brought forth by all of the participants. One participant described caring interactions she had engaged in with oncology nurses and how they encouraged her to mobilize her coping strategies as a parent. She gave the following example:

And so you kind of get close to those nurses and they just said, “*Take the time.*” You may be stuck on the couch but at least you can take the time and enjoy your kids. You know, you can sit on the couch, you can play games with them, you can do stuff like this”, and [I] said, “You know what, you’re right.” And *after that things did change.* [I] started to do a lot more with my kids, and paying a lot more attention to them and not worrying so much that I’m going to hurt myself, or hurt— Something like that. Because it is kind of at that point, I mean, that was probably a good six months ago that, that was said to me. So and, at that point I was still afraid of getting hurt or having them jump on me and cause pain. And now it’s like, *you know what, it’ll go away* [laugh].

This example provides a clear representation of how oncology nurses offer holistic care to include the family as a core element of an individual's life and well-being. The nurses were sensitive to this young woman's role as a mother and her fears as a patient. Positive coping strategies of play therapy and spending quality time with her children were mutually negotiated as the nurses brought suggestions to the patient and she decided to use them in her every day interactions with her children. The patient expressed that this fostered effective coping for her and her family.

Another participant felt that a caring presence is a key component of high quality nursing care:

This nurse came in and she was younger.... She was... *just so caring and so supportive*. And...she sat down and...even when other nurses were calling her...she would say "Just a sec"... because she was there talking to me.... Talking to me through what was going to happen and stuff like that because I was alone. My wife was home getting my clothes and stuff like that.... Any question I had. And she...she could tell I was upset and things like that... There was nothing she could say to make it better or anything but...she was really comforting you know... She was just there...*was genuine*. You knew she wasn't one of those nurses who was just in it for the money. She was actually there because she cared and she wanted to help.

Another participant highlighted some of the positive aspects of being connected with an oncology nurse during the cancer experience. He discussed the value of having access to a knowledgeable professional and being treated with respect when health concerns arose. Specifically, he talked about working with home care nurses to learn his own self-care. He also felt reassured to have a contact number for an oncology nurse for counseling and support in the follow up phase of his illness. Another participant also felt that the oncology nurses looked out for her best interests and attempted to coordinate her care to

suit her needs as a mother. She gave an example of a community nurse who initiated play therapy with her children when coming into the home to provide dressing changes.

In comparison, one participant opened up and honestly described a time when she felt her individualized concerns were not addressed by oncology nurses. She identified the workload of nurses and the use of technology as barriers to personalized care. This same individual also experienced positive interactions with her nurses and suggested oncology nurses are the most appropriate members of the health care team to engage in follow-up care for young adults with cancer. It is evident that it is important for nurses to combine their expertise in technical skills with true listening to patients and addressing psychosocial and follow-up concerns to bring about improved quality of care.

All of the participants talked about entering a new world of medical language, multiple diagnostic tests, and complex medication regimens after receiving their diagnoses. They felt nurses were key team leaders who assisted them with understanding the intricate elements of the health care system. This established an element of trust and security that the health care team would assist them as they transitioned through various phases of their illness.

In this way, the theme *Trusting Relationships with Health Care Professionals Make a Difference* is a critical component of the cancer experience for young adults with cancer. Some of the participants offered their unique perspectives for areas of improvement in the health care system. Many also discussed the positive aspects of the care they received as young adults with cancer. The importance of being supported by one's health care team was a relevant theme from my interpretation of all of the participants' interviews. This included at the time that the treatment regimen was decided

and when modifications were needed. For one young man, this was when the goal of treatment was no longer being reached and palliative treatment options to enhance quality of life needed to be considered. The participants talked about how they valued having consistent team members to call upon when things changed with their health. Teaching and counseling were recognized as important skills that oncology nurses provided to enhance coping for young adults with cancer. All seven participants acknowledged how their relationships with members of the health care team served to promote or to impede how they coped with their cancer journeys. The sub-themes of this theme include the need to be supported in one's decisions in relation to treatment and end of life issues, the significance of continuity of care, and a need for an oncology nurse to provide personalized care within the complexities of the health care system.

(vii) *Financial Worries*

This is another interpretive theme that arises in the data. All of the participants discussed the struggles they faced as young adults attempting to establish themselves in occupations at the time they were diagnosed with a life threatening illness. They talked about having to stop work to participate in complicated treatment regimens to combat their cancer. The participants came from different family situations and socioeconomic backgrounds, which is important as the sample represents various socioeconomic situations. All identified specific financial burdens associated with their cancer diagnoses. Sub-themes of the theme *Financial Worries* include the cost of child care, the cost of medication, and the cost of food.

A number of participants were unable to continue with paid employment and were forced to access social assistance programs. Two participants were single parents who experienced particular financial hardships after taking a leave from paid work to complete treatments. One of these individuals had to access short term disability benefits during his time away from his work. He spoke about the huge financial burden of being a single working parent and being diagnosed with cancer:

Through my treatment and plus when I went through surgery and I had complications, I took time off. But if I was self employed or with some other company that doesn't have insurance. I wouldn't have been able to do it. You know, *I would have had no choice*. But, financially...landlords and that, they don't care, they want their money, they don't understand....I took a pay cut basically, paying the bills, getting by, so that was a good thing.

An example he gave was of the cost of health care supplies. The second individual who was also a single parent, discussed taking time away from her career and how she benefited from financial assistance for food and transportation. Four of the participants were married and said how that they relied on their partners' incomes at the time of illness. One stated:

It *completely* changed it...I had to become dependent on my wife....We ended up having to fight for my EI [Employment Insurance]. It was this whole process. And so it wasn't until I was actually back to work that I got reimbursed for all my EI. So we went from October until February, just nothing but on her income. And...we had just gotten a new car and...moved in to our new apartment and stuff. Because we moved here from [another province] and we were living with parents until we found our own place. So...all the costs of getting a new apartment started. We had all these bills coming at us but... It was a *very big thing* for me....I was always worrying. I was feeling like it was a big—.... I felt bad because I felt like *I should be the one who's working and providing* for her and everything. And I mean I could hardly walk and stuff.

Unique to this individual's discussion was his experience of not having critical illness insurance and the long process of applying for unemployment insurance benefits. He also discussed the unexpected cost of sperm banking options; that is, he had to make a decision about sperm banking very quickly, because when it was presented to him, treatment could not be delayed. Meanwhile, he did not have money saved to pay for such an expense, his potential for future offspring/children suffered.

Another individual indicated that his financial situation would have been burdensome if had he been unable to return to work after the completion of his treatment. He felt he was in an advantageous position as his partner continued working throughout his diagnosis and treatment and their teenage children had part-time jobs. He hypothesized that if his children had been younger, the financial concerns for his family would have been consequential.

In comparison, another participant with young children considered the challenges of being a middle income family facing a life threatening illness while not qualifying for social assistance programs. She brought up the cost of child care, the cost of equipment in the home and the cost of medication. Specifically:

I think childcare is a *huge thing*. There needs to be something in place, some kind of subsidies, no matter how much you make. Just because my husband makes enough for me to stay at home with the kids, *doesn't mean we can afford to pay for childcare* which will cost you \$600-\$800 a month and that's just for during the day. My case, I would require a live-in nanny. I'd have to have a nanny. I can't afford that even though I was a stay-at-home mom and my husband makes enough. We couldn't afford to pay that and I find the financial cutoff very frustrating.... Just because we have that kind of money coming in it doesn't mean we can afford to shell out all this extra money because it's not—it's not a difference of, okay, \$10,000 a year. It's a difference of \$800 a month, which is an extra, almost \$10,000 a year. And we can't necessarily take that off our pay cheque. We'd end up using our savings and stopping our savings from growing and all that stuff and I just feel like it's frustrating. I don't want

my future to be gone financially when I'm going through this. *It's just not fair* that I should have to. *I'm going through enough already* and why do I have to lose money, my future, my savings and all that stuff as well.... I'm sure there's a lot of people that could echo that.

This sentiment was shared by another individual who reported financial worries associated with arranging child care during episodes of prolonged illness and hospitalization. She spoke of the importance of her partner maintaining a career outside of the home to ensure financial security for their family. She also talked about the impending costs of arranging transportation and purchasing medications.

Finally, another participant without a life partner said he was completely dependent on his family for housing and requiring social assistance to buy food and medications. He stated, "Some other expensive pills—... I remember one of them was... \$100 a pill and there was...six of them I had to take...for the month". He felt that he could not start living independently with his advanced cancer illness.

In summary, the interpretive theme *Financial Worries* is reflected by data from all of the participants. Differences in the participants' family situations and socioeconomic backgrounds led to differences in specific financial concerns. Sub-themes associated with this theme include the cost of child care, the cost of medication and the cost of food.

(viii) *Follow Up Care*

Follow Up Care is a significant interpretive theme revealed by the participants. All of them remarked on how they would like to see the development of peer support groups for young adults with cancer. Participants seemed to agree that such support groups would be most helpful during and after treatment for cancer. There were individual concerns related to post-treatment support and survivorship, as each participant was in a different phase of his/her cancer journey. Sub-themes include living

with cancer, maintaining connections with the Cancer Centre, and the importance of a peer support group for young adults with cancer.

One participant identified feelings of social isolation and the difficulty she experienced attempting to connect with others through the Internet and web-sites. She expressed frustration that there did not seem to be other young adults with a similar cancer experience to hers with whom she could talk. Another individual was concerned about post-treatment support and maintaining a connection with the Cancer Centre. She spoke about how cancer will forever remain a part of her life. She broached the ideas of returning to the workplace and resuming normal activities such as exercise and gardening. Her fears and concerns were about her transitioning back to her regular life and she was worried about cancer relapse. She stated:

We should maybe have...the group that we had at the beginning.

[I: Support groups.]

Yes, it could even be like the chemo again; you could come and then attend [the group].

[I: Yes.]

Because each other helping and what has happened and compare everything.

She saw value in companionship and empowering young adults with cancer to support each other. This idea encourages oncology nurses to develop and implement support groups for young adults with cancer. Such groups could be co-led by an oncology nurse and a young adult with a goal of providing information, support, and sense of community for young adults with cancer.

Another individual commented on the value of having a consistent link to the Cancer Centre and specialized care after his treatment. He felt he needed to return to work and to his “normal life” when his treatment completed. After the tape-recorded

interview was completed, he said he would be interested in participating in a peer support group for young adults, were it to be offered. The need for consistent follow-up care by a highly skilled oncology professional was similarly discussed by many of the participants. This will be elaborated on in Chapter Five: Discussion.

Another participant discussed the unique challenges he would face after the completion of his treatment while integrating back into the workplace with a changed functional status. He identified the need for greater education and support for employers and all members of society about how to support young adults during this transition period:

Even at work...some of the *upper management* and stuff don't understand why I can't do some of the things I can't do anymore. And...*it's just because they don't have any knowledge* about [disease], and they have never heard of it before so....It's just, *there's not a lot* of understanding.

One of the things that we've actually talked about doing is... starting a support group...because there really isn't one for [his disease].

One individual's cancer journey differed from this one in that the goal of treatment was no longer curative. Despite the reality of disease progression and risk of death, this individual still felt that peer support in the post-treatment phase of one's illness would be worthwhile.

Two other participants also emphasized the importance of connecting with other individuals who have lived through a cancer experience. Participants discussed how companionship, advice, and discussions on topics of interest as benefits of sharing with those involved in a peer support group.

The interpretive theme *Follow-Up Care* reflects concerns voiced by all of the participants. The type of recommended follow-up care varied with each individual, and

was influenced by his/her expectations for the after-care phase of the cancer journey. Young adults living with cancer want to prepare themselves for the sequence of events that they can expect after their treatment has completed. I have described the sub-themes of this theme which include living with cancer, maintaining connections with the Cancer Centre, and the importance of a peer support group for young adults with cancer.

Summary of the Findings

It Is Hard Being a Parent with Cancer, Symptom Management is a Challenge, Social Support is Imperative, Information Access is Essential, Fear of Recurrence and Mortality, Trusting Relationships with Health Care Professionals Make a Difference, Financial Worries and Follow-Up Care are significant themes for oncology care providers to be cognizant of when they interact with young adults with cancer. By understanding these themes as priorities for young adults with cancer, oncology nurses can provide care that is individual focused, and consider the unique perspective of the person living with the cancer diagnosis. These themes are different from each other as they encompass the various influences of health and wellness from the perspectives of young adults living with cancer. They are similar to each other in that they illustrate that cancer care needs to go beyond the traditional biomedical view of treating the disease to evaluating how the meaning of illness as it is experienced by the individual. As described by the participants in this study, holistic care can be achieved through the establishment of a trusting relationship, advanced assessment of personalized needs, mutual goal setting, and continuity of care.

These findings clearly answer the research question, “How do young adults aged 20 to 44 who are diagnosed with cancer and currently undergoing chemotherapy and/or

radiation treatment describe their needs?” by providing personal-experience based insights derived from in-depth conversations with seven individuals who were well qualified to articulate their needs and suggest ways to meet them. The eight interpretive themes that arose from the study data fulfill the purpose of the investigation are summarized in Table 2.

Table 2

Summary of Interpretive Themes, Sub-Themes, and Participant Needs

<u>Theme</u>	<u>Sub-Themes</u>	<u>Participant Identified Needs</u>
It Is Difficult Being a Parent with Cancer	<ul style="list-style-type: none"> • Altered adjustment for children • Issues of child care • Changing roles and responsibilities • Risk of genetic predisposition • Difficulties with family planning 	<ul style="list-style-type: none"> • Additional support about talking to children about one’s illness • Arranging and paying for child care • Eliciting family, friends, and community support • Consistent assistance so that children can remain in their daily routines • Using play as appropriate to prepare children for parents’ daily medical procedures • Assumption of greater responsibility for household management (especially older children) by family, friends, and community • Greater support for older children in dealing with a parent’s illness • Better understanding of genetic risk to my unborn children • Greater information about the side effects of treatment including any potential harm to one’s future children

<u>Theme</u>	<u>Sub-Themes</u>	<u>Participant Identified Needs</u>
Symptom Management is a Challenge	<ul style="list-style-type: none"> • Pain, breathlessness, mucositis • Nausea/vomiting, weight loss • Fatigue, alopecia, risk of infection, constipation • Loss of mobility, exercise as rehabilitation • Changes in sexual desire 	<ul style="list-style-type: none"> • Assistance dealing with side effects of chemotherapy • Advice on how to deal with weakness and decreased energy levels • A key contact person for when complications occur after surgery • Assistance dealing with uncontrolled pain, nausea, constipation, feeling sick • Support on trying to keep active to a safe and personally acceptable level
Social Support is Imperative	<ul style="list-style-type: none"> • Parental assistance • Spousal support • Changes in relationships • Social Isolation 	<ul style="list-style-type: none"> • Someone to depend on with full trust, such as a life partner • Emotional, financial, and practical, every day support from parents • Modified social life that fits with a busy treatment regimen • Maintaining friendships • Finding a faith community • Understanding and accepting that family members and friends respond in different ways to one's illness • Advice on how to support family members • Peer support , e. g., support groups, Internet • Advice on dealing with feelings of loneliness • Family close by • Advice on dealing with the social stigma living with a chronic illness at a young age
Information Access is Essential	<ul style="list-style-type: none"> • Lack of information specific to certain disease sites • Importance of knowledge as power • A need for individual education • Celebrity status promotes certain diseases • A need for increased public awareness of certain disease sites 	<ul style="list-style-type: none"> • Greater information on one's specific cancer • Better education about treatment choices • Being listened to and treated as a person • A "road map" of care expectations for future planning • Greater understanding amongst the oncology care providers and the public that celebrities promote only certain cancers which consequently get more attention • Greater education for the public about cancer in young adults

<u>Theme</u>	<u>Sub-Themes</u>	<u>Participant Identified Needs</u>
Fear of Recurrence and Mortality	<ul style="list-style-type: none"> • Intense emotional response • Fear of relapse • Dealing with the possibility of death • Inner resilience as a coping strategy • The need to maintain hope 	<ul style="list-style-type: none"> • Assistance dealing with the feeling of being “half dead” • A need to fight the disease • The right to decide what we want • Greater support in making life decisions • Assistance with setting goals • Support for maintaining hope
Trusting Relationships with Health Care Professionals Make a Difference	<ul style="list-style-type: none"> • Treatment support • End of life support • Significance of continuity of care • Personalized care 	<ul style="list-style-type: none"> • Trust in one’s physician • Having a health care professional listen to one’s concerns • Having relationships based on empathy and trust with health care team members • Greater accessibility of health care team members • Being supported for decision-making and decisions made • The flexibility of working with the team to change one’s plan of care as necessary • Connection with a cancer care team after treatment ceases
Financial Worries	<ul style="list-style-type: none"> • The cost of child care • The cost of medication • The cost of food 	<ul style="list-style-type: none"> • Greater financial support for the purchasing food, equipment, medication, child care • Assistance accessing government assisted financial support for time spent away from paid work • Greater awareness of the importance of critical illness and life insurance for young adults
Follow-Up Care	<ul style="list-style-type: none"> • Living with cancer • Maintaining connections with the Cancer Centre • Importance of a peer support group 	<ul style="list-style-type: none"> • Greater support in dealing with the feeling that cancer does not leave you • Being able to get a hold of a cancer specialist when there are problems • Someone to talk in the workplace and with friends about the long term effects of treatment • Groups where young adults can get together led by people who have similar experiences and/or nurses

While the interpretive themes are unique to the young adults who participated in this study and were conceptualized by me as the Principal Investigator, they do fall within the domains of physical, psychological, social, and spiritual well-being as outlined by the QOL model that is part of the theoretical forestructure for this investigation (Ferrell et al., 1995; King, 2006). This research provides a critical analysis of a myriad of issues from the perspectives of young adults faced with cancer. In turn, the findings have meaningful implications for oncology administrators, policy makers, researchers, educators, physicians, allied health providers, and specialized nurses. Selected implications are addressed in the following Chapter Five: Discussion.

CHAPTER FIVE: DISCUSSION

Significance of this Research

The focus of this research was to learn about the needs of young adults with cancer, recognizing that those living with the cancer are experts of their own experiences and are best able to describe their own needs. By learning about the subjective cancer experience, oncology care professionals are better able to consider the thoughts, insights, and reflections of the patients they serve, and plan care accordingly. The age at which an individual is diagnosed with cancer requires careful consideration when developing personalized care. Young adulthood is a life stage filled with many psychological and social milestones, such as finding mutually satisfying relationships, finding meaningful employment to support oneself independently, and making decisions in regards to raising children (Harder, 2002). In North American culture, it is recognized that young adulthood is the most productive period of one's life; hence, a cancer diagnosis in this developmental period has many implications within the domains of physical, psychological, social, and spiritual well-being (Ferrell et al., 1995; King, 2006). Canadian research indicates that improved survival and stable incidence rates will lead to more young adults living with a cancer diagnosis in the next decade (CCO, 2006). Therefore, understanding the salient, multifaceted needs of this group of individuals and their families is an important issue facing oncology care providers.

I designed and carried out an interpretive description research study (Thorne, Reimer Kirkham, & O'Flynn, 2004; Thorne, 2008) to learn more about the needs of young adults with cancer, specifically their views about their issues of concern. I believe that, through the process of critical analysis, interpretation, and clinical application,

oncology care providers can empower young adults to obtain and maximize the support, knowledge, and skills they need and to gain expert knowledge about issues of survivorship. The idea of survivorship is relevant for young adults with cancer but controversial for those living with advanced cancer illness. Doyle (2008) conducted an extensive literature review of this topic and concluded that survivorship is a process that begins when one is diagnosed with cancer and it always involves uncertainty. From the data that arise within the present study, it is evident that young adults diagnosed with cancer have unique experiences and care providers can learn from these experiences. Within these personalized understandings, however, a number of universal themes can be found that might influence current and future oncology nursing practice. My research identified these interpretive themes: (i) *It Is Hard Being a Parent with Cancer*; (ii) *Symptom Management Is a Challenge*; (iii) *Social Support is Imperative*; (iv) *Information Access is Essential*; (v) *Fear of Recurrence and Mortality*; (vi) *Trusting Relationships with Health Care Professionals Make a Difference*; (vii) *Financial Worries*, and (viii) *Follow-Up Care*.

Limitations

This research had a number of limitations. The first pertains to the size of the study group. Whereas I initially planned to conduct interviews with approximately 10-12 participants or a number that provided enough data for saturation of the themes (Lincoln & Guba, 1985), the final number of participants in the study was seven. I had little success with poster recruitment and opted instead to enlist colleagues to inform potential candidates about the study and increase recruitment. Because I maintained my clinical employment during this time, however, it was a challenge to constantly promote the

study to my peers, who also had busy practices. In addition, any clients in this age-group in my own caseload were excluded, further reducing the sampling pool. Although 11 individuals initially expressed interest in participating in the study, four of these withdrew at the time of informed consent due to declining health status and/or difficulties that they were experiencing with the side effects of treatment. Several cross-reaching themes among the remaining seven participants were identified. A larger sample size may have brought forth new variations to enhance the interpretations to influence nursing care for young adults with cancer. However, the seven young adults in this study articulated their needs through sharing their subjective experiences. As such, the findings revealed recurrent patterns for this specialized group. The findings contribute to the knowledge and understanding of those needs. Rigour was achieved through the elements of trustworthiness previously discussed: **Truth value, Applicability, Consistency, and Neutrality** were maintained and they serve to strengthen the credibility of the research (Lincoln & Guba, 1985).

Another limitation of this study is related to the timing of participation. My findings indicate that young adults desire greater support during the period following completion of treatment. This suggests that the post-treatment support period may be a more opportune and effective time in the illness trajectory to investigate the needs of young adults with cancer.

I recognize the limits of knowledge that are specific to the perspectives of the seven individuals who were in my study. Thorne (2008) notes that a single study permits only a selected range of conclusions, and therefore discussions should include the context of the available literature to broaden applicability. Applicability refers to how the themes

can be applied to other situations and to those involved in the phenomenon (Carradice, Shankland, & Beail, 2002). There are few threats to applicability in qualitative research as it emphasizes the study of phenomena in natural settings with few controlling conditions (Sandelowski, 1986).

A final limitation to mention concerns the study's focus on the general experience of having cancer as a young adult, irrespective of the type of cancer and treatment. This non-categorical approach has produced a broad understanding of the general concerns of young adults with cancer and their families. There are, however, specific issues and concerns for young adults that are related to the particular cancer type and treatment. There will also be common side effects and needs associated with specific treatment regimes for each young adult with cancer. Thus, while this study revealed supportive care concerns for seven young adults with cancer within the domains of quality of life, it does not detail specific themes with particular disease types or treatment protocols. Literature related to the themes drawn from this study's data will be discussed further with recommendations for the delivery of oncology care.

Synthesis of the Findings and Related Literature

The findings of this small study do support and build on previous research within the field of oncology supportive care and quality of life for young adults with cancer. The theme *It Is Hard Being a Parent with Cancer* is about being a young adult with cancer and having the responsibility of balancing one's health with the responsibilities of being an engaged parent. The young adults in this study spoke about altered family coping. They commented on the importance of having on-going care for their children to foster growth and development, and even those who are currently childless noted the significant

impact that knowing one has cancer has on child-rearing decisions. This was also reported by Su and Ryan-Wegner (2007), who studied the parent-child relationship during illness and concluded that there are many changes in parent-child interactions that are due to a parent's illness and threat of death. Armistead, Klein, and Forehand (1995) indicated that various dimensions of a parent's illness may affect their children's adjustment to it, such as onset, course, outcome/prognosis, and degree of incapacitation. Further, children's knowledge of cancer is related to personal experience and can be supported by oncology care providers through skilled medical play therapy (Bluebond-Langner, 1978; as cited in Buchbinder, 2008). These findings indicate that oncology care providers might consider the parenting aspect of being a young adult with cancer, to improve the quality of care for this specialized population. Also based on these findings, greater research examining parenting and the parent child relationship during a cancer illness would be valuable.

It Is Hard Being a Parent with Cancer is a theme that will guide oncology care providers to consider how they can support the young adults they work with in relation to parenting and altered family functioning. The family as the unit of care is an approach to nursing that many nurses embrace in their daily interactions with young adults (Hayes & McElheran, 2002); as such a full family assessments [e.g., completing genograms and ecomaps] at the entry point to the oncology care system and on-going support and communication with those that the patient identifies as his/her family are thoughtful considerations for nursing practice.

The theme *Symptom Management Is a Challenge* is about the milieu of body changes and physical side effects that young adults in this study voiced as impacting their

well-being and quality of life. The young adults in this study spoke about experiencing nausea, vomiting, pain, breathlessness, and fatigue those symptoms directly impacted their quality of life. Difficulty in managing symptoms was identified by all the young adults in my study and has been revealed by other researchers. This theme is explored in the current literature by research into the supportive care needs of individuals with cancer. Specifically, investigations by several Canadian researchers concluded that certain symptoms are often dependent on the particular type and stage of cancer, and that the most common symptoms associated with cancer treatment include pain, loss of appetite, fatigue, weakness, weight loss, constipation, difficulty breathing, confusion, nausea, vomiting, dry cough, and dry or sore mouth (Ashbury, Finlay, Reynolds, and McKerracher, 1998; Fitch & Steele, 2003; Fitch, 2005). In the future, greater examination into symptom meaning for young adults with cancer would serve as an expanse of this research.

Symptom Management Is a Challenge is a theme of particular importance for oncology care providers to consider when interacting with young adults with cancer. Comprehensive symptom assessments for young adults in active treatment for cancer is beneficial to improve quality of life for young adults (Lacasse & Beck, 2007). As such, it is a nursing implication that can be derived from this research. How symptoms impact the daily life of young adults, and their meaning to young adults, is another implication that could be explored further by interdisciplinary oncology professionals. Most oncology care professionals are well educated on the best medical approach to dealing with complex symptoms associated with various treatment protocols; however, this study brings forth the discussion that understanding symptoms from the perspective of the

individual living with them could shift the delivery of health care to a more holistic patient-focused approach.

Social Support Is Imperative is a theme that is about the importance of social relationships to sustain well-being in young adults with cancer. The young adults in this study spoke about the contributions of friends, family, and members of their faith community which facilitated their every day coping with cancer. It is a theme that is supported by the literature as previously mentioned; social well-being encompasses issues of appearance, financial burden, leisure activities, role and relationships, family distress, and occupational/academic endeavors (Ferrell et al., 1995; King, 2006). More research is needed into supporting family and friends as caregivers. Peer support for young adults with cancer was a predominant need brought forth in my study and the literature supports this as an area for planned development and evaluation. Further, despite support, social isolation was experienced by all the participants in my study. This coincides with research by Siegel, Gluhoski, and Gorey (1999) into age-related distress among young women with breast cancer in which it was found that women often feel different and isolated from other young women their age.

The theme *Social Support Is Imperative* provides pertinent information for understanding the needs of young adults with cancer. Oncology care providers talk with young adults to understand their social supports and to mobilize community resources for this specialized group. In addition, the participants in this study discussed the possibility of the development of peer support groups for young adults. One might consider that oncology nurses could lead peer support groups. Such initiatives would require full

collaboration of key stakeholders, such as, senior leadership teams and supportive care teams within integrated Cancer Centres.

The theme *Information Access is Essential* is about providing the required information and education to young adults with cancer at the most appropriate time and through a method that will support individual learning styles. The sub-themes of lack of relevant information specific to certain diseases, importance of knowledge as power, a need for individualized education, how celebrity status promotes certain diseases, and the need to increase public awareness of specific cancers are significant concerns and areas for discussion. The young adults in my study articulated that there was little information available specific to their unique cancers. They spoke about wanting to be knowledgeable and prepared for their treatments. Some of the participants talked about the timing of education and support, recognizing the time of initial diagnosis as an overwhelming period in their cancer journey in which informational support would need to be reiterated on numerous occasions. Informational support empowers young adults with some of the expectations of their cancer journey and provides them with resources to empower them. The findings of this study bring forth the informational needs of seven young adults with cancer. This resonates with other research that has shown the importance of information for patients about their bodies, their diseases, the treatment options, and side effects (Fitch, Gray, & Franssen, 2000; Fitch et al., 2004; Fitch, 2005). *Informational Access is Essential* is a finding that challenges oncology care providers to define informational support as it is characterized **by the person living through the cancer experience**. In the future, oncology care professionals will need to give careful consideration to the best way to transfer knowledge and to provide educational support to their patients.

Fear of Recurrence and Mortality is an important theme that is about uncertainty and the fear of dying at a young age. All of the young adults in this study discussed concern for their future well-being in the event that their illness worsened or progressed. This theme is present in current literature. Specifically, Fitch (2005) concluded that when a person is not able to meet his/ her own expectations and to maintain relationships, psychological distress and altered negative coping can occur throughout the course of the illness. Alfano and Rowland (2006) discussed fear of recurrence as one of the biggest concerns for people who survive cancer regardless of the type of cancer. Similarly, Lynam's 1995 article on the issues facing young adults with cancer identified "acknowledging the possibility of death" as an important theme for this age group. In her study, young adults spoke about an awareness of high cure rates for most cancers affecting their age group but always living with the possibility of one's own mortality. Lee, Cohen, Edgar, Laizner, and Gagnon (2006) investigated meaning-making as the complex process of appraising one's cancer and searching for meaning and purpose in one's life with the outcomes of positive adjustment. They concluded that the search for order and meaning is often associated with great psychological distress, which resonates with the accounts of the present participants.

Fear of Recurrence and Mortality when interacting with young adults with cancer is a relevant theme for oncology care providers. Many people feel there is a sense of injustice if someone dies at a young age. Specialized care and attention for young adults with cancer through discussions on personal strengths, the meaning of the illness, and how to cope with the preoccupation that one might succumb to their illness are recommendations for oncology care providers to consider. In turn, oncology

administrators and educators might consider the importance of offering additional educational support for health professionals about how to have discussions on recurrence and mortality with young adults.

Trusting Relationships with Health Care Professionals Make a Difference is a theme about the therapeutic relationship oncology care providers have with their patients and how it is essential to improve quality of life for young adults with cancer. The participants in this study spoke about how they valued continuity of care and the accessibility of competent, knowledgeable cancer specialist. This theme can also be found in literature within the field of study. Specifically, in a study by Kyngas and colleagues (2000), which investigated young adults coping with the onset of cancer, participants revealed that enhanced coping was associated with the comfort level that they experienced from the shared professional knowledge of their primary physician and nursing team. These authors found that the coping mechanisms of young adults with cancer were influenced by the time of diagnosis and who was responsible for informing them of the diagnosis. Coping was also related to how effectively they felt their care was managed. This attests to the significance of the interpretive theme *Trusting Relationships with Health Care Professionals Make a Difference*. Further, it emphasizes that the time of diagnosis and effective communication are core elements of the patient relationships between health care professionals and young adults with cancer.

Enhanced understanding among health professionals of the importance of trusting relationships will strengthen the development of innovative strategies to address communication and support gaps in oncology care. Health care administrators might consider built-in time for oncology professionals to address the questions and concerns of

oncology patients with less time constraints. It would be beneficial to have educational courses woven into academic programs to support oncology care professionals about how to address psychosocial issues and how to communicate effectively with the young adult population.

Financial Worries was a theme about the monetary concerns of young adults faced with financial burdens directly related to the cost of the basic necessities of life, medication, transportation, and child care. The widespread nature of financial concerns, even in the context of socialized health care, as a major issue facing young adults with cancer supports research cited in the literature review of this thesis. Specifically, the study by Roberts, Piper, Denny, and Cuddeback (1997), who evaluated an innovative support group to facilitate young adults' adjustment to cancer, cited financial and vocational concerns as major obstacles to effective coping.

Financial Worries describes significant needs for young adults with cancer. By identifying this theme as important to the care of young adults with cancer, oncology nurses are better positioned to lobby for financial support through endowment funds and charitable organizations. The theme encourages oncology care providers to consider the social determinants of health and the part they play a part in an individual's overall well-being. Greater financial support is needed for this specialized population. The economic impacts of living with cancer at a young age are concerns for politicians and policy makers to consider at the provincial and federal level to include this specialized population in future resource allocation.

Follow Up Care was a theme about living with cancer, living through the various stages of cancer illness, and having appropriate care in the post treatment phase of illness.

The participants in this study mentioned a need for a peer led support group with an oncology nurse as a consultant in the follow up phase of cancer for young adults. This theme is supported by current literature examining the topic of survivorship in cancer. Alfano and Rowland (2006) remarked that although there have been many advances in controlling and curing cancer, there are specific concerns for individuals in the period after treatment. This period brings with it a great potential for long lasting physical and psychological effects. The need for *Follow Up Care* is a consideration for oncology care providers as more young adults are surviving cancer. Young adults want to prepare themselves for the sequence of events that they can expect after their treatment has completed, and this is an important consideration as new roles and approaches to care for young adults are developed. Much of the research on cancer survivorship, however, has focused on breast cancer, and a greater understanding of the late effects of treatment for other cancers within the domains of quality of life might be considered (Alfano & Rowland, 2006). For administrators and researchers, the topic of cancer survivorship needs greater clarification and a strategic plan for addressing survivorship. Educators might consider the development of oncology specialized curriculums to address quality of life issues throughout the cancer trajectory. Clinicians might consider new roles for experts in the long term effects of cancer and the development of follow-up clinics for young adults with cancer.

Finally, a study by Canadian researchers Corsini and Ammerman (2008) identified family, friends, spirituality, the health care team, and the workplace as important social supports for young adults with cancer. Of interest, 33% of the participants in Corsini and Ammerman's study reported that they either were not

receiving adequate support or were unsure if the support they received was adequate. In my study, the participants identified their supportive needs within the domains of quality of life and indicated which aspects of their cancer experience they valued and which areas that could be improved. I analyzed the data to uncover meaning relevant for clinical practice. My study therefore expands on the findings of Corsini and Ammerman by highlighting examples of support that young adults find helpful, gaps they see in the current oncology system, and solutions that they feel would benefit future health care planning.

Nursing Implications

As previously mentioned, there are broad and important implications for oncology nurses to consider when interacting with young adults with cancer. Nurses are often the first point of contact for young adults once a cancer diagnosis is confirmed. Young adults look to them for expert advice, support, and counseling throughout their cancer journeys. The interpretive themes revealed in my research challenge oncology nurses to consider creative strategies that they could use to address the needs of young adults with cancer. Oncology nursing practice is situated within the context of caring theory. Oncology nurses aim to address the consequential domains of physical, psychological, social, and spiritual well-being for individuals with cancer and their families (Watson, 2005; Howell, Fitch, & Caldwell, 2002; King, 2006).

The Canadian Association of Nurses in Oncology (2001) has developed standards of care for oncology nurses. These comprehensive standards guide oncology nurses to act as strong leaders to bring forth the concerns relevant to specialized populations and to encourage resource allocation to enhance quality of life for those living with cancer.

Advocacy for young adults with cancer is a core component of oncology nursing leadership. Thus, the interpretive themes developed in this research are especially relevant to oncology nurses, administrators, policy makers, researchers, and educators. I make six specific suggestions about ways that these themes can be used to guide improvements in oncology care. These are outlined in Table 3 (pp. 113).

Six Suggestions for Oncology Nurses

First, oncology nurses need to conduct **comprehensive supportive care needs assessments** when interacting with young adults with cancer and their families.

Determining what information young adults with cancer are seeking is the first step to understanding the multidimensional needs of this population. Determining how young adults want to access information is critical to ensuring that their needs are met. For example, thoughtful consideration should be given if an individual prefers Internet, written, or verbal informational material and teaching. The increased awareness of reputable and relevant web-sites to share with young adults with cancer is important for oncology nurses as they act as key resources for this group of patients.

Second, oncology nurses might consider the **use of models to guide their practice** in empowering young adults living with a life threatening illness. Two examples of models are the Supportive Care for Cancer Patients Framework (Fitch, 2000) and the Transactional Model of Stress (Folkman & Lazarus, 1984). Identification of psychological and social support is imperative to facilitating effective coping and adjustment to illness in young adults. In my study, the importance of social support was highlighted by all of the participants. Oncology nurses therefore should consider the family and friends that young adults rely on throughout their cancer journeys. Margaret

Fitch's Supportive Care for Cancer Patients Framework (2000) presents oncology nurses with seven categories to consider when conducting in-depth assessments of supportive care needs. The categories include the assessment of physical, emotional, practical, informational, spiritual, social, and psychological needs (Fitch, 2000). Nurses also should consider strategies to understand the complicated emotional responses young adults have when faced with a cancer diagnosis.

Recent research by Laubmeier and Zakowski (2004) regarding the psychological adjustment of people with cancer supports the use of the Transactional Model of Stress for oncology care providers (Folkman & Lazarus, 1984). According to the model, individual perception of life threat is a key element that correlates with distress; thus, this model is an example of a useful framework to guide nursing interactions with young adults with cancer. Nursing leaders need to be role models to recognize the importance of putting conceptual frameworks into practice to articulate nursing's contribution to improving patient satisfaction and quality of life.

Third, nurses have a role in setting appropriate **mutually negotiated short term and long term goals** with the young adults in their care. During this process, the themes of this research will provoke oncology nurses to be cognizant of the developmental concerns of young adults. For example, one young adult might have a goal to complete treatment and to resume academic studies, whereas another young adult might be a parent whose primary focus is to support the adjustment of her school age children to her illness. Every young adult with cancer will have individualized concerns that oncology nurses can recognize and share with the oncology care team. This in turn will foster an atmosphere of partnership with and support from the care team.

Fourth, there is a need for oncology care nurses to educate and empower young adults with **strategies for managing their physical symptoms** associated with the disease and side effects of treatment themselves. This may include teaching about pharmacological and diet management of nausea and vomiting and/or providing resources for exploring fertility related options for sperm banking and egg preservation.

Exercise as rehabilitation was a sub-theme identified by the participants in this study; as such, oncology nurses might consider adopting health promotion strategies to help young adults maintain healthy lifestyles. Nurses need to be resourceful on cancer rehabilitation programs in the community so that they can pass on information to young adults in their care as appropriate.

Fifth, oncology nurses might consider proactive ways to rally increased **financial support** for young adults with cancer. Oncology nurses are commonly the first professionals to whom young adults will voice their financial concerns. As such they can play a critical role, facilitating referrals to social work colleagues and to have an awareness of the types of financial supports that are available for young adults with cancer. Often nurses are leaders of interdisciplinary collaboration and as such are the health professional that links with other disciplines to bring forth patient concerns and to ensure all issues are met by the oncology care team.

Finally, oncology nurses must seize the opportunity to develop innovative strategies to provide **post-treatment support** to young adults with cancer. One possibility is to partner with their interdisciplinary colleagues to develop peer support groups for young adults with cancer. Over the next decade, oncology nurses will be increasingly challenged to address the issue of cancer survivorship and its meaning for all

individuals with cancer. It is clear from this study that young adults with cancer would appreciate counseling and advice from oncology nurses on the long term effects of treatment and appropriate follow up care. Nurse led follow up clinics serve to provide expert advice, support and linkages for young adults at completion of active treatment; the health care delivery system needs more of these as efficient and cost-effective ways to provide high-quality care for this vulnerable population. Table 3 provides an overview of the eight interpretive themes, participant identified needs, and nursing care implications.

Table 3

Nursing Care Implications

<u>Theme</u>	<u>Participant Identified Needs</u>	<u>Nursing Care Implications</u>
It is Difficult Being a Parent with Cancer	<ul style="list-style-type: none"> • Additional support about talking to children about one's illness • Arranging and paying for child care • Eliciting family, friends, and community support • Consistent assistance so that children can remain in their daily routines • Using play as appropriate to prepare children for parents' daily medical procedures • Assumption of greater responsibility for household management (especially older children) by family, friends, and community • Greater support for older children in dealing with a parent's illness • Better understanding of genetic risk to my unborn children • Greater information about the side effects of treatment including any potential harm to one's future children 	<ul style="list-style-type: none"> • Oncology nurses to conduct comprehensive supportive care needs assessments • Oncology nurses to review current resources and offer support to young adults on talking to their children about cancer through counseling and role playing • Administrators and oncology nurses to lobby non-profit charitable organizations to consider financial amelioration of child-care expenses for young adults with cancer • Interdisciplinary team members within integrated cancer programs to consider on-site child care and designated play areas for children accompanying young adults during treatment • Oncology nurses to develop innovative strategies to educate young adults on cancer and the side effects of treatment through written, verbal, and interactive teaching material, e. g., DVD's and web-sites • Oncology nurses to work in collaboration with genetic counselors to form joint clinics to educate young adults

<u>Theme</u>	<u>Participant Identified Needs</u>	<u>Nursing Care Implications</u>
Symptom Management is a Challenge	<ul style="list-style-type: none"> • Assistance dealing with side effects of chemotherapy • Advice on how to deal with weakness and decreased energy levels • A key contact person for when complications occur after surgery • Assistance dealing with uncontrolled pain, nausea, constipation, feeling sick • Support on trying to keep active to a safe and personally acceptable level 	<ul style="list-style-type: none"> • Oncology nurses to conduct one-on-one teaching sessions with young adults on the side effects of treatment • Oncology nurses to be accessible by phone to counsel young adults on evidenced based symptom management strategies and self-care strategies • Administrators to support and allocate resources for non-pharmacological rehabilitation for young adults with cancer • Oncology nurses to collaborate with occupational therapists, physiotherapists, and personal trainers to develop workshops and programs on maintaining full functional capacity through exercise, rehabilitation, and energy conservation strategies
Social Support is Imperative	<ul style="list-style-type: none"> • Someone to depend on with full trust, such as a life partner • Emotional, financial, and practical, every day support from parents • Modified social life that fits with a busy treatment regimen • Maintaining friendships • Finding a faith community • Understanding and accepting that family members and friends respond in different ways to one's illness • Advice on how to support family members • Peer support , e. g., support groups, Internet • Advice on dealing with feelings of loneliness • Family close by • Advice on dealing with the social stigma living with a chronic illness at a young age 	<ul style="list-style-type: none"> • Oncology nurses to conduct comprehensive supportive care needs assessments with attention to the patient-identified family, social, and spiritual supports • Oncology nurses and researchers to examine the family as the unit of care for young adults with cancer • Oncology nurses, administrators, and policy makers to develop a stronger infrastructure for development of family caregivers • Bringing forth caregiver support as a key issue for program planning in oncology care by including caregivers in strategic planning initiatives • Oncology nurses to become active members on community coalitions and/or organizations to contribute to public education and advocacy for young adults with cancer • Oncology nurses to lead the development of peer support groups for young adults with cancer; such programs can be co-lead by or passed to young adults once established

<u>Theme</u>	<u>Participant Identified Needs</u>	<u>Nursing Care Implications</u>
Information Access is Essential	<ul style="list-style-type: none"> • Greater information on one's specific cancer • Better education about treatment choices • Being listened to and treated as a person • A "road map" of care expectations for future planning • Greater understanding amongst the oncology care providers and the public that celebrities promote only certain cancers which consequently get more attention • Greater education for the public about cancer in young adults 	<ul style="list-style-type: none"> • Relevant, up to date information specific to the cancer they are dealing with • Administrators and senior leadership team members in integrated cancer programs to develop strategic plans to address the informational and decision-making support that young adults with cancer require • Additional time and budget for oncology nurses to add this to their practice is required • Researchers to further examine the informational and decision-making support needs of young adults with cancer • Oncology care providers to be cognizant of how celebrity status and media endorsement can influence public attention to only certain diseases • Oncology care providers might consider coming together as interdisciplinary groups to consider social marketing strategies to increase public awareness of cancer in young adults
Fear of Recurrence and Mortality	<ul style="list-style-type: none"> • Assistance dealing with the feeling of being "half dead" • A need to fight the disease • The right to decide what we want • Greater support in making life decisions • Assistance with setting goals • Support for maintaining hope 	<ul style="list-style-type: none"> • Oncology administrators and educators to provide additional educational support for oncology care through specialty courses and in-servicing on how to talk to young adults about their fears of recurrence and death • Oncology nurses to engage in conversations with young adults about their fears and concerns about living with cancer • Oncology nurses to adapt the use of conceptual models in their every day practice to facilitate young adults' effective coping and adjustment to illness • Oncology nurses to develop with young adults mutually set goals to guide their care • Oncology educators to study the theme of hope and how it relates to oncology nursing and how oncology nurses can be educated to use hope promoting strategies • Oncology researchers to conduct evaluative research into newly developed programs aimed to improve quality of life and sense of well-being

<u>Theme</u>	<u>Participant Identified Needs</u>	<u>Nursing Care Implications</u>
Trusting Relationships with Health Care Professionals Make a Difference	<ul style="list-style-type: none"> • Trust in one's physician • Having a health care professional listen to one's concerns • Having relationships based on empathy and trust with health care team members • Greater accessibility of health care team members • Being supported for decision-making and decisions made • The flexibility of working with the team to change one's plan of care as necessary • Connection with a cancer care team after treatment ceases 	<ul style="list-style-type: none"> • Oncology care providers to work in partnership with young adults with cancer to address their priorities for care • Care plans developed on mutually negotiated short term and long term goals • Oncology care providers must recognize young adults as a specialized population • Greater research on quality of life issues faced by young adults with cancer
Financial Worries	<ul style="list-style-type: none"> • Greater financial support for the purchasing food, equipment, medication, child care • Assistance accessing government assisted financial support for time spent away from paid work • Greater awareness of the importance of critical illness and life insurance for young adults 	<ul style="list-style-type: none"> • Oncology nurses to partner with social work colleagues to create informational packages on all financial supports related to unemployment/disability benefits, insurance coverage, medication coverage, equipment purchasing and loaning, child care subsidies and community funded nutritional support programs • Administrators and oncology nurses to lobby non-profit charitable organizations to consider financial burdens for young adults and to establish endowment funds
Follow-up Care	<ul style="list-style-type: none"> • Greater support in dealing with the feeling that cancer does not leave you • Being able to get a hold of a cancer specialist when there are problems • Someone to talk in the workplace and with friends about the long term effects of treatment • Groups where young adults can get together led by people who have similar experiences and/or nurses 	<ul style="list-style-type: none"> • Administrators to plan for a greater number of young adults living with the long term effects of treatment for cancer • Administrators and policy makers to consider the implementation of oncology nurse led follow-up clinics for young adults • Oncology nurses and researchers to conduct evaluation research to determine the effectiveness of nurse led clinics

The results of this study indicate that oncology nurses can act as change agents to advocate for young adults as a specialized group within the field of oncology care—as

well as and while they provide safe, expert care. Oncology nurses may consider the development and implementation of innovative care solutions to address the developmental considerations of cancer in young adulthood as described by young adults themselves within the domains of quality of life (Ferrell et al., 1995; King, 2006).

Other Implications

In addition to its nursing implications, this study also leads to a number of implications and recommendations for administrators, policy makers, funders, researchers, and educators. Administrators and policy makers can benefit from the results of the present study with regard to finances, resource planning, and knowledge transfer. Administrators should consider the development of strategic direction and mission statements that entail client centered care to achieve quality across the spectrum of care from hospital to community settings. In the future, administrators and policy makers will work collaboratively to articulate the term survivorship. This will determine future cancer quality care planning and allocation of resources to meet the supportive care needs of those living with cancer. The highest standard of care would be for young adults to live well with cancer, not to fight a complex system to get the rehabilitation support they need to lead fulfilling lives after active treatment for cancer. Administrators should consider partnerships with key stakeholders and community organizations such as provincial cancer boards and national non-profit charitable organizations to access funding to develop new programs for young adults with cancer. Full interdisciplinary lobbying and fundraising will increase accessibility and create endowment funds for extra financial supports for young adults with cancer and their families. Further, investments in web-site

support groups, DVD take-home, and Internet-based educational materials might be considered and evaluated when budgeting for supportive care services.

With respect to research, the results of this study offer valuable insight into the common needs associated with young adults with cancer. At the same time, they also highlight a number of key areas where further research is warranted. For example, more extensive study is needed to gain a deeper understanding of the needs of young adults with specific disease types and treatment protocols. These findings also suggest that more research into the survivorship issues of young adults with cancer is urgently needed. In addition, there is a need for a randomized control trial- or evaluation research of programs to support young adults with cancer to examine specific support approaches and the effects of support groups. Greater research on informational communication with young adults and health care professionals would build on this research and provide insights to enhancing coping for this group.

In turn, this could guide educators to provide courses on cancer communication skills for interdisciplinary professionals. Nursing education and interdisciplinary continuing education with role modeling and practical application of frameworks that foster coping in young adults with cancer are thoughtful considerations for educators. Further, in-service training for interdisciplinary professionals to increase their skills in working with this group is called for. Specific educational material would draw attention to the specialized needs concerned with child care, promoting family and friend support, educating employers, and financial concerns. Subsequently, oncology educators might consider follow-up care as an important component of the cancer continuum as they prepare professionals for oncology specialization. Partnerships with academic institutions

will provide nursing students with the opportunity to gain experience in leading wellness workshops and building health promotion strategies into oncology care.

The implications of my study therefore encompass recommendations for specialized oncology nurses, administrators, policy makers, funders, researchers, and educators. Addressing these key needs will ensure significant progress in the evolution of young adults as a specialized oncology population.

Conclusion

The needs for young adults with cancer are multifarious. They have unparalleled care concerns that arise from their diseases and associated treatments. Their needs deserve critical reflection by their health care team members in the context of young adults' own, "real" lives. This research has generated new knowledge about the subjective experience of young adults living with cancer and begins to address the needs outlined in the document "Cancer in Young Adults in Canada" (2006):

Because survival is good and mortality rates are dropping, while incidence rates and young adult population size are projected to be either stable or declining only slightly, the number of Canadians living with a cancer diagnosed during young adulthood is only going to increase over at least the next 15 years. Furthermore, enhanced risk of cancer-related adverse health events (such as a second cancer) may become apparent only many years after diagnosis. These add to the urgency of establishing research and surveillance protocols focused on short-, medium-, and long-term effects. Only after issues are identified can young adults expect to get the support they need, and can research to reduce long-term treatment risks be undertaken. (p. 86)

This study represents a broad understanding of these needs as they are described by young adults living with cancer. The participants in this study articulated many reflections and deliberations pertinent to their cancer experiences, ultimately leading to the development of eight interpretive themes. In turn, these themes can guide oncology

care and oncology nursing practice in powerful ways. This interpretive description brings forth the voices of young adults with cancer and provides an in-depth examination of the concerns of young adults with cancer from the time of the diagnosis and throughout treatment, and what nurses can do to make a difference in their cancer journeys.

REFERENCES

- Addison, R., & Packer, M. (1989). *Entering the circle: Hermeneutic investigation in psychology*. Albany: State University of New York Press.
- Alfano, C., & Rowland, J. (2006). Recovery issues in cancer survivorship: A new challenge for supportive care. *Cancer Journal, 12*, 432-443.
- Anderson, R. T., Aaronson, N. K., Wilkin, D. (1993). Critical review of the international assessments of health-related quality of life. *Quality of Life Research, 2*, 369-395.
- Antonovsky, A. (1979). *Health, stress and coping*. Jossey-Bass, San Francisco.
- Antonovsky, A. (1993). The structure and properties of the sense of coherence scale. *Social Science of Medicine, 36*, 725-733.
- Armistead, L., Klein, K., Forehand, R. (1995). Parental physical illness and child functioning. *Clinical Psychology Review, 15*, 409-422.
- Ashbury, F., Findlay, H., McKerracher, K., & Reynolds. (1998). A Canadian survey of cancer patient experiences: Are their needs being met? *Journal of Pain and Symptom Management, 16*, 298-306.
- Bloom, J., & Spiegel, D. (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning of women with breast cancer. *Social Science and Medicine, 19*, 831-837.
- Bluebond-Langner, M. (1978). *The private worlds of dying children*. Princeton, NJ: Princeton University Press.
- Bradshaw, J. (1972). A taxonomy of social need. *New Society, 30*, 640-643.
- Brandt, B.T. (1987). The relationship between hopelessness and selected variables in women receiving chemotherapy for breast cancer. *Oncology Nursing Forum, 14*(2), 35-39.
- Brunas-Wagstaff, J., Griffiths, C., Norton, L., & Wagstaff, G. (2002). Existential concerns in late stage cancer. *European Journal of Oncology Nursing, 6*, 243-246.
- Buchbinder, M. (2008). 'You're still sick?' Framing, footing, and participation in children's medical play. *Discourse studies, 10*(2), 139-159.
- Canadian Association of Nurses in Oncology (CANO) (2001). *CANO standards of care, roles in oncology nursing, and role competencies*. Retrieved September 17, 2005 from the Canadian Association of Nurses in Oncology Web site: www.cos.ca/cano/web/en/index.html

- Cancer Care Ontario. (2006). *Cancer in young adults in Canada*. Toronto, ON: Author.
- Carradice, A., Shankland, M., & Beail, N. (2002). A qualitative study of the theoretical models used by UK mental health nurses to guide their assessments with family caregivers of people with dementia. *International Journal of Nursing Studies*, 39, 17-26.
- Carr, L. (1994). The strengths and weaknesses of quantitative and qualitative research: What method for nursing? *Journal of Advanced Nursing*, 20, 716-721.
- Cella, D. (1994). FACT Manual (Version 3). Chicago: Rush-Presbyterian-St. Luke's Medical Center.
- Cella, D., Tulksy, D., Gray, G., Sarafian, B., Linn, E., & Bonomi, A. (1993). The functional assessment of cancer therapy (FACT) scale: development and validation of the general measure. *Journal of Clinical Oncology*, 11, 570-579.
- Ceronsky, C., Drew, D., Gutknecht, S., Koopmeiners, L., Kreitzer, M., Post-White, J., & Watrud Mackey, K. (1996). Hope, spirituality, sense of coherence, and quality of life in patients with cancer. *Oncology Nursing Forum*, 2, 1571-1578.
- Charlson, M. E., Pompei, P., Ales, K. L., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: Development and validation. *Journal of Chronic Disease*, 40, 373-383.
- Corner, J., Bredin, M., Krishnasamy, M., Plant, H., Bailey, C., A'Hern, R. (1999). Multicentre randomized controlled trial of nursing intervention for breathlessness in patients with lung cancer. *British Medical Journal*, 318, 901-904.
- Corsini, L., & Ammerman, D. (2008). Young adults and cancer: Reaching out with technology to enhance psychosocial care. *Oncology Exchange*, 7(3), 23-25.
- Crooks, D., Whelan, T., Reyno, L., Willan, A., Tozer, R., Ming, D., et al. (2004). The initial health assessment: An intervention to identify the supportive care needs of cancer patients. *Support Care Cancer*, 12, 19-24.
- Degner, L.F., Hack, T., O'Neil, J., & Kristjanson, L.J. (2003). A new approach to eliciting meaning in the context of breast cancer. *Cancer Nursing*, 26, 169-178.
- Derogatis, L. (1992). *The brief symptom inventory (BSI) administration, scoring and procedures manual-II (2nd ed.)*. Baltimore, MD: Clinical Psychometric Research.
- Derogatis, L., & Melisaratos, N. (1983). The brief symptom inventory: An introductory report. *Psychological Medicine*, 13, 595-605.

- Doyle, N. (2008). Cancer survivorship: evolutionary theme analysis. *Journal of Advanced Nursing*, 62, 499-509.
- Ebright, P., & Lyon, B. (2002). Understanding hope and factors that enhance hope in women with breast cancer. *Oncology Nursing Forum*, 29, 561-568.
- Eick-Swigart, J. (1995). What cancer means to me. *Seminars in Oncology Nursing*, 11, 41-42.
- Elixhauser, A., Steiner, C., Harris, D.R., & Coffey, R.M. (1998). Comorbidity measures for use with administrative data. *Medical Care*, 36, 8-27.
- Ferrans, C., & Powers, M. (1985). Quality of life index: development and psychometric properties. *Advances in Nursing Science*, 8(1), 15-24.
- Ferrell, B., Hassey Dow, K., Leigh, S., Ly, J., & Gulasekaram, P. (1995). Quality of life in long term cancer survivors. *Oncology Nursing Forum*, 22, 915-922.
- Ferris, B.G. (1978). Epidemiology standardization project. (American Thoracic Society). *American Review of Respiratory Disease*, 118(6,Pt.2), 1-120.
- Fitch, M. (2000). Supportive care for cancer patients. *Hospital Quarterly*, 3, 39-46.
- Fitch, M. (2005). Needs of patients living with advanced disease. *Canadian Oncology Nursing Journal*, 15(4), 230-235.
- Fitch, M., Gray, R., & Franssen, E. (2000). Women's perspectives regarding the impact of ovarian cancer. *Cancer Nursing*, 23(5), 359-366.
- Fitch, M., & Steele, R. (2003). Supportive care needs of cancer patients: Looking beyond the obvious. *Supportive Care Cancer*, 11(6), 423.
- Fitch, M. Steele, R., Alderson, D. Barrow, K., Constantine, T., & Doyle, C. (2004). Understanding the supportive care needs of patients with gynecological cancer. *Supportive Care Cancer*, 12(6), 411.
- Folkman, S., & Lazarus, R. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behaviour*, 21, 219-239.
- Folkman, S., & Lazarus, R. (1984). *Stress, Appraisal, and Coping*. Springer, New York.
- Geist, R., & Grdisa, V., & Otley, A. (2003). Psychosocial issues in the child with chronic conditions. *Best Practice & Research Clinical Gastroenterology*, 17, 141-152.
- George, L., & Bearon, L. (1980). *Quality of life in older persons*. New York: Human Sciences Press.

- Goetz, J., & LeCompte, M. (1981). Ethnographic research and the problem of data reduction. *Anthropology and Education Quarterly*, 12, 51-70.
- Giorgi, A. (1985). *Phenomenology and psychological research*. Pittsburgh: Duquense University Press.
- Golden, S, Horwich, C., & Lockrich, J. (1980). *Chemotherapy and you (DHEW Publication No. (NIF) 77-1136)*. Bethesda, MD: National Institutes of Health.
- Greer, S. (1989). Can psychological therapy improve quality of life for patients with cancer? *Journal of Cancer Care*, 59, 149-151.
- Gustafon, D. (2005). Needs assessment in cancer. In J. Lipcomb, C. Gotay, C. Synder (Eds.), *Outcomes assessment in cancer: Measures, methods, and applications* (pp.305-328). Cambridge, UK: Cambridge University Press.
- Haase, J., & Phillips, C. (2004). The adolescent/young adult experience. *Journal of Pediatric Oncology Nursing*, 21, 145-149.
- Harder, A. (2002). *The Developmental Stages of Erik Erikson*. Retrieved July 2008, from Learning Place Online.Com Web Site:
www.learningplaceonline.com/stages/organize/Erikson.htm
- Hayes, V.E., & McElheran. (2002). Family Health Promotion within the Demands of Pediatric Home Care and Nursing Respite. In L.E. Young, & V.E. Hayes (Eds.), *Transforming Health Promotion Practice: Themes, Issues, and Applications*. Philadelphia: FA Davis.
- Hays, J., & Morales, L. (2001). The RAND-36 measure of health-related quality of life. *Annals of Medicine*, 33, 350-357.
- Heidenreich, A., & Hofman, R. (1999). Quality of life issues in the treatment of testicular cancer. *World Journal of Urology*, 17, 230-238.
- Herth, K. (1991). Development and refinement of an instrument to measure hope. *Scholarly Inquiry for Nursing Practice*, 5, 39-51.
- Herth, K. (1992). Abbreviated instrument to measure hope: Development and psychometric evaluation. *Journal of Advanced Nursing*, 17, 1251-1259.
- HopeSpring Cancer Support Centre. (2007). *History and Mission Section*. Retrieved January 11, 2007 from HopeSpring Cancer Support Centre Web Site:
www.hopespring.ca/pgs/history.html
- Houldin, A., & Lewis, F. (2006). Salvaging their normal lives: A qualitative study of patients with recently diagnosed advanced colorectal cancer. *Oncology Nursing Forum*, 33, 719-725.

- Howell, D., Fitch, M., & Caldwell, B. (2002). The impact of interlink community cancer nurses on the experiences of living with cancer. *Oncology Nursing Forum*, *29*, 715-723.
- Huang, S.M., Lee, C.H., Chien, L.Y., Liu, H.E., & Tai, C.J. (2004). Postoperative quality of life among patients with thyroid cancer. *Journal of Advanced Nursing*, *47*, 492-499.
- Jones Jessop, D., & Stein, R. (1982). A non-categorical approach to chronic childhood illness. *Public Health Reports*, *97*, 354-362.
- Katz, J. N., Chang, L. C., Sangha, O., Fossel, A. H., & Bates, D. W. (1996). Can comorbidity be measured by questionnaire rather than medical record review? *Medical Care*, *34*, 73-84.
- King, C. (2006). Advances in how clinical nurses can evaluate and improve quality of life for individuals with cancer. *Oncology Nursing Forum*, *31*, Supplement, 5-11.
- King, C., Hinds, P., Dow, K., Schum, L., & Lee, C. (2002). The nurse's relationship-based perceptions patient quality of life. *Oncology Nursing Forum*, *29*, E118-E126.
- Knafl, K., & Deatrick, J. (2002). The challenge of normalization for families of children with chronic conditions. *Pediatric Nursing*, *28*(1), 49-57.
- Knafl, K., & Webster, D. (1988). Managing and analyzing qualitative data: A description of tasks, techniques, and materials. *Western Journal of Nursing Research*, *10*, 195-218.
- Kritcharen, S., Suwan, K., & Jirowong, S. (2005). Perceptions of gender roles, gender power relationships, and sexuality in Thai women following diagnosis and treatment for cervical cancer. *Oncology Nursing Forum*, *32*, 682-688.
- Kyngas, H., Mikkonen, R., Nousianinen, E.M., Ryttilahti, M., Seppanen, P., Vaattovaara, R., et al. (2000). Coping with the onset of cancer: Coping strategies and resources of young people with cancer. *European Journal of Cancer Care*, *10*, 6-11.
- Lacasse, C., & Beck, S. (2007). Clinical assessment of symptom clusters. *Seminars in Oncology Nursing*, *23*(2), 106-112.
- Languis, A., Bjorvell, H., & Antonovsky, A. (1992). The sense of coherence theme: it's relation to personality traits in Swedish sample. *Scandinavian Journal of Caring Sciences*, *6*, 165-171.
- Laubmeier, K., & Zakowski. (2004). The role of objective versus perceived life threat in the psychological adjustment to cancer. *Psychology and Health*, *19*(4), 425-437.

- Lawton, M.P. (1983). Environment and other determinants of well-being in older people. *The Gerontologist*, 23, 349-357.
- Lee, V., Cohen, R., Edgar, L., Laizner, A., & Gagnon, A. (2006). Meaning-making and psychological adjustment to cancer: Development of an intervention and pilot results. *Oncology Nursing Forum*, 33, 291-302.
- Levinson, D.J. (1978). *The seasons of a man's life*. New York: Ballantine Books.
- Lewisohn, P.M, Seeley, J.R., Roberts, R.E., & Allen, N.B. (1997). Centre for Epidemiologic Studies Depression Scale (CES-D) as a screening instrument for depression among community-residing older adults. *Psychology of Aging*, 12, 277-287.
- Liang, J.H. (1984). Dimensions of the life satisfaction and index A: A structural formulation. *Journal of Gerontology*, 39, 613-622.
- Lincoln, Y., & Guba, E. (1981). *Effective Evaluation*. San Francisco: Jossey-Bass.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. Thousand Oaks, CA: Sage.
- Lindop, E., & Cannon, S. (2001). Evaluating the self-assessed support needs of women with breast cancer. *Journal of Advanced Nursing*, 34, 760-761.
- Lock, K.K., & Willson, B. (2002). Information needs of cancer patients receiving chemotherapy in an ambulatory-care setting. *Canadian Journal of Nursing Research*, 34(4), 83-93.
- Lynam, M. J. (1995). Supporting one another: The nature of family work when a young adult has cancer. *Journal of Advanced Nursing*, 22, 116-125.
- May, K. (1989). Interview techniques in qualitative research: Concerns and challenges. In J. Morse(Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 188-201). Newbury, Park, CA: Sage.
- Mayfield, D., McLeod, G., & Hall. P. (1974). The CAGE questionnaire: Validation of a new alcoholism screening instrument. *American Journal of Psychology*, 131, 1121-1123.
- McCorkle, R. & Young, K. (1978). Development of a symptom distress scale. *Cancer Nursing*, 1, 373-378.
- McNair, D., Lorr, M., & Droppleman, L. (1971). *Manual for the profile of mood states*. San Diego: Educational and Industrial Testing Service.
- Molzahn, A. (2004). *Course syllabus: Project/Thesis manual. Session five: Writing the thesis* (pp. 85-95). Victoria, BC: University of Victoria School of Nursing.

- Morse, J. (2007). Strategies of intraproject sampling. In P. Munhall, *Nursing Research: A qualitative perspective* (4th ed.), (pp. 529-539). Sudbury, Massachusetts: Jones and Bartlett.
- Morse, J., & Field, P.A. (1995). *Qualitative research methods for health professionals*. Thousand Oaks, CA: Sage.
- Morse, J., & Neihaus. (2007). Combining qualitative and quantitative methods for mixed-method designs. In P. Munhall, *Nursing Research: A qualitative perspective* (4th ed.), (pp. 541-568). Sudbury, Massachusetts: Jones and Bartlett.
- Mottier, V. (2005). The interpretive turn: History, memory, and storage in qualitative research. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 6(2), Art. 33. Retrieved October, 2008 from Web Site: www.qualitative-research.net/fqs-texte/2-05/05-2-33-e.htm
- Myers, M. (2000). Qualitative research and the generalizability question: Standing firm with proteus. *The Qualitative Report* [On-line serial], 4(3/4). Retrieved October,, 2008 from Web site: www.nova.edu/ssw/QR/QR4-1/myers.html
- National Cancer Institute of Canada. (2003). Cancer incidence in young adults: Special topic from Canadian Cancer Statistics 2002. Retrieved January, 2007 from the National Cancer Institute of Canada Web site: www.ncic.cancer.ca/ncic/internet/standardpf/0,3621,846582243_85787780_9103580
- Nelson, E., Wasson, J., Kirk, J., Keller, A., Clark, D., & Dietrich, A. (1987). Assessment of function in Routine clinical practice: Description of the COOP chart method and preliminary findings. *Journal of Chronic Disease*, 40, 55-63S.
- Neugarten, B.L., Havighurst, R.J., & Tobin, S.S. (1961). The measurement of life satisfaction. *Journal of Gerontology*, 16, 134-143.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods*. Thousand Oaks, CA: Sage.
- Penman, D., Holland, J., Bahna, G., Morrow, G., Schmale, A., Derogatis, L., et al. (1984). Informed consent for investigational chemotherapy: Patients' and physicians' perceptions. *Journal of Clinical Oncology*, 2, 849-855.
- Pentheroudakis, G., & Pavilidis, N. (2005). Juvenile cancer: Improving care of adolescents and young adults within the frame of medical oncology. *Annals of Oncology*, 16, 181-188.
- Persson, L, Larsson, G., Ohlsson, O., & Hallberg, I.R. (2001). Acute leukemia or highly malignant lymphoma patients' quality of life over 2 years: A pilot study. *European Journal of Cancer Care*, 10, 36-47.

- Polit, D. F., & Beck, C. T. (2004). *Nursing research: Principles and methods* (7th ed.). Philadelphia: Lippincott Williams & Wilkins.
- Polit, D., & Hungler, B. (1991). *Nursing research: Principles and methods*. New York: JB Lippincott.
- Post-White, J., & Ceronsky, C., & Kreitzer, M. J., Nickelson, K., Drew, D., Watrud-Mackey, K., et al. (1996). Hope, spirituality, sense of coherence, and quality of life in patients with cancer. *Oncology Nursing Forum*, 23, 1571-1579.
- Powel, L. (1993). The impact of cancer on psychological well-being. *Quality of Life*, 1(2), 60-64.
- Radloff, L.S. (1977). The CES-D scale: A self report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401.
- Radloff, L.S., & Terri, L. (1986). Use of the Center for Epidemiologic Studies-Depression Scale with older adults. *Clinical Gerontologist*, 5, 119-136.
- Rehm, R., & Franck, L. (2000). Strategies of children and families affected by HIV/AIDS. *Advances in Nursing Science*, 23(1), 69-82.
- Ringdahl, G.I., & Ringahl, K. (1993). Testing the EORTC quality of life questionnaire on cancer patients with heterogeneous diagnosis. *Quality of Life Research*, 2, 129-140.
- Roberts, C., Piper, L., Denny, J., Cuddeback, G. (1997). A support group intervention to facilitate young adults' adjustment to cancer. *Health and Social Work*, 22, 133-141.
- Roberts, C., Severinsen, C., Carraway, C., Clark, D., Freeman, M., & Daniels, P. (1997). Life changes and problems experienced by young adults with cancer. *Journal of Psychosocial Oncology*, 15(1), 15-25.
- Rosenberg, M. (1979). *Conceiving the self*. New York: Basic Books.
- Rubenowitz, S. (1980). *Development of Methods To Map Out Psychological Factors Which Should Be Taken Into Consideration in Regional Planning* (3). Goteborg, Germany. Department of Psychology/University of Goteborg, Goteborg.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27-37.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23, 334-340.
- Sarna, L. (1993). Correlates of symptom distress in women with lung cancer. *Cancer Practice*, 1, 21-28.

- Sarna, L., Brown, J., Cooley, M., Williams, R., Chernecky, C., Padilla, G., et al. (2005). Quality of life and meaning of illness of women with lung cancer. *Oncology Nursing Forum*, 32(1), 9-19.
- Schag, C., & Heinrich, R. (1988). CARES Cancer Rehabilitation Evaluation System. Los Angeles, CA: CARES Consultants.
- Siegel, K., Gluhoski, V., & Gorey, E. (1999). Age related distress among young women with breast cancer. *Journal of Psychosocial Oncology*, 17, 1-19.
- Smith, B., Tang, K., & Nutbeam, D. (2006). WHO health promotion glossary: new terms. *Health Promotion International*, 21(4), 340-345.
- Smith, C., Haynes, K., Lazarus, R., & Pope, L. (1993). In search of the “hot” cognitions: Attributions, appraisals, and their relation to emotion. *Journal of Personality and Social Psychology*, 48, 813-838.
- Soanes, C., & Stevenson, A. (2005). *Oxford dictionary of english* (2nd ed.). London, England: Oxford University Press.
- Spiegel, D. (1992). Effects of psychosocial support on patients with metastatic breast cancer. *Journal of Psychosocial Oncology*, 10, 113-120.
- Stevens, M. (2005). The “Lost Tribe” and the need for a promised land: The challenge of cancer in teenagers and young adults. *European Journal of Cancer*, 42, 280-281.
- Su, Y., & Ryan-Wenger, N. (2007). Children’s adjustment to parental cancer. *Cancer Nursing*, 30(5), 363-381.
- Thewes, B., Meiser, B., Taylor, A., Phillips, K.A., Pendlebury, S., Capp, A., et al. (2005). Fertility and menopause related information needs of younger women with a diagnosis of early breast cancer. *Journal of Clinical Oncology*, 23, 5155-5165.
- Thomas, D. (2007). Adolescents and young adults with cancer: The challenge. *Palliative and supportive care*, 5, 173-174.
- Thorne, S. (2002). Health promoting interactions: Insights from the chronic illness experience. In L. Young, & V. E. Hayes, *Transforming Health Promotion Practice: Themes, Issues, and Applications* (pp. 59-69). Philadelphia: FA Davis.
- Thorne, S. (2008). *Interpretive description*. Walnut Creek, California: Left Coast Press Inc.
- Thorne, S., & Patterson, B. (2000). Two decades of insider researcher: What we know and don’t know about the chronic illness experience. *Annual Review of Nursing Research*, 18, 3-25.

- Thorne, S., Reimer-Kirkham, S., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health, 20*, 169-177.
- Thorne, S., Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge of interpretive description. *International Journal of Qualitative Methods, 3*, 1-21.
- Touhy, T. (2004). Dementia, personhood, and nursing: Learning from a nursing situation. *Nursing Science Quarterly, 17*(1), 43-49.
- Trask, P., Paterson, A., Fardig, J., & Smith, D. (2003). Course of distress and quality of life in testicular cancer patients before, during, and after chemotherapy: Results of a pilot study. *Psycho-Oncology, 12*, 814-820.
- Tucker, R., & Rahr, V. (1990). Nursing care of the patient with non-Hodgkin's lymphoma: A case study. *Cancer Nursing, 13*, 229-234.
- Van Weert, E., Hoekstra-Weebers J., May, A., Korstjens, I., Ros, W., & van der Schans, C. (2008). The development of an evidenced-based physical self-management rehabilitation programme for cancer survivors. *CP Patient Education & Counselling, 71*, 169-90.
- Vidich, A., & Lyman, S. (2000). Qualitative methods: Their history in sociology and anthropology. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research* (pp.37-84). Thousand Oaks, CA: Sage.
- Wang, S., Ku, N., Lin, H. & Wei, J. (1998). The relationship of symptom distress, social support and self-care behaviours in heart transplant recipients [Chinese]. *Journal of Nursing Research, 6*, 4-18.
- Ware, J., Kosinski, M., & Dewey, J. (2000). *How to score version two of the SF-36 Health Survey*. Lincoln, RI: Quality Metric Incorporated.
- Ware, J., Kosinko, M., & Keller, S. (1994). *Interpretation: Norm-based. In SF-36 physical and mental health summary scales: A user's manual* (pp. 8:3-8:38). Boston: Health Assessment Lab.
- Watson, J. (2005). *Caring science as sacred science*. Philadelphia, PA: Davis.
- Weinert, C. (1987). A social support measure: PRQ85. *Nursing Research, 36*, 273-277.
- Wolf, Z. R. (2007). Ethnography: The method. In P. Munhall, *Nursing Research: A Qualitative Perspective* (pp. 293-330). Sudbury, MA: Jones and Bartlett.
- Woodgate, R. (2006). The importance of being there: Perspectives of social support by adolescents with cancer. *Journal of Pediatric Oncology Nursing, 23*, 122-134.

World Health Organization. (2006). *Cancer: WHO cancer control programme*. Retrieved

October, 2006 from the World Health Organization Web site:

www.who.int/entity/cancer/en/

Young, L. (2002). Transforming health promotion practice: Moving toward holistic care.

In L. Young & V. E. Hayes, *Transforming Health Promotion Practice: Themes, Issues, and Applications* (pp. 3-21). Philadelphia: FA Davis.

Youngmee, K., Baker, F., Spillers, R., & Wellisch, D. (2006). Psychological adjustment of cancer caregivers with multiple roles. *Psycho-Oncology, 15*, 795-804.

APPENDIX A: RECRUITMENT POSTER



Are you a young adult between the ages of 20 and 44 who has been diagnosed with cancer and is currently undergoing chemotherapy and/or radiation treatment?

You are invited to take part in a study led by a nurse researcher to learn how you describe your needs as a young adult living with cancer. I am a Masters in Nursing student at the University of Victoria and this is my thesis work. It has been approved by the University of Victoria Ethics Board

Your involvement will be voluntary and strictly confidential.

Study Title: The Needs of Young Adults with Cancer

Purposes:

- **To learn more about the needs of young adults aged 20 to 44 living with newly diagnosed cancer and currently undergoing chemotherapy and/or radiation treatment.**
- **To enhance oncology care providers' understanding of the described needs of young adults with cancer.**
- **To identify nursing interventions that support the needs of young adults with cancer.**

What is Involved: One on one interviews in a private setting of your choice at home

Time Commitment: One to three meeting dates with the nurse researcher; approximately one to five hours in total of time commitment.

Duration: From

Contact Information for the Nurse Researcher/Principal Investigator:

Jennifer Parkins RN, BScN, CON(c), MN (candidate)

E-mail: parkins@rogers.com

Phone: 519 749-4370 ext. 5179

Thesis Supervisor: Dr. Virginia Hayes

University of Victoria

E-mail: vhayes@uvic.ca

Phone: 604 875-2000 loc 6723

APPENDIX B:
SEMI-STRUCTURED INTERVIEW PROMPTS

Potential questions will be as follows:

1. Please tell me a bit about how it's been for you living with your diagnosis (Houldin & Lewis, 2006).
2. Can you tell me how the cancer experience has impacted your family and social life?
3. Please tell me a bit about how you manage your symptoms.
4. Please share with me the experience living with the diagnosis of cancer and any difficulties you may be having.
5. Can you tell me about any spiritual affiliations you may have that have contributed to your life since the diagnosis of cancer?
6. Please share with me a time when a nurse was particularly supportive during your cancer experience and what he/she did that was supportive for you.

APPENDIX C:

CONTRACT FOR TRANSCRIPTIONIST

You have agreed to be a transcriptionist in a study entitled *The Needs of Young Adults with Cancer* that is being conducted by Jennifer Parkins. Jennifer Parkins is a graduate student in the department of Human and Social Development at the University of Victoria and you may contact her if you have further questions by phone: _____ or e-mail: parkins@rogers.com. As a graduate student, I am required to conduct research as part of the requirements for a degree in the Master's of Nursing, Advanced Practice Nursing Leadership program. You may contact my committee as follows:

Dr. Virginia Hayes (supervisor), (604) 875-2000 loc 6723 or e-mail vhayes@uvic.ca;

Dr. Kelli Stajduhar (committee member) (250) 721-7487 or e-mail kis@uvic.ca;

In addition to being able to contact the researcher and the committee at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research the University (250) 472-4362.

This is my contract for transcription of interview tapes constitutes an agreement between Jennifer Parkins, principal investigator and _____, transcriptionist. In agreeing to this contract, I _____ agree to the following:

- Audiotapes are to be transcribed verbatim, and in detail, according to the formal instructions of the principal investigator
- As the transcriptionist; I will maintain the confidentiality and privacy of participants. I will repeat no part of the participant dialogue and if I am aware of the identity of the participants, I will not reveal this information to anyone.
- The audiotapes, disks, and hardcopies of the data, when not being actively used by me for the transcription will be kept in a locked filing cabinet or a locked box supplied to me by the principal investigator.
- Once tapes and transcriptions (disks and hardcopies) are returned to the principal investigator, I will erase any and all computer files pertaining to this research.
- Payment will be made upon completion of transcripts at a rate of \$20.00 per hour of work. It is expected that each one hour tape will require three to four hours of transcription time.

Your signature below indicates that you understand the above contract conditions and that you have had the opportunity to have your questions answered by the researcher.

Name, address, phone number of Transcriptionist

Signature

Date

Name, address of Principal Investigator

Signature

Date

Name of Witness

Signature

Date

APPENDIX D:
WRITTEN CONSENT FORM

Faculty of Human and Social Development Participant Consent Form
University of Victoria

The Needs of Young Adults with Cancer

You are invited to participate in a study entitled The Needs of Young Adults with Cancer that is being conducted by Jennifer Parkins RN, BScN CON(C), Masters in Nursing student and Dr. Virginia Hayes of the University of Victoria, BC.

Jennifer Parkins is a graduate student in the School of Nursing at the University of Victoria and you may contact her if you have further questions by e-mail: parkins@rogers.com, _____

As a graduate student, I am required to conduct research as part of the requirements for a degree in Masters in Nursing. It is being conducted under the supervision of Dr. Virginia Hayes. You may contact my supervisor at 604 875-2000 ext. 6723.

This research is being funded by the Canadian Nurses Foundation.

Purpose and Objectives

The purpose of this research project is to learn more about the described needs of young adults aged 20 to 44 living with newly diagnosed cancer and currently undergoing chemotherapy and /or radiation treatment, to enhance oncology care providers' understanding of the described needs of young adults aged 20 to 44 and living with cancer, and to identify nursing interventions that support the needs of young adults aged 20-44 living with cancer.

Importance of this Research

Research of this type is important because a diagnosis of cancer changes every aspect of an individual's life. When a young adult has cancer he/she must attempt to balance peer and/or occupational endeavours in combination with managing a life threatening illness and complicated side effects. Therefore, health care providers need to examine the described needs of this population to enhance quality care and support systems.

Participants Selection

You are being asked to participate in this study because you are a young adult between the ages of 20 to 44 that has been diagnosed with cancer and are undergoing chemotherapy and/or radiation. The research team is interested in learning about your described needs.

What is involved?

If you agree to voluntarily participate in this research, your participation will include meeting with Jennifer Parkins on one to three occasions. The first meeting will be approximately thirty minutes to sixty minutes to discuss the study purpose, discuss informed consent and to sign the form agreeing to your participation in the research during the first meeting or in a second meeting, we will talk in a semi-structured way for about one hour about your experiences with cancer and your needs. Our conversation will be tape recorded. Afterwards, it will be professionally transcribed and analyzed to determine the themes concerning how you describe your needs, you may be asked to meet again with Jennifer, for approximately thirty minutes or an hour to discuss the general themes about young people living with cancer that she is finding in the data and also at that time you can clarify their relevance and meaning for your own cancer experiences. So the total time commitment will be between one and five hours.

Meetings will take place in a quiet room in a setting of your choice at your home or _____ Cancer Centre. Jennifer will encourage you to talk about your cancer experience, respecting you as the expert about your own health care “journey”. During the conversation, Jennifer will listen attentively to your ideas and will occasionally, make brief written notes. She will ask prompting questions about quality of life, health, and nursing care that you think is necessary. If you wish to terminate the interview or to stop the audiotape at any time, Jennifer will do so immediately. Everything you say on tape (data) will be stored in secured filing cabinets in a locked office and computer data will be stored with access protection for Jennifer Parkins only. Findings of the study will be shared with all members of the thesis committee at the University of Victoria, with other young adults with cancer at community events as appropriate, with the oncology care providers at educational activities and may be written up for scholarly presentation in an accredited nursing journal.

Inconvenience

Participation in this study may cause some inconvenience to you, including time commitment for study participation.

Risks

There are some potential risks to you related to participating in this research. You may feel sad, negative, or have other feelings, as you share your cancer experiences with the investigator. To prevent or to deal with these risks the following steps will be taken: Jennifer will maintain a respectful and a supportive research relationship with you at all times. If at any point you wish to stop the interview process or you wish to withdraw from study participation, your decision will be respected. Your treatment or access to services will in no way be affected by the decision to participate or not to participate in the study. Referral to psychosocial services at _____ Cancer Centre will be offered if you wish.

Benefits

The potential benefits of your participation in this research include: participants may experience therapeutic benefits in sharing their experiences and in describing their feelings as experts of their own health care journey. The described needs of the participants will serve to inform other young adults with cancer, health care providers, policy makers and society on how to improve quality supportive care for those living with and undergoing treatment for cancer.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be removed from the database and destroyed in the confidential waste system at _____ Cancer Centre or if you give permission, the existing data will be included in the analysis.

Researcher's Relationship with Participants

Jennifer is a Registered Nurse at _____ Cancer Centre. If you are a patient under the direct care of Jennifer, you will be excluded from the pool of participants to avoid any power associated with her role as a member of the health care team affecting the research. Jennifer will engage in a respectful and supportive research relationship with you at all times.

On-going Consent

To make sure that you continue to consent to participate in this research, at each new interview session you will be reminded of your voluntary participation, your right to withdraw at any time, and the study title, purpose, time commitments and length of

involvement and so on. You and Jennifer will record on tape your on-going consent. If you decide to withdraw from the study and you consent to have your comments up to that point, included as part of the data analysis, they will be utilized as part of the data analysis. This will be an additional signature on this consent form. If you do not wish to have your data included as part of the data analysis, they will not be included and will be disposed of in confidential waste.

Anonymity

In terms of protecting your anonymity, you will be required to meet with the investigator in a setting of your choice in a quiet room at your home or at _____ Cancer Centre. You may be seen coming in for your appointment for study participation by members of the community and by members of your health care team. The investigator will not discuss the names or identity of any of the study participants. Your participation in the study will be kept confidential.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by a locked filing cabinet and a computer with a security code for access in a locked office space. The principal investigator and thesis committee will be the only individuals with access to the collected data until the investigation is complete.

Right to Review

You have the right to ask Jennifer about the data being collected about you for the study and the purpose of these data. You also have the right to ask Jennifer to let you see your personal information and to make any necessary corrections to it.

Dissemination of Results

It is anticipated that the results of this study will be shared with study participants in the following ways: When the study is complete, Jennifer will mail you a thank you letter with an enclosed summary of the study results. You can specify whether or not you wish to receive these and the address to which they should be sent on the last page of this form. Also, if you wish to meet in person with Jennifer to discuss study results, a meeting will be set up at a mutually agreed time and place. The study finding will also be used for academic purposes as part of thesis completion requirements for the University of Victoria. The findings may be presented in an educational format to oncology care providers. They will also be reported as part of a progress report to the Canadian Nurses Foundation as part of the reporting structure for scholarship recipients. Further, the findings may be used in publication in a professional nursing journal.

Disposal of Data

Data from this study will be disposed of by computer deletion of files and disposal of all written material in the confidential waste collection system at _____ Cancer Centre. Data will be kept for five years post completion of the study and then will be destroyed in the confidential waste at _____ Cancer Centre. All audiotapes will be erased by Jennifer Parkins at such time.

Contacts

Individuals that may be contacted regarding this study include Jennifer Parkins RN, BScN, CON(C), MN (candidate) and Dr. Virginia Hayes. Please refer to contact information at the beginning of this consent form.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca) and Chair of the _____ Research Ethics Board, _____. You may contact my supervisor Dr. Virginia Hayes at 604 875-2000 ext. 6723. Locally you may contact thesis committee member Esther Devolin RN, CON(C), MSC at _____.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

NAME OF PARTICIPANT

SIGNATURE

DATE

CONSENT TO USE MY
EXISTING DATA DESPITE
PART WAY WITHDRAWL
FROM THE STUDY

INITIALS

DATE

A copy of this consent will be left with you, and a copy will be taken by the researcher