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SUPPORTING HOPE IN MIDLIFE CANCER SURVIVORS: INTERVENTION
WORKSHOP

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Abstract

Supporting Hope in Midlife Cancer Survivors: Intervention Workshop

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Problem: Cancer patients lack information and support needed to make the transition to survivorship. This problem was addressed by testing a psycho-educational group intervention, the Mid-Life Directions Workshop, for its effect on hope and quality of life in midlife cancer survivors.

Participants: Twenty-six midlife adults (23 women, 3 men, mean age = 54.3 years, range 40-65) with breast cancer (n = 19), colorectal cancer (n = 4), lung cancer (n = 2), and malignant melanoma (n = 1) stages I, II and III were recruited from two hospital-affiliated Cancer Centers in the Northeastern United States. Mean time since completion of active primary treatment was 11.5 months (SD = 6.67, range, 0-28 months). Most participants were non-Hispanic (96.2%) and white (100%) with some college or a college degree (88.5%).

Method: A multimethod experimental design randomly assigned 17 participants to the treatment group, receiving the Workshop in six 2-hour sessions, and 9 participants to the control group, receiving a Nutrition Program in six 1-hour sessions. Hope was measured pre- and post-intervention using the Herth Hope Index as was quality of life using the Quality of Life Instrument, Patient/Cancer Survivor Version. Written reflections were created by treatment group participants post-intervention.

Findings: The quantitative measures revealed a significant increase in hope ($p = .047$) for the control group. The treatment group reported positive effects on hope and quality of life by means of written reflections. Six themes emerged: 1) examining what is, 2) feeling connected, 3) accepting what is, even the painful, 4) embracing one's life experiences, 5) exploring new possibilities, and 6) moving forward with enthusiasm.

Implications: The Mid-Life Directions Workshop demonstrated positive effects on hope and quality of life for this group of midlife cancer survivors. The richness of the qualitative findings highlights the importance of multimethod design for future studies. The Nutrition Program also merits further study. This study provides an increased understanding of interventions that may support hope in midlife cancer survivors following active primary treatment.

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and supported me in this research using the Mid-Life Directions Workshop with cancer survivors. It has been my privilege to be affiliated with their groundbreaking work recognizing the challenges of midlife and creating workshops to assist people to move forward with integrity in the second half of life.

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Chapter 1
The Problem and Its Significance

Chapter 1

The Problem and Its Significance

Today 41% of all Americans can expect to be diagnosed with cancer during their lifetimes. There are currently 12 million cancer survivors and this number is growing, due to advances in cancer diagnosis and treatment. An individual is considered to be a cancer survivor “from the time of cancer diagnosis through the balance of his or her life” (Institute of Medicine, 2005, p. 2). While the term *cancer survivor* is used to refer to persons from the diagnosis of cancer onward, the term will be used in this study to refer to those who have completed active primary treatment for cancer.

Statement of Problem

The quality of life of the cancer patient and his or her family is integral to survivorship care. The National Cancer Institute’s Office for Cancer Survivorship considers the enhancement of the quality of life of the cancer survivor and his or her family to be a major part of its mission (National Cancer Institute, 2009). The National Institute for Nursing Research names quality of life as one of its four areas of research emphasis (Department of Health and Human Services, 2006).

Hope is an important component of quality of life and a key factor in coping with illness (Ersek, 2006; Ferrell, Hassey-Dow & Grant, 1995; Felder, 2004). Hope has been described in the nursing literature as multidimensional and dynamic (Cutcliffe & Herth, 2002; Dufault & Martoccio, 1985) and changing over time (Reb, 2007; MacLeod & Carter, 1999). Hope is the first strength which develops in infancy and is needed throughout the lifespan (Erikson, 1963). Hope plays an important role during life

transitions, providing strength for solving problems, setting goals and coping with loss (Rustoen et al., 1998). In the cancer population higher levels of hope are correlated with better quality of life (Herth, 2000; Duggleby et al., 2007).

How a person experiences the physical, psychological, spiritual and social well-being domains of his or her life is crucial to the cancer survivor's quality of life (Dow, Ferrell, Haberman & Eaton, 1999). Most cancer patients transition from active treatment to the post-treatment phase with little preparation for living with the medical, functional, and psychosocial consequences of cancer and its treatment (Rancour, 2008). While providing well for the physical aspects of care, most healthcare providers fail to adequately address the spiritual, psychological and social needs of the patient and his or her family. The Institute of Medicine's recent report (2007), *Cancer care for the whole patient: Meeting psychosocial health needs*, has set a new standard for the provision of appropriate psychosocial health services to all persons receiving cancer care. For the cancer survivor, transitions, such as the transition from active treatment to survivorship, are particular times of stress (Institute of Medicine, 2005). Times of transition require the attention of all healthcare providers, but especially nurses, in order to help patients maintain quality of life (Ferrell, Virani, Smith & Juarez, 2003; Meneses, McNees, Loerzel, Su, & Hassey, 2007).

The transition from active treatment to survivorship is a period of uncertainty which can affect the person's hope and quality of life. When a person is able to define and direct his or her quality of life, living takes on a meaning that is full and satisfying (Anderson, 2008). Yet navigating life's transitions is a challenging task, and the distress

of making the transition to an uncertain future can be great (Allen, Savadatti & Levy, 2009; O'Collins, 1995). Of particular concern to cancer survivors making the transition to the post-treatment phase are the fear of recurrence, fear of death, worry, and physical symptoms such as fatigue, trouble sleeping, and trouble concentrating (Institute of Medicine, 2005). Concerns may also include an altered sense of health and life itself, difficulties making life decisions, and other existential and spiritual issues (Institute of Medicine, 2005). Most people need information and support in order to make transitions successfully (Brewi & Brennan, 2004). It is reasonable to assume that the better the preparation is for the transition from active treatment to survivorship, the better will be the experience of quality of life during this phase of life.

The Institute of Medicine's *From cancer patient to cancer survivor: Lost in transition* (2005) has brought to attention the difficulties of this population. "Cancer survivors report ongoing struggles to achieve a balance in their lives and a sense of wholeness and life purpose after a life-altering experience" (Institute of Medicine, 2005, p.66-67). Furthermore the Institute of Medicine (2005) has specifically called for research on "interventions to improve the quality of life of cancer survivors" (p. 13). This research will address the problem that cancer patients are lacking information and support needed to make the transition to survivorship by testing a psycho-educational group intervention, *Mid-Life Directions: A Workshop for Personal and Spiritual Growth* (Brennan & Brewi, 2003), for its effect on hope and quality of life in midlife cancer survivors transitioning from active primary treatment to survivorship.

Significance of the Problem

Five-year survival rates for all cancers have increased from 50% in the 1970s to 66% at the beginning of this decade (American Cancer Society, 2009). Fourteen percent of all cancer survivors in the United States are living more than 20 years after diagnosis (Lewis, 2006).

The nearly 1.5 million people diagnosed with cancer every year in the United States face numerous challenges, many of which arise after initial treatment is completed and survivorship begins (Lewis, 2006). Most people who are faced with a life-limiting illness such as cancer, experience psychological distress and spiritual disorientation (Boyle, 2006; Breitbart, 2002). They remember the time, place and circumstances of their diagnosis. Time seems to stop for many people in that instant and the rest of their life is forever changed. Furthermore from the point of diagnosis forward the future will seem to the person as forever uncertain (Gorman, 2006; Mishel et al., 2005).

The time immediately following a diagnosis of cancer typically involves the crisis of telling loved ones about the illness and making treatment decisions. Many persons who are diagnosed with cancer follow the recommended course of treatment suggested by their doctors, and focus on the present. Feelings of denial, anger, depression, bargaining and acceptance may weave their way in and out of their day to day experiences (Gorman, 2006). Some sense of routine is achieved through the treatment regimen. At least while undergoing therapy, whether surgery, radiation, chemotherapy or some combination of therapies, most patients receive support from their physicians, nurses, family and friends (Mitchell, 2006). Side effects can be unpredictable and days can be occupied with doctor

visits, diagnostics and treatments. Communication with the healthcare team is consistent and often reassuring (Gorman, 2006).

Once the treatment phase is completed, the patient is placed on a follow-up plan with less frequent clinical evaluations. Life returns to a more routine pattern and doctor's visits are less frequent. In a sense, the support system provided by frequent contacts with the healthcare team is lessened, and the person may feel lost (Ferrell & Sun, 2006).

Coping during the post-treatment phase of survivorship has been the subject of recent studies, and the literature has been summarized by Boyle (2006) into seven themes. These are: 1) reactions of loss and grief, 2) recurrence of anxiety, 3) feelings of isolation and abandonment, 4) coping with transitional crisis, 5) dilemmas associated with reentry and work, 6) reevaluation of life priorities, and 7) family coping. Given these themes, the post-treatment phase presents an opportune time for the individual to re-evaluate and re-interpret what has happened in what may be experienced as a whirlwind (Rancour, 2008). The post-treatment phase can be used as a time to integrate what has happened and find new meaning and hope (Boyle, 2006). By supporting patients' hope as they address these themes, healthcare providers can promote improved quality of life in this patient population (Duggleby et al., 2007; Herth, 2000).

A long-accepted definition of hope has been articulated as "a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant" (Dufault & Martocchio, 1985, p. 380). Reflecting on this definition and the life situation of the person with cancer who is transitioning to survivorship, it is

reasonable to propose that hope is needed to create a life that is meaningful and desired, given all that has changed due to the diagnosis and treatment of cancer.

Hope has been found to influence positive adjustment in persons with cancer (Oncology Nursing Society, 2009). Research shows that hope is associated with increased quality of life in adults with cancer (Duggleby, 2007; Herth, 2000). Hope is needed by the cancer survivor to deal with the uncertainty of transitioning to life after cancer treatment.

As with all major life forces, hope is related to the person's developmental process (Erikson, 1963). Potentially, knowledge of the process of normal growth and development along with an opportunity to reflect on the cancer experience and redefine goals can assist the person to navigate his or her life into a preferred future, where hope is actualized and quality of life likely improved. One such opportunity can be provided to midlife cancer survivors by the Mid-Life Directions (MLD) Workshop.

Purpose of the Study

The purpose of this study is to test a psycho-educational group intervention, the MLD Workshop, for its effect on hope and quality of life in midlife cancer survivors. This includes adults between 40 and 64 years of age in the post-treatment phase of cancer, diagnosed at stages I, II or III, transitioning from active primary treatment to survivorship.

Definitions

Hope – Conceptual definition – “Hope is a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant” (Dufault & Martocchio, 1985, p. 380). Dimensions of hope included in this definition are: 1) cognitive-temporal, 2) affective-behavioral, and 3) affiliative-contextual.

Hope – Operational definition – A number on a scale of 12 to 48 (with a higher score denoting a higher level of hope) on the Herth Hope Index (Herth, 1992). Hope dimensions measured include: 1) temporality and future, 2) positive readiness and expectancy, and 3) interconnectedness. Instrument dimensions relate to the conceptualizations in the conceptual definition above.

Mid-Life Directions Workshop – Conceptual definition – A psycho-educational program which addresses the four hope attributes: experiential, relational, spiritual/transcendent and rational thought processes. The workshop provides external input and stimulates internal input to the four hope attributes.

Mid-Life Directions Workshop – Operational definition – A 12-hour program, delivered in six 2-hour sessions. Topics include psychological growth and development with a focus on the second half of life and open contemporary Judeo-Christian spirituality. The workshop is self-reflective, communal and experiential (Brennan & Brewi, 2003).

Midlife Cancer Survivors – Persons between 40 and 64 years of age in the post-treatment phase of cancer.

Post-treatment Phase of Cancer – The time after active primary treatment for cancer when follow-up care occurs. Initial therapy must be complete, but treatment with maintenance drug therapy, such as hormone or antibody therapy, will be considered part of routine post-treatment care.

Quality of Life – Conceptual definition – The person’s physical well-being, psychological well-being, spiritual well-being and social well-being as determined by the person.

Quality of Life – Operational definition – A score from 0 to 410 (with a higher score denoting better quality of life, and with subscales measuring each of the four dimensions mentioned in the conceptual definition) measured by the City of Hope Quality of Life Instrument, Patient/Cancer Survivor Version.

Assumptions Based on Existing Knowledge

The following are assumptions which underlie this research:

1. The diagnosis of cancer is experienced by the patient as a life-threatening event (Gorman, 2006).
2. While the second half of life is psychologically distinct from the first half of life, it is an extension of and continuous with the development achieved in the first half of life (Erikson, 1997; Jung, 1933).
3. For a person in midlife, a successful transition through the crisis of a life-threatening event, such as diagnosis and treatment for cancer, can be facilitated by exposure to knowledge, skills and experiences related to psychological and

spiritual growth and development in the second half of life (Brennan & Brewi, 2003).

4. A MLD Workshop provides knowledge, skills and experiences related to psychological and spiritual growth and development in the second half of life (Brennan & Brewi, 2003).
5. An opportune time for a person to find meaning in the life-threatening event of a diagnosis of cancer may be during the post-treatment phase of cancer.
6. Most individuals are capable of redefining their hope.
7. A successful transition through an experience of a life-threatening event can provide the basis for successful transitions through future life-threatening events.

Research Questions

1. Is there a difference in the level of hope of the treatment group when compared to the control group of midlife cancer survivors after the treatment group participates in a MLD Workshop?
2. Is there a difference in the quality of life of the treatment group when compared to the control group of midlife cancer survivors after the treatment group participates in a MLD Workshop?

Hypotheses

1. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have a higher level of hope.

2. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have greater gains in level of hope from pre-intervention to post-intervention.
3. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have a higher level of quality of life.
4. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have greater gains in level of quality of life from pre-intervention to post-intervention.

Chapter 2
Literature Review

Chapter 2

Literature Review

The focus of this research is the support of hope and quality of life in the midlife cancer survivor following initial treatment for cancer. Research shows that hope is needed throughout the cancer experience (Cooper, 2006) and that the post-treatment phase is a time when the individual is open to change (Allen, Savadatti & Levy, 2009). Addressing hope can lead to an increase in quality of life. Addressing hope in a developmentally appropriate way is supported by the literature (Bush, 2006), and can potentially be achieved by the Mid-Life Directions (MLD) Workshop. This chapter will outline the theoretical basis for this study and review the literature. The literature review will focus on hope and quality of life in adults with cancer and the psychology and spirituality of midlife. The MLD Workshop will be described as a potentially effective way of filling a crucial gap in the literature regarding interventions to support hope in midlife cancer survivors following initial treatment for cancer.

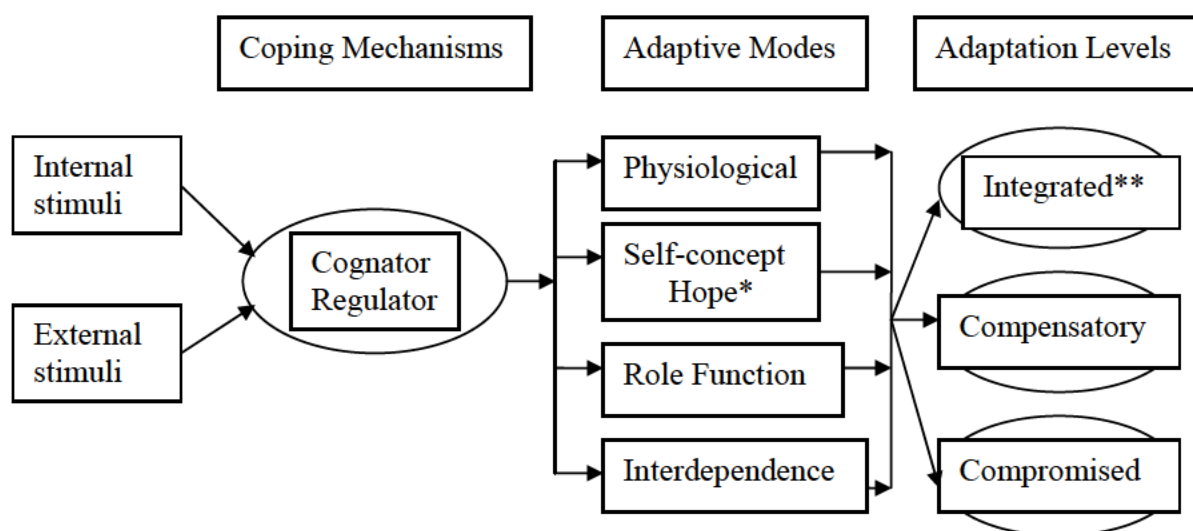
Theoretical Basis

The Roy Adaptation Model, the City of Hope Quality-of-Life Model for Cancer Survivorship, the Hope Process Framework, and Erikson's stages of psychosocial development form the basis from which the study framework is drawn. The first variable of hope is noted in each figure throughout with an asterisk (*), and the second variable of quality of life with a double asterisk (**).

The Roy Adaptation Model. The Roy Adaptation Model (Roy, 2009) provides the nursing theoretical basis for this research (see Figure 1). First described in the 1970s as a framework for nursing, the Roy Adaptation Model has undergone revision and development throughout the intervening years, and is still a work in progress, according to its author, Sister Callista Roy. Roy sees the role of the nurse to be the promotion of positive adaptation. She defines adaptation as “the process and outcome whereby thinking and feeling people, as individuals or in groups, use conscious awareness and choice to create human and environmental integration” (Roy, p. 26). In this model, when life processes are integrated with one another and the environment, “the structures and functions of a life process are working as a whole to meet human needs” (Roy, p. 27). Thus the integrated adaptive process is promoted by nurses for the individual and the group through nursing interventions. The ultimate goal of nursing interventions is to facilitate “humanization, meaning, choice, quality of life, and healing” (Willis, Grace & Roy, 2008, p. E28).

Figure 1

Grand Theory Level: Roy Adaptation Model (locating hope)



In line with this view of human adaptation in Roy's model, the MLD Workshop as a psycho-educational intervention promotes human integration. For the midlife person in the post-treatment phase of cancer, the workshop provides an opportunity to gain new knowledge and skills which may help the individual to integrate the personal experience of illness into the new experience of life as a cancer survivor by promoting positive adaptation through conscious awareness and choice.

According to the Roy Adaptation Model, there are four adaptive modes which "are related to how human systems respond to stimuli from the environment" (Roy, 2009, p.89). For the individual, these modes are the physiologic mode, the self-concept mode, the role function mode and the interdependence mode. The model is based on an interactive and holistic understanding of the self in the four adaptive modes. This study will focus on hope within the context of the self-concept mode. The self-concept mode involves making choices when facing changes in one's health and therefore applies to the person transitioning from cancer treatment to survivorship. Self-concept is defined as "the composite of beliefs and feelings that one holds about oneself at a given time" (Roy, p. 323). For the adult in the post-treatment phase of cancer care, the self-concept mode is utilized to adapt to the challenges of life after cancer diagnosis and treatment. "Adaptation in this mode affects the other three modes because people act out of who they are" (Roy, p. 321).

The self-concept mode includes the personal self and the physical self, with the basic processes of the developing self, the perceiving self and the focusing self. The focusing self will be the process used to explain hope in this framework. The focusing

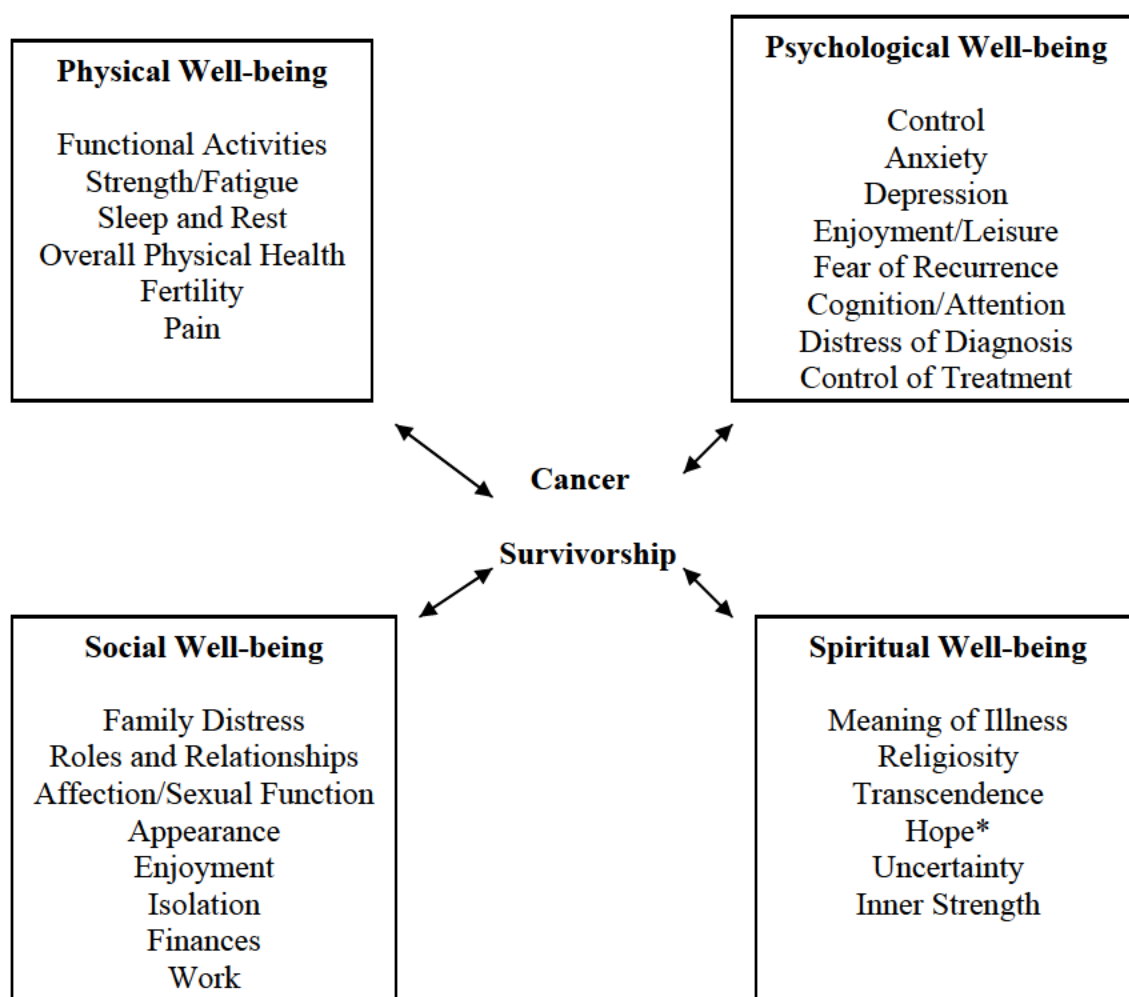
self is defined as “the process of being in touch with the physical and personal self in a way that surfaces hope, energy, continuity, meaning, purpose, and pride to be an individual self within the whole community; awareness of self, consciousness and meaning are transformed in person and environment integration, which the person focuses on by way of thinking and feeling” (Roy, 2009, p. 322). The person uses the focusing self “to maintain consistency and unity in the midst of many changes” (Roy, p. 331). This process explains how the cancer survivor is aware of the changes imposed by the diagnosis and treatment of cancer and how the cancer survivor finds the hope to transform the situation into healthy survivorship. Hope is related to quality of life which by definition is located in the concept of integrated adaptation.

The City of Hope Quality-of-Life Model. Related to the four adaptive modes in the Roy Adaptation Model is the City of Hope Quality-of-Life Model for Cancer Survivorship (Ferrell, Hassey-Dow & Grant, 1995). The Quality of Life Model is a framework that situates hope in the cancer survivor as part of quality of life (see Figure 2). According to this model quality of life consists of four domains – physical well-being, psychological well-being, spiritual well-being and social well-being. These can be seen as manifestations of the four adaptive modes in the Roy Model – the physiologic mode corresponding to the domain of physical well-being, the self-concept mode corresponding to the domains of psychological well-being and spiritual well-being, and the role function and interdependence modes corresponding to the domain of social well-being. When one of the quality of life domains is affected, the others are impacted as well, just as in the Roy model, adaptation in one mode affects the other three modes. Within the Quality of

Life Model, hope is identified as a part of the domain of spiritual well-being. This Model is used then to explain how hope functions as part of quality of life in the cancer survivor.

Figure 2

*Middle Range Theory: City of Hope Quality of Life Model for Cancer Survivorship***

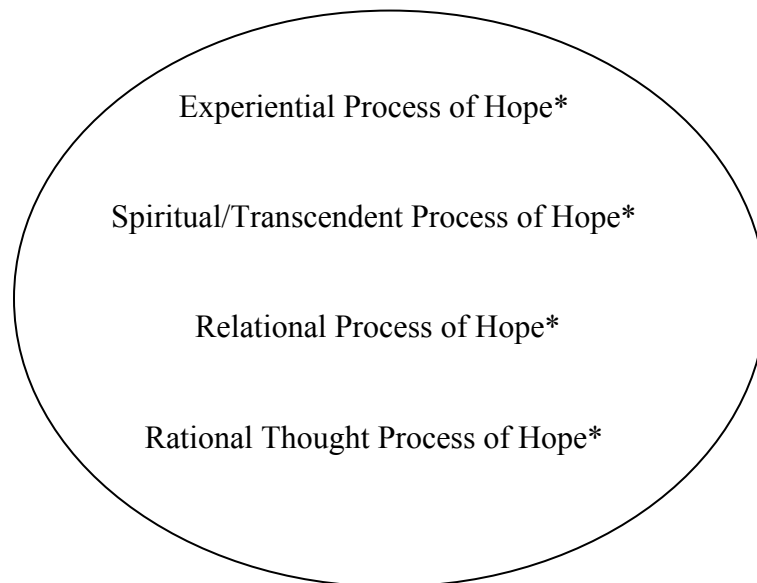


The Hope Process Framework. The Hope Process Framework of Farran, Herth & Popovich (1995) identifies four major attributes of hope and will be used to describe hope within the MLD Workshop (see Figure 3). The attributes include experiential,

spiritual/transcendent, relational and rational thought processes. Farran, Herth & Popovich say, “We think of the experiential process as the *pain* of hope, the transcendent or spiritual process as the *soul* of hope, the rational process as the *mind* of hope, and the relational process as the *heart* of hope” (p. 6).

Figure 3

Practice Level: Hope Process Framework



Erikson’s stages of psychosocial development. Erikson’s stages of psychosocial development (Erikson, 1963) will serve as a framework for changes in hope throughout the lifespan, with a focus on the adulthood (midlife) developmental stage and thus quality of life (see Table 1). Erikson’s theory is based on the premise that “human psychosocial development is not a random process, but an ordered unfolding of a ground plan existing in each person” (Phillips, 1992, p. 169). For Erikson, hope is the first strength to emerge as a result of the tension of trust versus mistrust in infancy. Hope then expands

throughout the lifespan to eventually extend between presumption and despair in the eighth developmental stage, that of old age (Erikson, 1997).

In midlife, the seventh developmental stage, hope expands within the specific developmental tension of generativity versus stagnation and is manifested through the adaptive strength of care. For the person in midlife, the task is to care for one's productivity and progeny in a way that is both self-giving and selfless, while avoiding the stagnation of self-absorption. For the cancer survivor, this task also can relate to quality of life.

Table 1

Practice Level: How Hope Expands in Erikson's Stages of Psychosocial Development

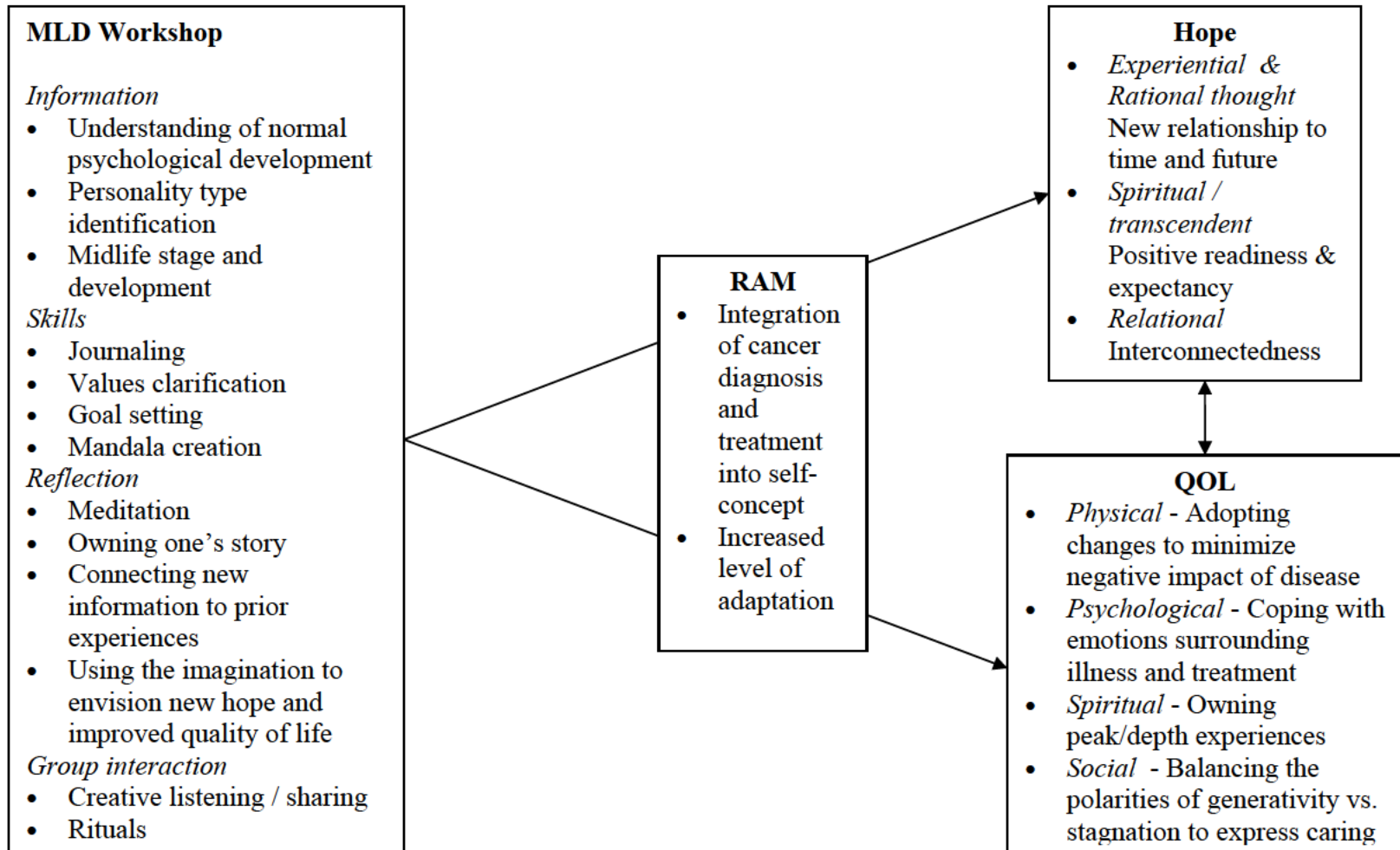
Stage	Age	Maladaptive Tendency	Syntonic	Adaptive Strength	Dystonic	Malignant Tendency
I	Infancy	Sensory maladjustment	Trust	<u>HOPE*</u>	Mistrust	Withdrawal
II	Early Childhood	Shameless willfulness	Autonomy	WILL	Shame & doubt	Compulsion
III	Play Age	Ruthlessness	Initiative	PURPOSE	Guilt	Inhibition
IV	School Age	Narrow virtuosity	Industrious-ness	COMPETENCE	Inferiority	Inertia
V	Adolescence	Fanaticism	Identity cohesion	FIDELITY	Role confusion	Repudiation
VI	Early Adulthood	Promiscuity	Intimacy	LOVE	Isolation	Exclusivity
VII	Adulthood	Overextension	Generativity**	CARE	Stagnation	Rejectivity
VIII	Old Age	<u>Presumption</u>	Integrity	WISDOM	<u>Despair</u>	Disdain

Research Framework

Based on the levels of theory discussed, the research framework is depicted in Figure 4. The variables, as defined conceptually and operationally in chapter 1, can be

summarized as flowing through a system of input, processes and output. The input is the psycho-educational intervention, the MLD Workshop. The workshop provides external stimuli in the form of workshop content, including information about the midlife psychological growth and development and skills such as values clarification and goal setting. The workshop also provides internal stimuli, generated from within the participant, through the workshop processes of reflection and group interaction. The MLD workshop assists the midlife cancer survivor to integrate the cancer experience through conscious awareness and choice, and transition to survivorship with an increased level of adaptation. The output is expected to be an increase in hope as measured by the Herth Hope Index in the dimensions of 1) temporality and future, 2) positive readiness and expectancy, and 3) interconnectedness. In addition an improvement in quality of life as measured by the Quality of Life Instrument, Patient/Cancer Survivor Version is expected in the domains of physical well-being, psychological well-being, spiritual well-being, and social well-being.

Figure 4

Research Framework

Review of Literature

For purposes of this project with cancer survivors, recent contributions to research on hope and quality of life in adults with cancer will be examined. The psychology and the spirituality of midlife will be described, and interventions to support hope in adults with cancer will be critiqued and synthesized. The Mid-Life Directions (MLD) Workshop, as an intervention to support hope in midlife cancer survivors, will be described as a potential way to fill a crucial gap in the literature.

Scope of the review of hope. In order to describe, critique and synthesize the literature regarding research on hope in adults with cancer, a primary research literature review was conducted. The time frame for the literature search ranged from 2005-2009. The reason for this time frame was that comprehensive reviews exist with summaries of the literature up to and including 2005 (Chi, 2007; Cooper, 2006). Literature available since this review is integrated into the discussion of findings in chapter 5. This chapter will review and critique current research and combine the findings with prior research.

The literature review focused on research on hope in adults with cancer. The criteria for inclusion were research studies investigating hope and quality of life in adults with cancer and published in the English language. Exclusion criteria were pediatric or adolescent studies, studies involving diseases other than cancer, and populations involving family or professional caregivers rather than patients.

Studies of hope. The sixteen articles reviewed involve both quantitative and qualitative research methods. Findings were critiqued and summarized using the research

framework for this study (see Figure 4). Studies were organized in tables representing qualitative studies (Table 2), non-experimental studies and one systematic literature review (Table 3), and experimental studies (Table 4). The research evidence was synthesized, and conclusions were drawn regarding opportunities for further study related to gaps in the literature and suggestions for advancing nursing knowledge particularly related to this study.

Qualitative studies. Six qualitative studies were reviewed (Table 2). The number of participants varied from 8-200 and populations consisted of the terminally ill (Elliott & Olver, 2007; Hong & Ow, 2007), women with breast cancer (Lindholm, Holmberg & Makela, 2005), ovarian cancer (Reb, 2007), those receiving chemotherapy (Mattioli, Repinski & Chappy, 2008) and cancer patients in general (Thorne, Hislop, Kuo & Armstrong, 2006). The studies were conducted in various countries – one study each in Australia, Canada, Finland, and Singapore, and two in the United States. All studies were critiqued for research purpose, sample, methods, data analysis and findings. Results were compared for contributions to knowledge of hope in adult cancer survivors. While taking into account the limited applicability of qualitative studies, results were analyzed for common themes. The following themes emerged: definitions of hope, communication, control, and spiritual and relational aspects of hope. Each of these themes will be described.

Table 2

Qualitative Studies

Author(s)	Purpose	Population	Design & Methods	Instrument(s) measures	Findings
Elliott & Olver, 2007	To examine the spontaneous use of hope in patients dying of cancer	28 terminally ill cancer patients (Australia)	Qualitative	Semi-structured interviews	Hope as a noun: need to fight disease, focus on medical domain; hope as a verb: active engagement in life, and individually defined good; hope involves responsibility, solidarity and interpersonal relationships. Even when dying, hope allows focus on the positive, connection with others, and engagement with life.
Hong & Ow, 2007	To explore hope from the patient's perspective	8 hospice patients (Singapore)	Qualitative	Interviews	Support from others, religion, acceptance of illness and knowledge of self in better condition than others were identified to promote hope. Decreased hope came from absence of family members. Healthcare providers were perceived as instilling hope when they provide care, provide emotional support and fulfill wishes. Spiritual and relational aspects of hope; open & honest communication with family members are important to patients.

Qualitative Studies

Author(s)	Purpose	Population	Design & Methods	Instrument(s) measures	Findings
Lindholm et al., 2005	To increase understanding of the significance of hope and hopelessness for patients' vitality	50 women with breast cancer (Finland)	Qualitative	Questionnaire with open- and closed-ended questions; one taped interview	Hope & hopelessness presuppose one other and stimulate vitality; sources of hope are: communion with others and meaning in life.
Mattioli et al., 2008	To explore and describe the meaning of hope and social support in patients receiving chemotherapy	14 cancer patients receiving chemotherapy	Qualitative descriptive	Semi-structured interviews	Focusing on the bigger picture (adaptation); taking cover in the storm (sheltering self from negative); keeping it normal (continuity with prior life); reaching out/not in this alone (seek faith, treatment potential, and others for support)
Reb, 2007	To describe the experience of hope in women with ovarian cancer	20 women with stage III or IV ovarian cancer	Grounded theory	Focused interviews	Facing the death sentence was the main concern, with three phases – shock, aftershock and rebuilding. Hope linked to core variable – transforming the death threat; hope necessary to find meaning, support & perceived control.
Thorne et al., 2006	To examine the impact of information provided in numerical form within provider communication from the patient	200 cancer patients (Canada)	Qualitative	Individual interviews, focus groups, written accounts	Undercurrent: context of cancer mortality; numerical information influenced hope; themes were calculating the odds, playing the odds, working against the odds; numbers perceived as being used to prevent or control unrealistic

Qualitative Studies

Author(s)	Purpose	Population	Design & Methods	Instrument(s) measures	Findings
	perspective				expectations with patient seeking to find hope, and professional seeking to manage unrealistic hope.

Definitions of hope. Hope was reported to be individually defined, and was recognized as both a noun and a verb by Elliott & Olver (2007). They studied 28 terminally ill cancer patients for their spontaneous use of hope in semi-structured interviews. As a noun hope was seen to involve the external forces of fighting a disease in medical terms. Hope was used actively as a verb indicating responsibility, solidarity and interpersonal relationships. While the analysis of spontaneous expressions of hope, and recognition of hope as individual to the patient were study strengths, limitations are inherent in separating the noun/verb aspects of an integral concept.

In a study of 14 cancer patients receiving chemotherapy, Mattioli et al. (2008) used semi-structured interviews to explore and describe the meaning of hope and social support in this population. Hope was seen as involving not only medical aspects, but all areas of life. In addition, hope had individual, multidimensional meanings for participants, and healthcare providers were seen as valuable sources of support. Other studies have supported their findings (Herth, 2000; Rusteon, Wiklund, Hanestad, & Moum, 1998). A limitation is that their sample involved mostly Caucasian and economically advantaged persons.

The experience of hope being challenged. Several studies referred to the experience of cancer as involving a death threat (Reb, 2007) and mortality (Thorne, et al., 2006; Lindholm et al., 2005) which challenged hope. Reb used grounded theory to describe the experience of hope in 20 women with advanced ovarian cancer. The main theme, identified as *facing the death sentence*, was closely linked to the core variable *transforming the death threat* in every phase of the patient's response. While the research was based on only one interview with each subject, the process of maintaining hope over time was constructed from the transcripts. In Thorne et al. examining the impact of information provided in numerical form (e. g. a therapy's success rate) within provider communication, an undercurrent of mortality was identified as a theme in their 200 Canadian cancer patients. Previous studies have supported this finding (Saleh & Brockopp, 2001; Buckley & Herth, 2004).

Lindholm et al. (2005) studied 50 women with breast cancer in Finland to increase understanding of the significance of hope and hopelessness for patients' vitality. Participants perceived hope to be in tandem with hopelessness, with one presupposing the other and stimulating vitality. "Hope, hopelessness and the core substance of health or vitality belong together. . . . Vitality is freed when hope and hopelessness are allowed to occur side by side" (p. 38). This study depicts hope in dynamic relationship with hopelessness. Hope then expands by means of the tension between hope and hopelessness. As noted, according to Erikson (1986) hope first emerges as a result of the tension between trust versus mistrust and expands through various forms of tension throughout the life span.

Communication. Communication was a theme that emerged in various studies as important to hope. Mattioli et al. (2008) spoke of patients receiving chemotherapy as sheltering the self from the negative by *taking cover in the storm* whereby communication was avoided at times to protect the self from negativity. Reb (2007) reported that ovarian cancer patients sought to both find and control information, thereby seeking to maintain hope.

Hong & Ow (2007) reported open and honest communication as important to hospice patients in Singapore. In interviews conducted to explore hope from the patient's perspective, communication with family members was identified as important to patients' hope.

Thorne et al. (2006) found that provider communication in numerical form was interpreted by patients as an attempt by healthcare professionals to manage the patient's unrealistic hope. This large study, involving 200 patient interviews, provided a unique focus on numerical information as specialized communication. The underlying theme of mortality has been noted. However, the authors also state, "Numerical information was powerfully associated in the patients' accounts with the desire to be hopeful and to have that hopefulness supported through reference to grounded, credible and 'reality-based' possibilities" (p. 327). This illustrates the variability of patient responses.

In general, communication was reported in all the studies reviewed as important to patients in relation to their hope. This communication involved both negative and positive elements which affected the patients' hope.

Control. Hope was seen as related to control issues for the patient. Control was reported by Reb (2007) as managing the uncertainty through various means of coping, such as rationalization, minimization, humor, and social comparisons to survivors. Different strategies used by patients at each of three phases of illness – shock, aftershock and rebuilding – were reported by Reb. For these women with ovarian cancer, hope was influenced by perceived control related to their illness. Elliott & Olver (2007) reported that hope in the terminally ill entailed an aspect of responsibility outside the self when hope was used as a noun. It was often focused on a cure, for which the medical profession was deemed responsible. The work of Thorne et al. (2006) also highlighted the theme of control in that, as noted earlier, patients interpreted provider communication in numerical form as an attempt to manage the patient's unrealistic hope.

One of Mattioli et al.'s (2008) findings was the need to maintain normalcy as an aspect of control. They reported that “many participants discussed the importance of continuing what they described as normal daily activities prior to their diagnosis of cancer and chemotherapy” (p. 826). Hong & Ow (2007) found in their sample of Singaporean hospice patients that hope involved acceptance of illness and seeking knowledge of themselves in a better state than others. This final finding was similar to patients in Reb's study (2007) comparing themselves to other survivors in order to bolster hope and maintain control of their disease.

Spiritual aspects of hope. Hope was seen as related to spiritual aspects and to relational aspects of patients' lives. Spiritual aspects of hope were identified by Hong & Ow (2007) as related to religion and by Reb (2007) and also by Lindholm et al. (2005) as

necessary to find meaning in life. Referring to the typical breast cancer participant in their study, Lindholm et al. noted, the patient “turns to God, and in the relation to an abstract other, she finds consolation and hope through prayer” (p. 36).

Relational aspects of hope. Relational aspects of hope featured prominently in most studies. In participants in Reb’s study (2007), hope was reinforced by support from family, friends and other survivors. In Hong & Ow’s (2007) participants, support from family and professional caregivers was important, and hope was diminished when family support was absent. Elliott & Olver (2007) mention the importance of interpersonal relationships, as do Lindholm et al. (2005) and Mattioli et al. (2008). Healthcare providers are mentioned (Hong & Ow) as instilling hope when they provide care, provide emotional support, and fulfill wishes.

Summary. In summary, the six qualitative studies speak of what constitutes hope and what is involved in the challenge of hope. In addition, the importance of communication and control is described, as well as hope’s spiritual and relational aspects.

Non-experimental studies. Non-experimental research (see Table 3) included six correlational descriptive studies, one repeated measures study, and one systematic review. The systematic review (Chi, 2007) will be integrated along with other studies into the discussion throughout this chapter. The number of participants per study ranged from 42-490 and included prostate cancer survivors (Blank & Bellizzi, 2006), women with breast cancer (Craig, 2005), newly diagnosed older patients (Esbensen, Osterlind & Hallberg, 2006), older Mexican American women with cancer (Farone, Fitzpatrick & Bushfield, 2008), patients receiving cancer treatment (Crothers, Tomter & Garske, 2005),

cancer patients in Taiwan (Lin & Tsay, 2005), and cancer patients in Italy before and after hospitalization (Vellone, Rega, Galletti & Cohen, 2006). All studies were critiqued for design, sample, measurement instruments, data collection, analysis, findings and discussion. Results were compared and summarized. Results are presented and levels of hope are identified.

Table 3

Non-Experimental Studies & One Systematic Review

Author(s)	Purpose	Population	Design & Methods	Instrument(s) or measures used	Findings
Blank & Bellizzi, 2006	To examine how hope, optimism, use of coping strategies, and primary treatment predict well-being, positive and negative affect, impact, depression, and adaptive changes among prostate cancer survivors	490 prostate cancer survivors	Correlational descriptive with regression analysis	Questionnaires including Snyder Hope Scale (measures hope agency & hope pathways)	Hope agency had significant, positive correlation with happiness and positive affect; significant negative correlation with depression and negative affect.
Chi, 2007	To synthesize the literature, develop generalizations, and identify issues that should be	26 studies on the role of hope in patients with cancer	Literature review 1982-2005	MEDLINE [®] , CINAHL [®] , PsycINFO databases	Hope had 4 major themes: exploring level of hope in patients with cancer; discovering how

Non-Experimental Studies & One Systematic Review

Author(s)	Purpose	Population	Design & Methods	Instrument(s) or measures used	Findings
	evaluated in the future in regard to hope and patients with cancer				patients cope with a cancer diagnosis; identifying strategies that patients use to maintain hope; and identifying nursing interventions to foster hope. New interventions to foster hope and instruments to measure hope were encouraged, as was the further development of the concept of hope.
Craig, 2005	To examine hope in women with breast cancer in relation to social support, resilience and self-esteem	137 women with breast cancer	Correlational descriptive with regression analysis	Herth Hope Index (HHI); Resilience Scale; Personal Resource Questionnaire; Rosenberg Self-Esteem Scale	Hope had significant positive correlation with social support, resilience and self-esteem. Regression analysis indicated that neither resilience nor self-esteem were mediators in the relationship between social support and

Non-Experimental Studies & One Systematic Review

Author(s)	Purpose	Population	Design & Methods	Instrument(s) or measures used	Findings
					hope.
Crothers et al., 2005	To obtain specific information re: the linkages between cancer patients' social support satisfaction and two QOL variables – affect and hope	42 patients receiving cancer treatment	Correlational descriptive with regression analysis	Social Support Inventory; HHI; Derogatis Affects Balance Scale	Hope had a high positive correlation with affect. Hope was predicted by social support satisfaction. Hope with relationship closeness predicted affective status.
Esbensen et al., 2006	To investigate quality of life (QOL) in persons aged 65 years and older diagnosed with cancer 3 months from the time of diagnosis; to investigate activities of daily living, hope, social network and support, and their relationship to QOL at 3 months after diagnosis	newly diagnosed older cancer patients T1= 101, T2= 85	Repeated measures correlational	European Organization for Research and Treatment of Cancer CLC-Q30 version 3; KATZ Activities of Daily Living Index; Nowonty Hope Scale	Hope was significantly decreased at 3 mo. on two subscales – <i>confidence</i> ($p = .003$) & <i>comes from within</i> ($p < .001$). Low level of hope, dependency in Instrumental Activities of Daily Living, and reduced economy were associated with a low level of QOL.

Non-Experimental Studies & One Systematic Review

Author(s)	Purpose	Population	Design & Methods	Instrument(s) or measures used	Findings
Farone et al., 2008	To explore the effects of hope and internal locus of control on the health and well-being of older women of Mexican origin who have been diagnosed with cancer	109 older Mexican American women with cancer	Correlational descriptive with regression analysis	Secondary data analysis of Hispanic Established Populations for the Epidemiologic Studies of the Elderly; Hope was taken from an item of the Center for Epidemiologic Studies Depression Scale	Hope had a significant positive association with health & well-being. Findings suggest an overlap between hope and locus of control. Hope was significantly associated with more favorable outcomes for self-rated health, restricted activity, negative affect, and somatic symptoms.
Lin & Tsay, 2005	To explore relationships among perceived diagnostic disclosure, health locus of control, and levels of hope.	124 cancer patients (Taiwan)	Correlational descriptive with regression analysis	HHI; Multidimensional Health Locus of Control Scale	Higher hope associated with knowledge of diagnosis; hope positively correlated with internal locus of control. Overall patients had medium level of hope.
Vellone et al., 2006	To describe the level of hope in Italian cancer patients; to compare the levels of hope	80 cancer pts during & after hospitalization (Italy)	Correlational descriptive	Hope Related Variable Questionnaire; Nowonty Hope Scale; Rotterdam Symptom	Hope was positively correlated with QOL, self-esteem, coping, adjustment to illness, well-

Non-Experimental Studies & One Systematic Review

Author(s)	Purpose	Population	Design & Methods	Instrument(s) or measures used	Findings
	during and after hospitalization; to determine if hope was correlated with QOL and several symptoms; to determine if the variables from the international literature also pertain to Italian patients			Checklist; Hospital Anxiety and Depression Scale	being, comfort in hospital, satisfaction with information received and support from family, healthcare professionals and friends. Hope was negatively correlated with anxiety, depression and boredom during hospitalization.

Factors positively correlated with hope. Hope was found to be positively correlated with multiple factors. Hope was positively correlated with health (Farone et al., 2008; Vellone et al., 2006), quality of life (Esbensen et al., 2006; Vellone et al.), well-being (Vellone et al.), happiness (Blank & Bellizzi, 2006), and comfort in the hospital (Vellone et al.). Studies by Craig (2005) and by Vellone et al. each found hope to be positively correlated with self-esteem, while Blank & Bellizzi and Crothers et al. (2005) found hope to be correlated with positive affect. Additionally, Craig determined that hope was positively correlated with resilience.

Once again, communication and information emerged in the findings of non-experimental studies as they did in qualitative studies. Knowledge of the diagnosis was found to be positively correlated with hope (Lin & Tsay, 2005). Vellone et al. (2006) found hope to be positively correlated with the degree of satisfaction with information received from health providers.

Coping and adjustment to illness were identified to be positively correlated with hope (Vellone et al., 2006) as was internal locus of control (Lin & Tsay, 2005). This is consistent with findings reported by Chi (2007). However, some overlap between the variables of hope and locus of control was identified by Farone et al. (2008) with hope mediating better outcomes.

Social support was correlated with hope (Craig, 2005) and related to the support of family, friends and healthcare providers (Vellone et al., 2006). Hope was predicted by social support satisfaction in the analysis done by Crothers et al. (2005). In the same study, hope and relationship closeness were found to predict affective status. The positive correlation of hope and social support/relationships is also consistent with many of the studies reviewed by Chi (2007).

Factors negatively correlated with hope. Hope was found to be negatively correlated with depression (Blank & Bellizzi, 2006; Vellone et al., 2006) and with negative affect (Blank & Bellizzi). Negative associations were also found with health locus of control based on chance, when the patient believes that outside factors control one's destiny (Lin & Tsay, 2005). Hope was also found to be negatively correlated with anxiety and boredom during hospitalization (Vellone et al., 2006).

Levels of hope. Levels of hope were reported on average to be moderate (Crothers et al., 2005; Vellone et al., 2006) or medium to high (Lin & Tsay, 2005) and not related to stage of disease (Crothers et al.; Vellone et al.; Lin & Tsay). However Esbensen et al. (2006) reported that levels of hope in older newly diagnosed cancer patients decreased after 3 months. Two factors as measured by the Nowonty Hope Scale were decreased (Esbensen et al.). These were the factors of *confidence* ($p < .05$) and of *comes from within* ($p < .001$). These factors pertain to the existential/spiritual attribute of hope identified by Farran, Herth & Popovich (1995).

Systematic review. The systematic review of the literature on hope in cancer patients from 1982-2005 represents a comprehensive review of the literature before 2005 (Chi, 2007). Significant results were that level of hope was not related to cancer stage; and that hope was positively correlated with level of control, level of coping and spiritual well-being. Also reported were strategies which patients used to maintain hope – religion and prayer, living in the present, relationships with others, situation control and symptom control, positive thinking, and uplifting memories.

Summary. In summary hope is positively correlated with health, quality of life, spiritual well-being, happiness, level of control, internal locus of control, level of coping, adjustment to illness, social support, knowledge of the diagnosis, and satisfaction with information received from health providers. Hope is negatively correlated with depression, negative affect, chance locus of control, and anxiety. Levels of hope were reported on average to be moderate to high, and not related to stage of disease. However

one study (Esbensen et al., 2006) reported that levels of hope in older newly diagnosed cancer patients decreased after 3 months.

Experimental studies. Three experimental studies were reviewed (Table 4). Each study provided a nursing intervention program to support hope in various populations of patients with cancer. A feasibility study (Cantrell & Conte, 2008) which examined the possibility of extending the Hope Intervention Program (Herth, 2000) to a new cancer population and in a new format, while not a true experiment, will also be reviewed in this section.

Table 4

Experimental Studies

Author(s)	Purpose	Population	Design & Methods	Instrument(s) measures	Findings
Duggleby et al., 2007	To evaluate the effectiveness of a psychosocial supportive intervention called the <i>Living with Hope Program</i> in increasing hope and QOL for older adult, community-living, terminally ill cancer patients	60 terminally ill persons with cancer, 60 years and older, living in the community (Canada)	Experimental mixed method, cross-over, with intervention group (n=30) and control group (n=30)	Herth Hope Index (HHI); McGill QOL Questionnaire; Interviews	The levels of hope and quality of life were significantly increased post intervention in the intervention group when compared with the control group. Qualitative data showed a majority of the subjects in the intervention group (61.5%) reported that the intervention increased their hope.
Herth, 2000	To determine whether a	115 persons	Quasi-experimental	HHI; Cancer Rehabilitation	The levels of hope and QOL were

Experimental Studies

Author(s)	Purpose	Population	Design & Methods	Instrument(s) measures	Findings
	nursing intervention would positively influence levels of hope and quality of life in patients with cancer	with a first recurrence of cancer, ages 21-80 years	with hope group (n=38), informational group (n=37) and control group(n=40)	and Evaluation Systems – short form (CARES-SF)	significantly higher for the hope intervention group compared to the other groups at 2 weeks, 3 months, 6 months and 9 months post intervention.
Rustoen et al., 1998	To evaluate the effect of a nursing intervention on hope and quality of life in cancer patients	96 newly diagnosed cancer patients, ages 26-78 (Norway)	Experimental design with intervention group (n=32), attention control group (n=23) and control group (n=41)	Nowonty Hope scale, Quality of Life Index, CARES-SF	The level of hope was significantly increased in the intervention group immediately post intervention, but not at 6 months post intervention. QOL was unchanged.

Rustoen, Wiklund, Hanestad & Moum (1998) studied an intervention program to increase hope and quality of life. The program was conducted with newly diagnosed Norwegian cancer patients in eight 2-hour sessions focused on various aspects of Nowonty's definition of hope. Themes included belief in oneself and one's own ability; emotional reactions after a cancer diagnosis; relationships with family, friends and colleagues; active involvement; spiritual beliefs and values; and acknowledging that there is a future. The 96 newly diagnosed cancer patients were randomly assigned to the intervention group (n=32), attention control group (n=23) or the control group (n=41). The attention control group received an equal number of sessions with information about

cancer and the human body; cancer treatment; symptoms; somatic side effects associated with the disease and its treatment; and self-help activities. The control group received usual care. Results showed a significantly higher level of hope in the hope intervention group ($p < 0.05$) as compared with the control and attention control groups, but the increase did not remain 6-months post intervention. There was no difference in quality of life measures. While this was a well-designed experimental study, only 28% of qualified patients consented to participate. There was, however, a 73% completion rate.

Herth, (2000) conducted a quasi-experimental study with 115 persons experiencing a first recurrence of cancer. The Hope Intervention Program (HIP), based on the four attributes of hope (Farran, Herth & Popovich, 1995) and delivered in eight 2-hour weekly sessions, included themes of searching for hope; connecting with others; expanding the boundaries; and building the hopeful veneer. Subjects were randomly assigned to the hope group ($n=38$), informational group ($n=37$) or control group ($n=40$). The informational group received information about cancer and the human body; cancer treatment; symptoms; and somatic side effects associated with the disease and its treatment. The control group received usual care. Those participating in HIP showed an increase in levels of hope and quality of life ($p < 0.05$) when compared with the informational and control groups. The increases in hope and quality of life were sustained over time as measured immediately post intervention, and at 3-, 6- and 9-months post intervention. This well-designed quasi-experimental study had 92% of eligible subjects consent to participate and a 95% study completion rate.

Duggleby et al. (2007) conducted a study in Canada with 60 terminally ill cancer patients over the age of 60 years. The subjects were randomly assigned to an intervention group (n=30) or a control group (n=30) and cross-over of the control group was made at the end of the study to allow all participants to benefit from the intervention, the Living with Hope Program. In this program participants viewed an award-winning film on hope and then chose one of three hope activities on which to work during a one-week period immediately following the viewing. The control group received standard care. Hope was measured pre-and post-intervention using the Herth Hope Index (Herth, 1992). Quality of life was measured using the McGill Quality of Life Questionnaire (Cohen, 1997). In addition, qualitative data were collected from the treatment group using open-ended questions about hope. Results showed a significant increase in hope ($p < 0.05$) from baseline to after the intervention in the intervention group when compared to the control group. Qualitative data confirmed the finding with more than half the intervention group reporting that the program increased their hope. In this well-designed study 88% of eligible subjects consented to participate and 97% completed the study. A limitation of the study is a lack of diversity in the sample (96.7% Caucasian).

The feasibility study (Cantrell & Conte, 2008) is evaluated here for its planned extension of the Hope Intervention Program (HIP) to a new population, young adult cancer survivors, and delivered in a new way, via the web. While HIP was initially developed and successfully used as an intervention by Herth (2000) using small group interactive format sessions to increase hope and quality of life in adults with a first recurrence of cancer, Cantrell & Conte examined the feasibility of adapting HIP to meet

the developmental needs of young adults when delivered online with the use of educational software that included web-based cameras and on-line voice and text chat capabilities. Evaluation was conducted with survey questions with a Likert-like scale rating helpfulness of the sessions at the end of the program, and a follow-up online session 6 months later to elicit thoughts and reflections. Limitations of the study were small sample size and the participation of only 3 members at the online 6-month evaluation session. However limited, the evaluation did support the web-based HIP intervention as an effective way to promote human-to-human interactions to foster hope.

Summary. These studies support the notion that nursing interventions designed to support hope can positively influence patients' hope and quality of life. Nursing as a profession has long advocated the integration of biological and behavioral aspects of the discipline's science (Jacox, Suppe, Campbell & Stashinko, 1999) and that adult education should be tailored, specific and concise using a multifaceted approach (Bugge & Higginson, 2006). These interventions demonstrate the use of various multifaceted interventions integrating the physical, psychological, spiritual and social aspects of care tailored to the support of hope and quality of life in persons with cancer. Two intervention programs were delivered in eight 2-hour sessions (Herth, 2000; Rustoen, 1998) with cancer patients experiencing a first cancer recurrence, and with the newly diagnosed, respectively, while the program for those who were terminally ill (Duggleby et al., 2007) was delivered in one week, a concise format appropriate for the palliative care population.

While various patient populations were studied (cancer patients who were newly diagnosed, those experiencing a first cancer recurrence or those who were terminally ill), none addressed the post-treatment phase of cancer when the person is transitioning to survivorship. In addition, all three of the experimental studies included midlife participants (Duggleby et al, 2007; Herth, 2000; Rustoen et al., 1998), but none focused on this cohort exclusively.

Hope in adults with cancer. Hope is defined as “a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant” (Dufault & Martocchio, 1985, p. 380). This classic definition by Dufault & Martocchio has helped to define the concept of hope in seriously ill patients. Many scholars agree that hope is complex and multidimensional (Clukey, 2007; Cutcliffe & Herth, 2002; Fitzgerald Miller, 2007). Hope is focused not only on a cure of disease, but changed and redefined by the patient over time (Reb, 2007; MacLeod & Carter, 1999).

Farran, Herth & Popovich (1995) describe hope as follows:

Hope constitutes an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving, and a way of relating to oneself and one’s world. Hope has the ability to be fluid in its expectations, and in the event that the desired object or outcome does not occur, hope can still be present. (p. 6)

This description includes the four attributes of hope in the Hope Process Framework – experiential, relational, spiritual/transcendent and rational thought processes – which

have been confirmed by subsequent research findings (Cantrell & Conte, 2008; Duggleby, 2007; Herth, 2000), and which form part of the framework for this study.

Hope influences positive adjustment in persons with cancer (Oncology Nursing Society, 2009) and is associated with increased quality of life in adults with cancer (Duggleby, 2007; Herth, 2000). A recent comprehensive review of 26 nursing research articles on hope published between 1982-2005, concluded that the level of hope is not related to cancer stage, and that the level of hope was significantly positively correlated with the patient's level of control and level of coping (Chi, 2007). This rigorously conducted review was an evaluation of the state of the science on hope in persons with cancer. The author concludes, "The most important finding was that nursing intervention programs demonstrated positive effects on hope" (p. 422), supporting the purpose of this study, which is to measure the effect of a nursing intervention program, the Mid-Life Directions Workshop, on hope in adults between 40 and 64 years of age transitioning to cancer survivorship.

Historical themes of hope generated by qualitative studies in the late 1970s and early 1980s were outlined by Herth (1992). These are: 1) the interpersonal element, 2) the time-oriented, future focus of hope, and 3) the goal-achievement expectation of hope. Additional dimensions of hope uncovered by qualitative research in the late 1980s through the early 1990s are: 1) a more global, non-time oriented sense of hope, 2) hope despite diminished or absent interpersonal relationships, 3) hope as a sense of *being* available and engaging in relationships as opposed to *doing* for oneself and others, and 4)

the potential of hope for controlling behavioral or emotional responses as opposed to control of events or experiences (Herth, 1992).

Summary of research findings. In summary, the literature has covered the major elements of the research framework for this study. The attributes of hope in the Hope Process Framework (Farran, Herth & Popovich, 1995) have been supported by the research. Qualitative and non-experimental studies describe hope as experiential, spiritual/transcendent, relational and involving rational thought processes. Nursing intervention programs designed to support hope have used the attributes in their composition (Duggleby et al., 2007; Herth, 2000; Rustoen et al., 1998).

The research supports the placement of hope in the domain of spiritual well-being in the City of Hope Model for Cancer Survivorship (Ferrell, Hassey-Dow & Grant, 1995). The qualitative literature identifies religion, turning to God in prayer, and searching for meaning as aspects of hope, which are labeled in the spiritual domain of the model as *meaning of illness* and *religiosity*. Non-experimental studies identify factors positively correlated with hope, which can be categorized as part of the other domains in the model. Control, anxiety and depression are part of the model's psychological well-being domain. Health is listed as part of the physical well-being domain. Social support can be understood as part of the social well-being domain. Given that each domain affects the others, the literature, by identifying these correlations, can be said to support the model.

The dynamic interaction of the adaptive modes in the Roy Adaptation Model (Roy, 2009) has been supported by the research. The research describes how the cancer

survivor seeks to maintain normalcy, both by controlling and seeking information, then interpreting information as it affects hope. This is consistent with the Roy Adaptation Model's description of how the person in the self-concept mode uses the focusing self through thinking and feeling to adapt to the challenges of life brought about by the cancer diagnosis and treatment. The theoretical perspective is not only supported but also confirms that nursing interventions can positively influence hope, which is expressed in the model as a higher level of integrated adaptation.

The research also supports Erikson's Stages of Psychosocial Development (Erikson, 1963). Issues identified by the research illustrating a dynamic tension of opposites include confronting mortality, that is, living or dying, and balancing hope between honesty and denial (sheltering the self from the negative). Studies show that hope and hopelessness can co-exist. Since in midlife the positive energy of generativity is in tension with the negative energy of stagnation, the basic strength of hope, along with all of the other strengths achieved in earlier life stages, expands within the tension of these opposites Erikson's Stages of Psychosocial Development help to place the dynamic aspect of hope within normal growth and development for the person in midlife. This dynamic will be described in greater detail in the section on the psychology of midlife.

Quality of Life

Because of its relationship to hope and because of its placement in this study as a dependent variable, quality of life (QOL) will be reviewed as a major concept in cancer care. QOL has appeared with progressively more frequency in the cancer literature over the past 25 years, especially in research (Haylard & Ferrans, 2008). The concept of QOL

in adults with cancer has been reviewed and knowledge synthesized in the nursing literature (King, 2006; Carr, 2008). Nursing research is augmented by QOL research in the fields of psychology, behavioral medicine, multicultural studies, consumer marketing, and mass communication (Carr, 2008; Diener, Shu, Lucas & Smith, 1999). Recently the measurement of QOL has begun to extend from the research arena to the clinical arena (Berry et al., 2004; Ferrell, 2008).

Concept development. The history of the development of this concept can be traced to the ancient Greek philosophers who debated what constituted the *good life* (Collinson & Plant, 2006). More recently Frankel's work on *making meaning* described as a basic human need (Frankel, 1963) has influenced interest in the study of quality of life. Quality of life has also been called subjective well-being (Diener et al., 1999). In 1967 Wilson described subjective well-being as the result of being young, healthy, well educated, well paid, extroverted, optimistic, worry free, religious, married, with high self-esteem, job morale, modest aspirations, of either sex and having a wide range of intellectual abilities (Diener et al., 1999). Over the past 40 years research has moved beyond categorizing the various resources and demographic factors that may be associated with QOL to a better understanding of the individual's personality traits, goals, culture, coping and adaptation, and how these factors work together to influence QOL (Cantrell, 2007).

The importance of QOL in healthcare became apparent in the early 1980s when advances in healthcare, and cancer care in particular, had demonstrated the ability to do harm. For example, chemotherapy side effects were often severe and sometimes life-

threatening. Nurse researchers began focusing on QOL and developing instruments to measure it (Ferrans & Powers, 1985; Ferrell, Wisdom, Wenzel & Schneider, 1989).

Instruments. Instruments to measure QOL have been developed ranging from scales rated by the healthcare provider, for example the Karnofsky Performance Scale, (<http://www.hospicepatients.org/karnofsky.html>), to scales rated by both patient and provider, for example the European Organization for Research and Treatment of Cancer QOL Questionnaires (http://groups.eortc.be/qol/questionnaires_q1qc30.htm), and scales rated strictly by patients, for example the City of Hope QOL instruments (http://prc.coh.org/qual_life.asp). These instruments capture various aspects of what would be considered health-related QOL, such as physical, medical, psychological, spiritual, economic, social, and family factors (Ferrans, 2007). Because they measure different aspects of QOL and therefore yield different results, the various instrument ratings are not necessarily able to be compared (Haylard & Ferrans, 2008).

As noted, the City of Hope QOL Model for Cancer Survivors (Ferrell, Hassey-Dow & Grant, 1995) was chosen for this study. The City of Hope Model defines QOL as a multidimensional construct with four dynamic domains. What distinguishes this model is that QOL is presented from the patient's perspective and as defined by the patient. Researchers at the City of Hope uncovered what patients had to say about their QOL (Dow, Ferrell, Haberman, & Eaton, 1999) and used this information to create the initial QOL instrument for bone marrow transplant survivors (Ferrell et al., 1992). Validation of core measures allowed for the evolution of instruments for specific cancer populations.

The City of Hope QOL model and tools are based on more than 25 years of research and over 50 clinical studies (Ferrell, 2008).

A research priority. In 1999 the National Institute of Nursing Research (NINR) began including QOL as one of its scientific goals (Grady, 1999). In recent years there has been a gradual shift in emphasis from treatment to prevention and from acute illnesses to chronic conditions. The current NINR Strategic Plan (2006-2010) includes “improving quality of life” as one of its four areas of research emphasis. The report states

Even successful treatment and survival of disease often leave patients facing many challenges in daily living. Our science offers many opportunities for research that will improve quality of life by enhancing the individual’s role in managing disease, relieving symptoms of disease and disability, and improving outcomes. (NINR, 2007, p. 17)

QOL is beginning to be recognized by the healthcare community as providing important information for clinical decision-making that might be otherwise overlooked (Haylard & Ferrans, 2008). While much progress has been made, current research seeks to expand the knowledge base by evaluating the applicability of QOL instruments to more diverse populations (Ferrell, 2008). Moving the evaluation of QOL into the clinical setting is important so that patients’ QOL is communicated, and that QOL concerns can be addressed with appropriate and timely interventions as part of quality cancer care (Ferrell, 2008).

Intervention studies. Relevant research for this study will focus on intervention studies to increase QOL in adult post-treatment cancer survivors. Studies conducted primarily with older adults (> 65 years) and survivors of childhood cancer were excluded. Three intervention studies which met these criteria were identified in the literature (Dirksen & Epstein, 2008; Meneses et al., 2007; Wonghongkul et al., 2008).

Dirksen & Epstein (2008) used cognitive-behavioral therapy as an intervention for insomnia and measured its effect on fatigue, mood and QOL in breast cancer survivors. A sample of 72 women, ages 29-86 years, who were at least 3 months post treatment with no recurrence were randomly assigned to an intervention group or a control group. Range of time since end of treatment was 5 months to 31 years, with a mean of 6.2 years. The intervention group received stimulus control instructions, sleep restriction therapy, and sleep education & hygiene, while the control group received sleep education & hygiene only. The 10-week study consisted of 2 weeks of pre-treatment, 6 weeks of treatment, and 2 weeks of post-treatment for each group. Study variables were measured pre- and post-treatment. QOL was measured using the Functional Assessment of Cancer Therapy – Breast (FACT-B), version 4, which measures by patient self-report, the following: physical well-being, emotional well-being, social well-being, functional well-being and relationship with doctor. Outcomes of the study included a significant improvement in fatigue, anxiety, depression and QOL ($p < .05$) in the intervention group post-treatment, and a significant increase in QOL ($p < .05$) in the control group post-treatment. A limitation of the study was the lack of diversity in the sample, which consisted of mostly white, married, well-educated women with high income levels. The study lends credence

to the use of nursing interventions to make a difference in the cancer survivor's quality of life. It should be noted that subjects in the intervention group exhibited a greater increase in measures of QOL than did subjects in the control group.

Meneses et al. (2007) studied the effects of a psycho-educational intervention on QOL in a sample of 256 breast cancer survivors within one year of completing treatment for early-stage disease. The median age of subjects was reported as 54.5 years (SD 11.58) without the actual range of ages. Subjects were randomly assigned to either the intervention group or the wait control group. The Breast Cancer Education Intervention (BCEI) was delivered by nurses in three face-to-face sessions in the first month to the experimental group, followed by 5 monthly follow-up sessions, 3 by telephone and 2 in person. The wait control group received four monthly attention control phone calls and the BCEI at month 6. Measures of QOL were obtained at three time points (baseline, 3 months and 6 months) for the groups using the City of Hope Quality of Life-Breast Cancer Survivor instrument. Total QOL score and subscores for each of the four domains (physical well-being, psychological well-being, spiritual well-being and social well-being) were analyzed. This well-designed study had a 98% retention rate. Baseline measures of QOL were determined to be equivalent for both groups. QOL scores for the intervention group were significantly improved at 3 months and showed continued improvement at 6 months, when compared to baseline ($p < .001$). QOL scores for the wait control group were slightly worse at 3 months, but improved somewhat by 6 months when compared to baseline. Significant differences were found in QOL for the intervention group when compared to the control group at both 3 months and 6 months

($p < .001$). This study adds support to the efficacy of intervention programs delivered by nurses to cancer survivors during the first year following treatment.

Wonghongkul et al. (2008) studied the effect of an Educative-Supportive Program (ESP) on quality of life in a sample of 61 breast cancer survivors in Thailand diagnosed for at least 5 years. Subjects were matched for age, education and year of survival and assigned to the intervention group or the control group. ESP was delivered every 2 weeks over 2 months in four 4-hour sessions. ESP included lectures, videos, discussions and stress reduction activities. Topics covered were: living with cancer after treatment, wellness of mind and body, fear of cancer recurrence, sense of control, uncertainty in illness and hope. Quality of life and self-management were measured pre-intervention, post-intervention and at 3 months after the intervention. A significant difference in QOL mean scores between groups was found at all three time points. Because group differences existed in QOL scores before the intervention, later group comparisons were not reliable. The QOL scores for both groups worsened over time, an unexpected finding. The intervention group QOL mean score decreased significantly (mean difference = .491, $p < .001$) from pre-intervention to 3 months post-intervention. The attempt to match subjects did not result in equal groups. Randomization would have made this a stronger study. Since the study population were survivors more than 5 years after cancer diagnosis, perhaps the sensitivity to interventions was not present 5 years or more after diagnosis.

In summary, recent studies of interventions affecting QOL in adult cancer survivors used a variety of methods – cognitive-behavioral therapy (Dirksen & Epstein,

2008), and a mixture of psycho-educational and supportive therapies (Meneses et al., 2007; Wonghongkul et al., 2008). Subjects ranged in time since diagnosis from up to one year (Meneses et al., 2007), 5 months to 31 years (Dirksen & Epstein, 2008), to more than 5 years (Wonghongkul et al., 2008). Two studies reported an increase in QOL following the nursing intervention programs (Dirksen & Epstein, 2008; Meneses et al., 2007). The best time to offer psycho-educational programs to affect QOL in cancer survivors is unknown. However these studies give preliminary support for achieving the best outcome with an intervention delivered during the first year after treatment (Meneses et al., 2007).

Conclusions. Of significance is the increase in published research from many different countries. In Chi's analysis of 26 studies from 1982-2005 examining the role of hope in patients with cancer, five of the studies (19%) came from countries other than the United States. However, eight of the 19 studies reviewed from 2005-2009 are from countries other than the United States (42%). This reflects the globalization which characterizes our world today. Nursing research has been enriched by global efforts to advance the science.

The following are offered as conclusions regarding the state of the science for hope and QOL in adults with cancer.

1. Hope is a multidimensional and dynamic concept.
2. The multidimensional components of hope can be categorized using the Hope Process Framework, and for the cancer survivor, the City of Hope Quality of Life Model for Cancer Survivors.

3. The dynamic components of hope involve coping and adaptation, change in level of hope over time, and the interaction of hope and hopelessness. These aspects can be explained in dynamic relationship to one another through the Roy Adaptation Model and Erikson's Stages of Psychosocial Development.
4. Nursing intervention programs designed to support hope and/or QOL can positively influence hope and/or QOL in patients newly diagnosed with cancer, patients experiencing a first cancer recurrence, terminally ill cancer patients, and cancer survivors at various lengths of time since diagnosis.
5. The advances in nursing research on hope and QOL reflect an increasing emphasis in nursing research around the globe.

It is important for nurse researchers to further identify interventions which support hope and QOL in adult cancer survivors. Nurses need to know which interventions are helpful and which are not and with whom. Since higher levels of hope may positively influence the patient's adaptation to illness and health, and lower levels of hope or hopelessness are associated with poorer QOL, lower self-esteem, anxiety, and depression, an important aspect of nursing care is supporting hope in patients.

The Psychology of Midlife

Scholars in the field of psychology contribute to our understanding of the stages of life. The second half of life is usually defined as age 40 and older, and as described by Jung (1933), consists of the stages of midlife and of old age. The second half of life is psychologically distinct from the first half. The first half of life, consisting of the stages of childhood and of youth, is characterized by psychological growth and development

influenced primarily by the environment (Jung, 1933; Brennan & Brewi, 2003). During the second half of life, however, growth and development proceed primarily from within the person as Jung states eloquently.

Wholly unprepared they embark upon the second half of life. Or are there perhaps colleges for forty-year-olds which prepare them for their coming life and its demands as the ordinary colleges introduce our young people to a knowledge of the world and of life? No, there are none. Totally unprepared we take the step into the afternoon of life; worse still, we take this step with the false presupposition that our truths and ideals will serve us as hitherto. But we cannot live the afternoon of life according to the programme of life's morning – for what was great in the morning will be little at evening, and what in the morning was true will at evening have become a lie. (Jung, 1933, p. 108)

The second half of life, beginning at midlife, is viewed as psychologically distinct from the first half of life. This notion, as articulated by Jung, has been further developed by other scholars.

O'Collins (1995) mapped the characteristics of the midlife crisis, which heralds the transition to the second half of life. He termed this phase of life as *the second journey* and delineated the following characteristics of the midlife transition: *thrust upon* them; crisis of feelings; an outer journey component; a change in meaning, values and goals; loneliness; and leading to a new wisdom and power. The diagnosis and treatment of cancer in the second half of life can be experienced as a second journey. The feeling that the disease and its treatment has been *thrust upon* the person, accompanied by a crisis of

feelings, loneliness, an outer journey to treatment centers, hospitals and healthcare providers, and a change in one's meaning, values and goals is frequently the experience of the person with cancer (Institute of Medicine, 2005). However the final characteristic, a new wisdom and power, is frequently out of sight for the person with cancer. The struggle to maintain hope becomes very real for many in the face of the changes brought about by a cancer diagnosis. Patients with cancer have been described as "facing one of the biggest crises of their lives" (Gorman, 2006, p. 10).

The Psychology of Hope in Midlife

A prominent psychology team addressed hope in relation to the psychosocial stages of life. Erik Erikson (1963) outlined the eight stages of life, each with a psychosocial crisis and leading to the development of an adaptive strength. Joan Erikson (1997) added a ninth stage of gerotranscendence to the original schema (after her husband's death and when she was well into her nineties) in which all the previous stages are revisited. Hope is named as the basic strength of stage one (infancy), gained from the developmental crisis of trust versus mistrust. Hope is seen as "mandatory for survival" and "needed for all other strengths" in future stages (Erikson, 1997, p. 5). The stages of development are depicted in chart form as a staircase (Erikson, 1997, p. 56-57). Each step on the chart represents a new stage of psychosocial growth and development, including and expanding the former ones.

Speaking of the eighth stage, the Eriksons (1997) say:

Located as it is chronologically in the upper right corner, its last dystonic item, we said is despair; and as we take a quick glance at the lower left corner we

remember that down there the first syntonic element is hope. . . . Hope connotes the most basic quality of “I-” ness, without which life could not begin or meaningfully end. (p. 62)

As seen through the eyes of the Eriksons, hope is necessary in all of life’s stages. They define hope in the following way:

Hope is “expectant desire,” a phrase well in accordance with a vague instinctual drivenness undergoing experiences that awaken some firm expectations. It is also well in accord with our assumption that this first basic strength and root of ego development emerges from the resolution of the first developmental antithesis; namely that of *basic trust vs. basic mistrust*. And as to suggestive linguistic connotations, hope seems to be related even to “hop” which means to leap; and we have always made the most of the fact that Plato thought the model of all playfulness to be the leap of young animals. At any rate, hope bestows on the anticipated future a sense of leeway inviting expectant leaps, either in preparatory imagination or in small initiating actions. (pp. 59-60)

Emerging as it does from the tension of basic trust (the syntonic element) vs. basic mistrust (the dystonic element) hope can be seen as requiring this tension in order to expand and grow. Joan Erikson (1988) insists that “It is important to respectfully defend and even applaud the dystonic elements of these tensions which promote vital strength and growth. The dystonic, I would maintain, actually mobilizes development” (p. 130). She goes on to describe the tension between trust and mistrust as a disharmony which can only be resolved through struggle and the creative process of growth. She says.

Our first basic strength, you may remember, was hope, the Latin source being the verb *sperare*, to hope. How appropriate, then, to find our form of this word *desperare* as the final dystonic element with which the aging individual must cope. (p. 125)

She is speaking here of the eighth stage, integrity vs. despair, where the maladaptive tendency is presumption. Relating this process to hope, Joan Erikson says that “these elements pull away from one another, causing tension; yet neither is strong or independent without the counter pull of the other” (p.114). She stresses “that the syntonic without the dystonic is meaningless” and “that none of the basic strengths is ever permanently achieved” (p. 113).

As noted in discussing this framework earlier, the dynamic presented is a tension created by the pull of despair on the one side and presumption on the other side, by means of which tension, wisdom emerges. It is the tension and discord created by the poles of presumption and despair that give new expansion to the basic strength of hope. (Table 1)

As noted in this schema, midlife is the seventh stage, represented by the developmental crisis of generativity versus stagnation, the resolution of which produces the strength of *care*. According to the theory (Erikson, 1963), each psychosocial crisis is resolved more or less completely and the cumulative strengths continue to expand and grow throughout each successive stage. Thus for the person in midlife, the strengths of prior stages (hope, will, purpose, competence, fidelity and love) expand and grow into

greater consciousness during midlife as the strength of care emerges. Hope therefore expands in midlife along with care.

The Eriksons describe the stage of midlife as follows:

Generativity, we said, encompasses *procreativity*, *productivity* and *creativity*, and thus the generation of new beings as well as of new products and new ideas, including a kind of self-generation concerned with further identity development. A sense of stagnation, in turn, is by no means foreign even to those who are most intensely productive and creative, while it can totally overwhelm those who find themselves inactivated in generative matters. The new “virtue” emerging from this antithesis, namely, care, is a widening commitment *to take care of the* persons, the products, and the ideas one has learned *to care for*. All the strengths arising from earlier developments in the ascending order from infancy to young adulthood (hope and will, purpose and skill, fidelity and love) now prove, on closer study, to be essential for the generational task of cultivating strength in the next generation. (Erikson & Erikson, 1997, p. 67).

This explanation of midlife clearly depicts growth and development to include and expand all prior stages of psychosocial growth. The person in midlife deals with the tension between generativity and stagnation by utilizing and expanding all the former strengths to develop care for what one had produced in life. For both Jung and Erikson, psychological growth is expressed in terms of expanded consciousness. In midlife, what one is creating and contributing to life (generativity) is in tension with what one may view as lack of purposeful involvement or being a bystander in life (stagnation). Growth

and development are achieved not by avoiding the challenges presented by life, but by bearing with them until resolution occurs.

Erikson's theory of psychosocial development is not without its critics. While acknowledging Erikson's contributions as "one of the most influential in the twentieth century," Welchman (2000, p. 127) summarizes four criticisms of his work. These are: 1) that he is idealistic, avoiding the negative aspects of life, 2) the second is either that his work supports the status quo or that it undermines traditional culture and values (depending on the critic), 3) that distortions in his work exist due to his own sex and culture, and 4) that his work lacks rigor and clarity. Stevens (2008) praises Erikson for his dedication to integration, including his interdisciplinary approach, which blends the disciplines of anthropology, history, and psychology, among others. For this research study, important aspects of Erikson's work include his emphasis on integration and his focus on normal growth and development rather than on pathology. While other theories of growth and development exist, Erikson's stages of psychosocial development were chosen to form part of the framework for this research study because of these features.

The person in midlife in the post-treatment phase of cancer is faced with a transition to life as a cancer survivor, which has many challenges. One of the challenges is to redefine hope. In the framework for this research study, hope is part of the self-concept adaptive mode in the Roy Adaptation Model and the spiritual well-being domain of the City of Hope Quality of Life Model for Cancer Survivors. A spirituality of midlife will be examined briefly next.

Spirituality in Midlife

In a recent work, Carfagna (2008) approaches the midlife transition by viewing it along with contemplation. She notes that midlife leads us to God, the ultimate source of wholeness and healing. She compares the midlife crisis to contemplation in the following way: “Both focus the individual on the immediate present. Both thrust the individual into the unknown. Both challenge the individual’s personal resources, assumptions and customary ways of proceeding” (Carfagna, 2008, p. vii). Like Jung (1933), she describes midlife in terms of a crisis of limits, a crisis of meaning, and a crisis of faith, emphasizing the potential for spiritual deepening; “For many people, crisis precipitates a degree of intimacy with God they might never have imagined” (Carfagna, 2008, p. viii).

Carfagna (2008) also describes the emotional and psychological states that accompany the midlife transition. Similar to the second journey described by O’Collins (1978/1995), she describes the following characteristics of midlife: a loss of identity; the presence of irreconcilable opposites; an awareness of personal weakness; the presence of emotional pain; feelings of anxiety, powerlessness, dependence, absence and emptiness; and the feeling that one is crossing an abyss into new life. These characteristics are illustrated through the life stories of Ignatius of Loyola, John of the Cross, Thomas Merton, Cardinal Joseph Bernardin, and others. Powerfully unsettling, the midlife period ultimately requires a response from the midlife person. This response calls forth a choice between hope and despair, described by C.S. Lewis (1955) as a wholly free choice, Carfagna says. She describes the surrender of the midlife person to God in terms of Kierkegaard’s blind leap of faith. By seeing the crisis in terms of spirituality, the midlife

person opens to a reality beyond his/her own limits. Carfagna describes a meeting of the finite with the infinite, the encounter being initiated by God, yet characterized by respect for the total freedom of the individual. If the person chooses to surrender to God, by taking a leap of faith, he/she experiences a personally unprecedented union with God, leading to new life.

Carfagna (2008) reveals a wonderful description of contemplation. She explores the classic and modern contemplative voices on the subject, and describes a transition from an experience of God's absence to the recognition that it is actually God's presence being experienced. Contemplation involves a transition from a use of words and strong feelings to one of silence, gentle peace, and contentment in God's presence, she explains.

Carfagna's (2008) words on contemplation reflect the psychological process of bearing the tension of opposites described by both Jung and Erikson.

If we remain faithful in crisis or in contemplation, the apparent absence of God whom we need so desperately extends the limits of our patience and strengthens our resolve. Our souls expand by reaching out to God, like muscles that develop by stretching. That God will come is as certain as the dawn, but when, where and in what form the divine will manifest itself remains unknown. (Carfagna, p. 120)

As Jung (1933) and Erikson (1963) explained growth in the psychological domain, the process of growth in the spiritual and religious domains is described by Carfagna as involving the expansion of consciousness. Contemplation involves bearing the tension of opposites – holding on in openness to God while experiencing absence, until an understanding of this new way of being with God evolves. The reality within one's

consciousness is broadened to accommodate a new image of God – not just a God of law but also a God of love.

The Relationship between Psychological and Spiritual Development

In order to adequately explain the intervention in this research, it is important to state why the MLD Workshop and other similar programs address both the psychological and spiritual domains of quality of life. It is recognized in the literature that a person's psychological development facilitates the person's spiritual development and vice versa (Fowler, 1981; Taylor, 2002). The two domains, though indeed separate, are at the same time closely aligned.

According to the research framework for this study, the self-concept mode in the Roy Adaptation Model, where hope resides, corresponds to the domains of spiritual well-being and psychological well-being in the Quality of Life Model. Programs that seek to affect hope typically include both spiritual and psychological elements. Building on what has been established thus far, an examination of the work of several leaders in program development for persons in midlife will be explored.

Programs Fostering Spiritual and Psychological Development in Midlife

Brennan & Brewi (2004) have written four books and developed the Mid-Life Directions Workshop, which will be used as an intervention in this research study. While the MLD Workshop process is well-established, its efficacy has not been formally tested. Anderson (2008) has written five books on midlife and developed a program for

women in midlife. These programs fostering spiritual and psychological growth in midlife contribute to our understanding of the needs in this important stage of life.

For over 25 years, Brewi & Brennan (2004) have conducted MLD Workshops internationally to foster psychological and spiritual growth in the second half of life. Their description of the opposites of integration will expand what has been presented thus far. Using Jungian psychology, they describe the midlife transition in terms of the ego, which is the developed part of the personality, giving center stage in midlife to the Self, the integrated personality. Brewi & Brennan say:

Individuation is impossible without exposing and dissolving an inflated persona and dethroning the ego. The unconscious Self, the Self that lies deep within us, is demanding emergence, and unification with the ego is the ideal. (p. 52)

However, an ideal is not always achieved. The person may choose to “end the crisis by regressing and putting the conscious personality securely on the throne again” (Brewi & Brennan, 2004, p. 53). One may seek to relive the first half of life all over again through a different scenario, but with the same developmental tasks appropriate to the first half of life – the development of the ego. The result is a one-sided personality – stunted, narrow minded, and without zest for life. Patton (2006) tells us, “Although everyone who does not die grows older, not everyone becomes wise. Growth is a choice rather than a necessity” (Patton, p. 306). Brewi & Brennan say :

The Self wants to maintain a living relationship with the ego and the unconscious. The ego tends to believe that it is the entire Self, and at the time of mid-life crisis to persist in identifying the ego with the Self means spiritual suicide, death to the

personality and to continual becoming. Closure occurs at this point – and unless it is reversed, there is no possibility of wholeness or self-realization.” (p. 56)

Thus one can choose to limit oneself to an already developed ego and alienate oneself from the true Self.

One can also surrender to the unconscious and follow every inclination without scrutiny. Neither of these narrow extremes is life giving. One must bear the tension of opposites, patiently holding on through the unfolding of the Self in order to reach the other side – the new shores of the second half of life, the integrated Self. Brewi & Brennan tell (2004) us:

Dreams, daydreams, imaginations, fantasies, art works, journals, dialogues with personifications of our archetypes, doodling, slips of the tongue, projections, prayer, and even complexes and neuroses can all be means by which we can contact our unconscious. (p. 61)

It is through interaction with unconscious material that individuation occurs. The process of becoming the true Self occurs through evaluation of the material from the unconscious, examining how it fits with one’s true Self, and integrating it or not. The midlife person may choose to face some of his/her unconscious material by embracing it with respect for what it is, and then letting it go.

Spirituality at midlife, built on the psychology of midlife, involves a unity of opposites in the person, a process of inwardness by which the true Self assumes its proper place of authority within, and relates to God in an I/Thou relationship. “The inwardness of the mid-life person brings about a spirituality that looks inward for its nourishment,

renewal and guidance. In possession of itself, it looks outward to all of creation in transpersonal love, looking for its own unique way to respond to the challenge” (Brewi & Brennan, 2004, p. 64).

Anderson (2008) in her book *The Second Journey* says that “second journeys most often commence in midlife when the power of youth is gone and the dreams of earlier years turn out to be shallow and pointless” (p. 193). During one of her own outer journeys with an inner component, she describes contemplation thus:

One of the strange laws of contemplative life is that when you are in it, you do not sit down and solve problems. Rather you bear with them until somehow they solve themselves. During the past few days I’ve sensed through one incidental experience after another that someone or something wants to find me, and that something is my soul. (p.162)

In the midst of her own midlife crisis, Joan Anderson met the older Joan Erikson, who guided her to experience her midlife journey from the perspective of the psychosocial stages. She quotes Joan Erikson as telling her, “You have to be willing to begin again and again. . . energy is generated in the tension, the struggle. The pull and tug is everything” (Anderson, 2008, p. 38). She also paraphrases Jung as saying, “For people over thirty, all problems are spiritual . . . you will only be able to come to terms with what really matters if you pause, break from the mundane, and process the grief that is partner to change” (Anderson, 2008, p. 130). She brings together the views of Jung and the Eriksons.

Psychotherapeutic interventions. Related to the psycho-educational nursing interventions to promote hope and quality of life are psychotherapeutic interventions to relieve suffering and distress. These psychotherapeutic interventions also have elements in common with programs fostering spiritual and psychological development in midlife. Two novel psychotherapeutic interventions that have been formulated by the psychiatric community for cancer patients at the end of life (Breitbart et al., 2009; Chochinov et al., 2005) will be reviewed here for their parallels to this proposed study.

Dignity Therapy is a novel intervention directed by the discipline of psychiatry and “designed to engender a sense of meaning and purpose” in the terminally ill (Chochinov et al., 2005, p. 5521). Patients are assisted to document issues that matter most and which they most want to remember. Clinicians then help patients to edit a final version of their words which can be bequeathed to a friend or family member. A multi-method feasibility study of Dignity Therapy conducted with 100 terminally ill patients in Canada and Australia resulted in a 91% satisfaction rate with the intervention; 76% of the subjects reported a heightened sense of dignity and 67% a heightened sense of meaning. Although hope was not measured, hopelessness was measured along with quality of life and satisfaction with quality of life. Post-intervention hopelessness showed a non-significant change toward improvement. Quality of life measures were inversely correlated with psychosocial distress. There was a significant improvement in measures of suffering and a significant reduction in depressive symptoms ($p < .05$). Although this feasibility study included only one sample of older patients, it holds promise as an intervention to address existential distress by promoting patient dignity. In praise of this

intervention, Ferrell affirms “that the end of life is a natural phase of life and that the lack of meaning or dignity is not a psychiatric disorder but rather a natural life occurrence” (Ferrell, 2005, p. 5427).

Meaning-centered group psychotherapy (Breitbart et al., 2009) is another psychotherapeutic intervention developed as an intervention to address patients’ emotional and spiritual suffering at the end of life. Delivered in eight 2-hour sessions to cancer patients with stage III or IV disease, this intervention’s goal is “to help patients with advanced cancer sustain or enhance a sense of meaning, peace and purpose in their lives” (Breitbart et al., p. 3). When studied in a randomized controlled trial (n = 90) significantly greater improvements in spiritual well-being ($p < .001$) and a sense of meaning ($p < .05$) were attained by the intervention group as opposed to the control group receiving supportive psychotherapy. Once again hopelessness was measured as opposed to hope, with this variable showing a non-significant change toward improvement in the intervention group.

Parallels to this proposed study include the use of interventions based on the premise that psychological distress is normal during times of transition; and the employment of non-pharmacological methods to address meaning, goal-setting, hope, quality of life, and spiritual well-being in order to foster adaptation in the face of illness.

Psycho-educational interventions. Psycho-educational interventions within the cancer community have been generally well-received. Psycho-educational group interventions have been described as “structured, time-limited education provided in a

supportive environment” in which “participants learn about specific topics and often gather a sense of confidence or empowerment as they learn” (Fitch, 2006, p. 431).

In a review of 13 psycho-educational interventions published from 1985-2005, covering 809 primary studies, Chan (2005) concluded that the overall effectiveness of psycho-educational interventions was inconclusive due to the study of mixed interventions and the inclusion of studies with significant as well as non-significant results. However, the use of patient education and progressive muscle relaxation were two forms of psycho-educational interventions that were clearly supported by the evidence to reduce physical side effects, such as pain (Chan, 2005). While this was a rigorous review, the identification of comprehensive, long-term outcomes was beyond the scope of many of the studies which were examined. Evidence has yet to be established to support the effectiveness of other psycho-educational interventions.

The Mid-Life Directions (MLD) Workshop

The MLD Workshop provides the participant with an opportunity to adapt to the psychological growth and development appropriate in midlife (Brennan & Brewi, 2003). According to the Roy Adaptation Model, the role of the nurse involves the promotion of positive adaptation which is “the process and outcome whereby thinking and feeling people, as individuals or in groups, use conscious awareness and choice to create human and environmental integration” (Roy, 2009, p. 26). The MLD Workshop promotes human integration. For the midlife person in the post-treatment phase of cancer, the workshop provides an opportunity to gain new knowledge and skills which may help to integrate the personal experience of illness into life as a cancer survivor by promoting positive

adaptation through conscious awareness and choice. The sessions of the MLD Workshop are outlined in Table 5.

Table 5

The MLD Workshop and Its Effect on the Cancer Survivor

Session	Topic	Process	Benefits to Cancer Survivor
1	Personal journal / Accomplishments First half of life Ego strengths	Creative listening Guided imagery – music meditation Stepping stones of life – journal dialogue	Understanding of normal psychological growth and development related to personal experiences
2	Jungian personality theory Understanding type and Mid-Life Growth	Personality type indicator Writing the chapters of one’s life – sharing	Connecting new information to prior experiences
3	Peak/depth experience Myths and symbols / rituals	Owning peak/depth experiences of the past Symbol of the self – mandala Small group sharing	Coping with emotions surrounding illness and treatment Exploration of changes in individual hope and quality of life
4	Return to wonder and the art of contemplation Shifting values Correspondence of outer values and inner life as individuating	Fantasy – prayer of the imagination Examining one’s typical day, week, year Music meditation	Using the imagination to envision new hope and improved quality of life Adopting changes to minimize negative impact of disease
5	Integrating the inner and outer journey Life transitions	Owning one’s story Creative listening / sharing Dialogue with wisdom figure	Integration of cancer diagnosis and treatment into self-concept

The MLD Workshop and Its Effect on the Cancer Survivor

Session	Topic	Process	Benefits to Cancer Survivor
6	Processes of inwardness and individuation The future	Imagining one's preferred future Planning goals and objectives HHI & QOL-CS instruments Written reflection	Accepting responsibility for maintaining hope and quality of life

Note. MLD = Mid-Life Directions.

Interventions Affecting Hope Attributes

As noted, there are four major attributes of hope as described in the nursing literature (Ersek, 2006). Articulated by Farran, Herth & Popovich (1995), these attributes of hope involve experiential, spiritual/transcendent, relational and rational thought processes. The experiential attribute of hope involves searching for hope, while the relational aspect involves developing a sense of interconnectedness with others. The spiritual/transcendent attribute involves finding meaning and being connected to something greater than oneself, while the rational thought process involves goal setting and cognitive reframing of what constitutes hope for the individual. These attributes have been researched to varying degrees in three nursing interventional studies designed specifically to support hope in clinical populations as discussed earlier (Duggleby et al., 2007; Herth, 2000; Rustoen et al., 1998).

The Mid-Life Directions Workshop as an intervention affecting the hope attributes. The MLD Workshop integrates the four major attributes of hope as described

in the nursing literature. While the Hope Intervention Program (Herth, 2000) addressed these four attributes separately, the MLD Workshop, like the Living with Hope Program (Duggleby et al., 2007) integrates them (see Table 6).

Table 6

The MLD Workshop Related to the Hope Attributes

Session	Topic	Hope Attributes
1	Personal journal / Accomplishments First half of life Ego strengths	Experiential, Rational thought process
2	Jungian personality theory Understanding type and Mid-Life Growth	Experiential, Rational thought process
3	Peak/depth experience Myths and symbols / rituals	Experiential, Spiritual/transcendent
4	Return to wonder and the art of contemplation Shifting values Correspondence of outer values and inner life as individuating	Experiential, Rational thought process, Spiritual/transcendent, Relational
5	Integrating the inner and outer journey Life transitions	Experiential, Rational thought process, Spiritual/transcendent, Relational
6	Processes of inwardness and individuation The future	Experiential, Rational thought process, Spiritual/transcendent, Relational

Note. MLD = Mid-Life Directions.

The MLD Workshop as an intervention addressing a gap in the knowledge.

The three nursing intervention studies specifically designed to increase hope in patients in the clinical setting show a development in complexity over time, addressing two attributes of hope, rational thought and experiential processes (Rustoen et al., 1998), and finally all four attributes, rational thought, experiential, relational and spiritual/transcendent processes (Herth, 2000; Duggleby et al., 2007). Each of the research studies resulted in increased levels of hope, with the Hope Intervention Program (Herth) showing sustained hope levels 9 months after the intervention. In addition the studies by Herth and Duggleby et al. resulted in an increase in quality of life. These studies support the claim that nursing interventions can positively affect patients' hope and quality of life.

The MLD Workshop will build on these research studies by providing an intervention to support hope specifically in midlife persons in the post-treatment phase of cancer who are transitioning to survivorship. Consistent with the psychological literature, midlife is an opportune time to address the transition to a new phase of life. It is a particularly significant time for the person in the post-treatment phase of cancer transitioning to the role of cancer survivor (Allen, Savadatti & Levy, 2009). Furthermore by utilizing all four attributes of hope identified in the nursing literature and integrating them throughout the workshop, the intervention can be expected to have a positive effect on hope and quality of life in this population.

This research study will add to the nursing knowledge of interventions to support hope in midlife cancer survivors by providing a MLD Workshop as an intervention for

persons between 40 and 64 years of age in the post-treatment phase of cancer. It will evaluate the effect of the intervention on hope and quality of life using a multimethod approach.

Chapter 3
Methods and Design

Chapter 3

Methods and Design

The purpose of this study was to test a psycho-educational group intervention, the Mid-Life Directions (MLD) Workshop, for its effect on hope and quality of life in midlife cancer survivors transitioning from active primary treatment to survivorship. The research framework for this study was based on the Roy Adaptation Model, the City of Hope Quality of Life Model for Cancer Survivorship, the Hope Process Framework, and Erikson's Stages of Psychosocial Development. The multidimensional, age-appropriate approach used in the study was congruent with the concepts of hope and quality of life (QOL) as defined in the literature. This chapter will address the study design, methods, and instruments used for data collection. Treatment and control group interventions will be described. Finally methods of data analysis and protection of participants will be delineated.

Study Design

This interventional study used a multimethod experimental design, comparing a treatment group to a control group. Each group received information in a group setting during six sessions. Quantitative baseline data was collected from both groups using a demographic form (Appendix A), the Herth Hope Index (HHI) (Appendix B) and the Quality of Life Instrument, Patient/Cancer Survivor Version (QOL-CS) (Appendix C) before the intervention. Data collection using the HHI and QOL-CS was repeated during the final session of each group. Qualitative data were collected in written form from the treatment group during the last workshop session in order to evaluate the participants'

perceptions regarding the effect of the content of the workshop on their hope and quality of life. Quantitative data were analyzed for group differences in hope and quality of life pre- and post-intervention. Quantitative and qualitative data were triangulated to synthesize and enhance understanding of the effect of the workshop on the participants' hope and quality of life.

Table 7 notes the study variables with their conceptual and operational definitions. Design and research questions were derived from the study variables.

Table 7

Definitions of Study Variables

Study Variable	Conceptual Definition	Operational Definition
Independent variable – Mid-Life Directions Workshop	A psycho-educational program which addresses the four hope attributes: experiential, relational, spiritual/transcendent and rational thought processes. The Workshop provides external input and stimulates internal input within the four hope attributes.	A 12-hour program, delivered in six 2-hour sessions. Topics include psychological growth and development with a focus on the second half of life and open contemporary Judeo-Christian spirituality. The Workshop is self-reflective, communal and experiential (Brennan & Brewi, 2003).
Dependent variable – Hope	“Hope is a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the	A number on a scale of 12 to 48 (with a higher score denoting greater hope) on the Herth Hope Index (Herth, 1992). Hope dimensions

Definitions of Study Variables

Study Variable	Conceptual Definition	Operational Definition
	<p>hoping person, is realistically possible and personally significant” (Dufault & Martocchio, 1985, p. 380). Dimensions of hope included in this definition are: 1) cognitive-temporal, 2) affective-behavioral, and 3) affiliative-contextual.</p>	<p>measured include: 1) temporality and future, 2) positive readiness and expectancy, and 3) interconnectedness. Instrument dimensions relate to the conceptualizations in the conceptual definition of hope.</p>
<p>Dependent variable – Quality of life</p>	<p>The person’s physical well-being, psychological well-being, spiritual well-being and social well-being as determined by the person, assumed to be associated with QOL.</p>	<p>A score from 0 to 410 (with a higher score denoting better quality of life, and with subscales measuring each of the four dimensions mentioned in the conceptual definition) measured by the City of Hope Quality of Life Instrument, Patient/Cancer Survivor Version. (Ferrell, Hassey-Dow & Grant, 1995)</p>

Methods

Sample. The sample included adults 40-65 years of age with stages I, II or III disease who had completed active primary treatment for cancer. Participants ranged from

only just having completed treatment to being 28 months post treatment. The sample consisted of Caucasian participants with one participant self-identified as having Hispanic or Latino or Spanish origin. Despite the attempt to recruit a sample reflecting the racial and ethnic mix of the population in the designated locations, the final sample lacked Asian and African American or Black participants.

Sampling procedures.

Sample size. Consultation with a research statistician was used as was the textbook by Burns & Grove (2009) to determine the appropriate sample size for the study purpose and methods. A sample size of 98 was determined by power analysis specifying a medium effect size ($f = .25$), power of .80, and an alpha level of .05 (one-tailed test) based on the effect of the intervention on measures of hope and quality of life, and comparing the effect over time of the treatment group to the control group. Allowing for a 25% attrition rate, the final sample size was set at 122 participants, 61 per group.

The actual sample size consisted was 26 participants, 17 in the treatment group and 9 in the control group. Approximately twice the number of participants was randomly assigned to the treatment group as to the control group (Dumville, Hahn, Miles & Torgerson, 2006). This was due to the practical issue of limited access to participants in a reasonable length of time. The study was implemented in two hospitals sequentially, with the treatment group given twice and the control group once at each site. The interventions were delivered to groups of 3 to 8 participants in six 2-hour sessions for the treatment group and to 3 to 7 participants in six 1-hour sessions for the control group.

Recruitment of participants. Participants were recruited from ambulatory Cancer Centers at two hospitals in the northeastern United States. Recruitment was conducted through a designated contact person at the proposed study sites. Potential participants were identified first by means of the Tumor Registration system using the study criteria. Data obtained included name, address, telephone number and treating physician of each potential participant. Persons identified were further screened by chart review to determine treatment completion date. The chart review at the first site was conducted by an RN designated by the site's Study Doctor. The chart review at the second site was conducted by the researcher per institutional preference.

Treating physicians were asked for permission to contact their patients identified as prospective participants. Those who were approved were sent a letter of invitation informing them about the study, and giving them the opportunity to opt out via return postcard if they did not wish to be contacted further. After mailing the letters of invitation, two weeks were allowed to elapse so that eligible persons who so chose could opt out. Those who opted out were removed from the list.

Phone calls were made by the researcher to the remaining persons to invite them to participate. During each phone call the researcher gave an explanation of the study, and offered the prospective participant the opportunity to ask any questions concerning the study. Each prospective participant who agreed to participate was given a time convenient to the participant for an initial meeting with the researcher at the Cancer Center.

One change to the recruitment process was requested mid-study at the first site by the hospital's Institutional Review Board (IRB) and implemented by the researcher. The change involved the letter of recruitment and the opt-out card. The recruitment letter was originally printed on Boston College letterhead, as requested by the hospital's IRB. However, upon receiving a complaint from one participant about the release of protected health information to Boston College without the potential participant's prior consent, the IRB requested that the process be changed in two ways: 1) the letter of invitation was to be printed on the hospital Cancer Center's letterhead, and 2) the opt-out card was to be changed to an opt-in card whereby the participants were asked to send the card back if they were interested in learning more about participation in the study. All IRB requirements were implemented. At the second site, the IRB approved the use of the hospital Cancer Center letterhead for the letter of invitation and the use of the original opt-out card process. No complaints were received at the second site.

Study procedures. During the initial meeting with the researcher, the participant's written consent (Appendix E) was obtained, and the demographic form developed by the researcher (Appendix A), the Herth Hope Index (Appendix B) and the Quality of Life Instrument, Patient/Cancer Survivor Version (Appendix C) were completed by the participant. After the baseline measures were completed, random assignment of the participant to either the treatment group or the control group was made by means of a table of random numbers.

Demographics of sample. The sampling plan included minority groups, and both female and male participants were recruited. Children were not recruited because they did

not meet the study criteria and would not be appropriate for the intervention, a workshop featuring content on development in midlife. Race/ethnicity data for the geographic location of the Cancer Centers (New England) is listed in the U.S. Census Bureau (2000) as 89% White, 5% Black or African American, 2% Asian, 4% some other race and 2% two or more races, with 7% Hispanic or Latino (of any race). Target goals for race/ethnicity were as follows for participants in the study: 109 White, 5 Black or African American, 2 Asian, 4 of some other race, and 2 of two or more races, with 7 Hispanic or Latino (of any race). Recruitment attempted to meet target goals for race/ethnicity. Due to historical data showing that more females have chosen to participate in past workshops an equal mix of male/female participants was *not* imposed on the study. Data were collected from August 2010 through September 2011.

Inclusion and exclusion criteria. It is assumed that persons in midlife will experience the transition from active primary cancer treatment to survivorship in a developmentally appropriate way. Therefore the inclusion criteria for the study were: 1) the person was between 40 and 64 years of age, 2) the person had completed active primary treatment for cancer within the past 18 months, 3) the person was diagnosed with a solid tumor, stages I, II or III, including lymphomas, 4) the person could speak, write and read English, and 5) the person was able to give informed consent. Exclusion criteria were: 1) the person had been diagnosed with stage IV disease, and 2) the person was diagnosed with dementia or another medical condition that impaired his or her ability to participate in the study procedures according to the judgment of the nursing or medical staff.

Rationale for inclusion criteria. The workshop was offered to persons who had completed active primary treatment for cancer because at this stage, the person typically has fewer healthcare appointments, more energy and more time to reflect on the significance of diagnosis and treatment for a life-threatening illness (Allen, Savadatti & Levy, 2009; Institute of Medicine, 2005). In other words, this may be an opportune time for the person to benefit from the intervention and complete ratings. Persons diagnosed with solid tumors, stages I, II or III, including lymphomas generally have a better prognosis than those with stage IV disease and a different disease trajectory than those without solid tumors. Therefore these persons may have more in common with one another regarding their views of hope and quality of life than persons diagnosed with cancers other than solid tumors or with stage IV disease. The person was required to speak, write and read English in order to understand the content of the workshop and interact with the other study participants. The rationale for including persons ages 40 to 64 was that a MLD Workshop was designed for the developmental stage of midlife and beyond, defined as ages 40 and older (Brennan & Brewi, 2003). Persons under 40 years of age were not considered developmentally appropriate for the content of the workshop. Persons over 64 years of age were considered to be beyond the midlife stage in this study. The purpose of the workshop was to support hope and quality of life during the transition from cancer patient to cancer survivorship during midlife.

Rationale for exclusion criteria. The rationale for the first exclusion criteria, that person had been diagnosed with stage IV disease, was that in this case the person may have viewed hope and quality of life in a manner that was more focused on end-of-life

issues. Therefore the individual may not have had his/her needs met in a group of persons facing earlier diseases stages. The rationale for the second exclusion criteria, that the person had been diagnosed with dementia or another medical condition that impaired his or her ability to participate in the study procedures, was because the person would not be able to fully participate in the intervention under those conditions. Neither would the person have been able to derive benefit from the purpose of the workshop, which was to support hope and quality of life during the transition from cancer patient to cancer survivorship during midlife.

Setting. Two hospital Cancer Centers in the Northeastern United States were the sites for this study. The sites provided treatment in outpatient settings. They each served diverse patient populations with respect to age, sex and race/ethnicity. All data collection and intervention sessions were conducted in designated self-contained conference rooms at the Cancer Centers or other nearby designated site.

All group sessions were conducted in designated self-contained conference rooms at the hospitals. Groups were held in the evenings and consisted of 6 two-hour sessions for the MLD group and 6 one-hour sessions for the NPS group. Groups were held on different days in order to avoid interaction between the participants of the two groups. At the conclusion of the final session of each group, the booklet *Facing Forward: Life After Cancer Treatment* was given to each participant to thank them for their participation in the study.

Intervention. Each MLD Workshop was led by the researcher. Mid-Life Directions co-founders Brewi & Brennan (2003) developed the MLD Workshop, a

workshop for personal and spiritual growth, which was used as the intervention. The researcher was trained to give workshops by these co-founders and was certified as a Mid-Life Directions consultant in 2001. The researcher had conducted 9 workshops prior to the study in various locations in the Northeast and Mid-Atlantic states with groups of midlife women.

The Workshop consisted of six 2-hour group sessions. A guidebook was used to structure the content and delivery of the sessions. As a group intervention, it was given to groups of 3 to 8 participants. While the participants ideally attended all 6 sessions of the workshop, each participant needed to attend at least 4 sessions in order to provide dependable data for the study and be included in the final analysis of data.

The main goal of the workshop, applied to this population, was to assist the midlife cancer survivor to integrate the cancer experience through conscious awareness and choice, and make the transition to survivorship with an increased level of adaptation, and an opportunity for improved hope and QOL. Each session of the workshop contributed to this goal.

A MLD Workbook was given to each participant in order for them to enter into each session's themes and activities. The content of each workshop session will be described now in detail with regard to session goal, topics, processes, and benefits to the cancer survivor.

Session 1: The life cycle. The first session of the workshop began with an overview of the goals and objectives of the workshop, and the expectations that 1) all personal information expressed in the group will be held in confidentiality by all

participants, and 2) that each participant attend all sessions. The goal of this session was to promote understanding of normal psychological growth and development as it relates to personal experiences. Topics for this session included the four stages of life – childhood, youth, midlife and old age; the similarity of the stages in the first half of life; the similarity of the stages in the second half of life; an emphasis on the midlife transition as not only physical, but psychological and spiritual; the major transition in the second half of life from an environmental influence to an inner influence; and the midlife task of individuation, becoming one's unique self. This session included the processes of creative listening to presentations and to other participants, guided imagery, music meditation, and journaling about one's life's story. The midlife cancer survivor can benefit from this session by owning and objectifying the past. The experience of diagnosis and treatment for cancer was placed into the context of the person's significant happenings, events, turning points and life transitions. The survivors listed their significant life events and documented in detail about one which was chosen. Thus the survivor was given the opportunity to step back and view his/her life as it had unfolded and what meaning it might have now.

Session 2: Understanding personality type and midlife growth. The goal of this session was to assist the participant to connect new information to prior experiences. Topics included Jungian personality theory; the distinction between the ego, developed in the first half of life, and the Self, developed in the second half of life; the dynamic interaction of both conscious and unconscious aspects of oneself; the importance of owning one's shadow; and the identification of one's personality type and shadow. The

process used to convey these topics included completing and scoring the Gray-Wheelwrights Survey (Mattoon & Davis, 1995), which can delineate the individual's personality type. It also included outlining the chapters of one's life. Using the survey results, the participant was guided to identify the reasonably well developed aspects of his/her personality, as well as the lesser developed aspects which are ready for acknowledgement and inclusion as appropriate into the expanding personality in midlife and beyond. This new information was connected to the individual participant's life story through journaling, music meditation and small group sharing. The midlife cancer survivor can benefit from this session by entering into the discovery of his or her developed self. The participant can realize that the preferred attitude, perception and judging skills are adequately developed, but leave much aptitude underdeveloped within the Self. The participants, as cancer survivors, can begin to understand their responses to diagnosis and treatment within the context of normal psychological growth and development.

Session 3: The role of peak/depth experiences, myths and symbols. The goal of this session was to support coping with the emotions surrounding the experience of illness and treatment and to explore changes in individual hope and QOL. Topics included an exploration of myths and symbols as being at the heart of the process of individuation; the role of myths and symbols in relating humankind to great archetypal, life-giving realities; mandalas as expressions of the Self; and peak/depth experiences as sources of meaning, decisions and integration. Processes used during this session were the consideration and exploration of the participant's peak/depth experiences, music

meditation, creation of a mandala collage, and small group sharing of the collages created. Benefits to the cancer survivor include use of memory to identify past experiences which were significant and to recall how one coped with them. This may have surfaced the realization that some peak/depth experiences, with their sustaining and/or challenging features, have been part of one's life story. Creation of the mandala provided the opportunity to use the imagination to identify images and to place them in an artistic context that can be viewed. This activity provided the opportunity to bring into consciousness the participant's unconscious hopes and dreams for the future.

Session 4: Aligning outer values and inner life. The goal of this session was to foster the use of the imagination to envision new hope and QOL as well as the adoption of changes to minimize the negative effects of the disease. Topics addressed during this session included the need for inwardness and interiority in order to live the second half of life well; the danger of becoming jaded and cynical with the end of naiveté; the recovery of wonder by bringing one's life experiences to bear on seeing one's present experiences at greater depth; and owning and identifying the shift in one's values at midlife. The processes used included the identification and prioritization of one's values and what they may mean at this point in time. Also included was the examination of one's typical day, week and year in light of these values. Finally, there was the activity of redesigning one's day, week and year to correspond to one's values as identified and prioritized at this point in time. There was time provided for an extended contemplative experience while listening to music, as well as an explanation of how bearing the tension of opposites results in healthy integration and peace within. A benefit to the cancer survivor was the

skill of bearing the tension created by life's opposing forces. For example, the tension between competition and accommodation, when brought together in balance, can combine both the need for assertiveness and the need for cooperation into effective collaboration. In addition, the survivor was offered the opportunity to begin to bring into closer alignment one's inner and outer experiences through values clarification and reimagining a preferred life.

Session 5: Integrating the inner and outer journeys. The goal of this session was to promote the integration of the cancer diagnosis and treatment into the individual's self-concept. Topics included the importance of being true to oneself in midlife, which can facilitate the individual's growth; that the fullness of life is experienced by being open to continual growing and becoming; and that the midlife crisis and transition is usually precipitated by an inner life or outer life catalyst, such as cancer. Processes employed during this session included participation in a ritual of renewal, a written dialogue with a wisdom figure, and creative listening and sharing. Benefits to the cancer survivor included an opportunity to connect the characteristics of the midlife crisis – thrust upon you, inner and outer components, crisis of feelings, new meanings, values and goals, loneliness, and new wisdom and power – with the participant's own inner and outer journeys. This beginning experience of integration can set the cancer survivor on a path to greater understanding of what the person hopes for now and a consideration of what QOL might be desired in one's future.

Session 6: Imagining one's preferred future. The goal of this session was to launch the participant into acceptance of responsibility for maintaining hope and QOL.

Topics included an understanding of the second half of life as involving: 1) coming to greater self-knowledge; 2) understanding one's personal psychology; 3) developing an inner life; and 4) continued generativity in one's outer life. Processes involved projecting one's future using the faculties of memory and imagination – memory of one's past life line and the imagination of one's future. Each group member was given the opportunity to express what he or she personally wished as the others affirmed them. Benefits to the cancer survivor may include renewed hope and increased QOL. Hope can be supported by allowing the participant to consider what is realistically possible and personally meaningful now. QOL can be enhanced by supporting a greater awareness of one's life story; its inner and outer unfolding, and the acquisition of new skills to direct one's life into a preferred future.

Control group. The control group participants received a Nutrition Program for Survivors (NPS) led by a research assistant at each of the Cancer Centers in designated conference rooms. Each program consisted of six 1-hour sessions with groups of 3 to 7 participants. The program consisted of information regarding improving nutrition during survivorship. Session topics and printed materials were taken from the American Cancer Society's Nutrition and Physical Activity Guidelines (Kushi et al., 2006) and included: 1) the benefits of good nutrition, 2) nutrition after treatment, 3) food and fitness, 4) cooking smart, 5) recipes and 6) summary. This program provided information important to cancer survivors following treatment, while not providing overlapping material with the MLD Workshop.

The research assistant for the first site was a certified nutritionist; for the second site the research assistant was a registered dietitian. Both the nutritionist and the dietitian were qualified to teach the content of the NPS by virtue of their education and certification. The researcher provided training to the research assistants during 30-minute individual sessions regarding the overall research plan, informed consent, human subjects' protection principles and the documentation of field notes. In addition, each research assistant completed human subjects' protection training modules as required by the IRBs. The research assistants were monitored by the researcher by meeting twice with the researcher during each intervention series to assure adherence to the research protocols and standards.

Data Collection

The data were collected using four different tools, three of which were quantitative and one qualitative. The demographic form, the HHI and the QOL-CS, which were quantitative, were completed by both the treatment and control groups after giving informed consent. The qualitative written reflection was completed only by the treatment group during the last session of the workshop after completing the HHI and QOL-CS instruments. The administration of the HHI and QOL-CS instruments was repeated during the final session of the workshop for both the treatment group and the control groups.

Instruments.

Demographic form. Information such as age, gender, education level, ethnicity, income, religious affiliation, type of cancer, date of diagnosis, and type of cancer treatment received were included on the this form. (Appendix A)

Herth Hope Index. The Herth Hope Index (HHI) (Appendix B) measured hope by means of 12 statements, each rated on a Likert-like scale from 1-4, with 1 indicating “strongly disagree” and 4 indicating “strongly agree” (Herth, 1992). The total score was obtained by summing the responses; statements 3 and 6 were reverse scored. Total possible scores could range from 12 to 48. Higher scores indicated higher levels of hope. The HHI was created from the original 30-item scale, the Herth Hope Scale, to reduce instrument/testing burden. The Herth Hope Scale has established reliability and validity (Herth, 1991). The HHI is based on research (Herth, 1991) which identified three factors constituting the concept of hope: 1) temporality and future, 2) positive readiness and expectancy, and 3) interconnectedness. The HHI has demonstrated reliability (test-retest $r = 0.91$, $p < .05$) and validity (concurrent validity $r = 0.84$, $p < .05$; criterion $r = 0.92$, $p < .05$; divergent $r = 0.73$, $p < .05$) with heterogeneous adult populations in various inpatient and outpatient clinical settings. There is a high correlation ($r = 0.92$) between the Herth Hope Scale and the HHI (Herth, 1992). It takes between 1-4 minutes to complete.

Quality of Life Instrument, Cancer Patient/Cancer Survivor Version (QOL-CS).

The QOL-CS (Appendix C) is a 41-item ordinal scale that was developed at the City of Hope to measure the four domains of quality of life including physical well-being, psychological well-being, social well-being and spiritual well-being (Ferrell, Hassey-

Dow & Grant, 1995). The patient is asked to read each question and decide if he/she agrees with the statement or disagrees according to the word anchors on each end of the scale from 0 (worst outcome) to 10 (best outcome). Several items are reverse scored: 1-7, 9, 16-27, 29-34 and 38. Possible scores range from 0 to 410. Subscales for each of the four domains can be created by adding all of the items within a subscale and creating a mean score. This instrument has demonstrated reliability and validity in the cancer survivor population with a test-retest reliability of 0.89 and an overall Cronbach alpha of 0.93, with alpha coefficients for the subscales of physical well-being $r = 0.77$, psychological well-being $r = 0.89$, spiritual well-being $r = 0.71$, and social well-being $r = 0.81$ (Ferrell, Hassey-Dow & Grant, 1995; Ferrell, Hassey-Dow, Leigh, & Gulasekaram, 1995).

Written reflection. The qualitative descriptive part of the study (written reflection) was administered to the treatment group during the last session of the workshop (Appendix D) after the HHI and QOL-CS instruments had been completed. As part of the workshop, the participants were asked to record their responses (written reflection) to the question: What meaning has the workshop had for you personally?

The participants were asked to create a reflection about their personal experience of participating in the workshop (written reflection). They were asked to think about the meaning that the workshop had for them personally. Then they were given paper (as much as desired) and asked to give themselves a pseudonym and write it on the cover page along with their actual name. In order to protect participant confidentiality and provide participant anonymity, the pseudonym was used instead of the person's actual

name in any quoted material in the final report. Using prose, poetry, art, music or any other form of expression, they were asked to capture how the content affected them and what it meant to them personally. At least 20 minutes of quiet time were provided for this purpose. The participants all completed their reflections and returned one or two hand-written pages to the researcher. Most participants completed the task within the 20 minutes allotted. A few extra minutes (5 to 10) were provided as needed so that each participant was able to finish his/her reflection as desired.

Data Analysis

Descriptive statistics. Prior to testing the hypothesis, descriptive statistics were completed on all study variables for all quantitative data. Data from the demographic form, the HHI and the QOL-CS were entered into individual data sheets. Administration of instruments during face-to-face sessions minimized the risk of missing data because the researcher could check completed forms prior to ending the session (Burns & Grove, 2009). When missing data did occur, it was handled as follows. Values for individual items on the HHI that were marked exactly between two numerical values were assigned the lower numerical value. A missing numerical value on the QOL-CS was calculated based on the individual's mean score for the questions directly preceding and following the missing value. On the demographic form, any dates that were missing the day in the month/day/year format were assigned "1" for the day. Data were then entered into the Statistical Software for the Social Sciences (SPSS[®]) version 18 for analysis.

Data were analyzed using descriptive statistics. Means, frequencies and measures of central tendency and dispersion were calculated. Chi-squared tests for categorical data

and T-tests for continuous data were used to determine any pre-existing differences in groups at baseline. The results were examined to determine the presence of marked skewedness and outliers. Steps were taken to correct problems using methods delineated in Burns & Grove (2009). The psychometric properties of each instrument were described.

Hypotheses.

1. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have a higher level of hope.

This hypothesis was tested by comparing the means of the post-intervention scores on the Herth Hope Index (HHI) for the treatment and the control groups using independent samples t-test analysis. Level of significance for all the analyses was set at $p < .05$.

2. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have greater gains in level of hope from pre-intervention to post-intervention.

This hypothesis was tested by comparing the HHI pre-intervention and post-intervention scores for the MLD and NPS groups using paired sample *t*-test analysis. Level of significance for the analysis was set at $p < .05$.

3. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have a higher level of quality of life.

Hypothesis #3 was evaluated with the QOL-CS scores as was described above with the HHI scores in hypothesis #1.

4. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have greater gains in level of quality of life from pre-intervention to post-intervention.

Hypothesis #4 was evaluated with the QOL-CS scores as was described above with the HHI scores in hypothesis #2.

Qualitative data. Qualitative data were typed into Word files and analyzed using Patton's thematic analysis (Flemming, 1997; Patton, 2002). The main qualitative points and topics were identified. From these main points and topics, themes were identified and numbered according to frequency of occurrence. Themes were organized using study framework categories and other categories that emerged. A cohesive summary presentation of the findings was made with linkages to the quantitative findings. In this way the summary provided a richer understanding of the workshop's effect on hope and quality of life by describing the benefits to participants using their own words. Benefits obtained by participants that were not captured on the HHI and QOL-CS instruments were captured in the qualitative thematic analysis.

Rigor. The quantitative and qualitative parts of this study, taken together addressed the research question – Is there a difference in the level of hope and quality of life of a treatment group when compared to a control group of midlife cancer survivors after the treatment group participates in a MLD Workshop? Each of the research methods answered the research question from its own perspective. Each method was implemented in a way that was true to its standards for rigor, as described below.

The quantitative research method can be classified as an experimental design. The independent variable is the Mid-Life Directions Workshop and the dependent variables are hope and quality of life. For quantitative designs, rigor involves “an adequate sample size, psychometrically sound tools, appropriate statistics, a lack of bias in choosing the sample and carrying out the design” (Gennaro, 2008). Each of these was addressed.

An adequate sample size was determined through power analysis. A study limitation is acknowledged to be that this sample size was not achieved due to the limited availability of participants for the study within a reasonable time frame. This is discussed further in chapter 5. Psychometrically sound tools were assured through the use of a demographic form that was clear, easy to use and which limited ambiguity (Burns & Grove, 2009), and the HHI and QOL-CS, which have established reliability and validity in the population being studied.

Data were checked for completeness by checking all responses on the demographic form, HHI and QOL-CS immediately after data collection. Any missing data were discussed with the participant and completed as possible. Data for each participant were kept together in a file designated for that participant. A study number was assigned to each participant and used for all data collected from the given participant. A process for accounting for missing data points, depending on the type of data, was utilized. A record of all decisions used to identify and handle issues was kept in a code book. Data were copied onto data summary sheets so that data could be reordered and entered into the computer more easily. All data points were checked twice by the researcher to assure accuracy. Data were entered into the Statistical Software for the

Social Sciences (SPSS[®]) and data analysis performed in the SPSS[®] computerized program. Accuracy of data entered into the computer was assured by the researcher who validated that data on data collection forms matched data files in SPSS[®]. Data were safely stored on a flash stick and backed up on a second flash stick. Original paper forms were stored in a locked filing cabinet in the office of the researcher. The entire data collection process was monitored and guided by the Dissertation Committee.

Appropriate statistics were used to analyze the data. Group differences were evaluated using *t*-test and Chi-squared tests to determine any bias before the intervention. Instrument stability was evaluated for the HHI and QOL-CS instruments using the Pearson correlation coefficient and internal consistency were evaluated using Cronbach alpha. Independent and paired sample *t*-test analyses were used to determine group differences over time (Munro, 2005). A research statistician verified all data analyses for appropriateness and accuracy.

Finally a lack of bias in choosing the sample and carrying out the design was assured by asking all qualified persons to participate in the study and by random assignment to either the treatment or the control group. As explained in chapter 4, one participant was involved in both groups at different times. As noted, the same researcher trained in providing MLD workshops provided the intervention using a guide book for consistent delivery of the workshop. A qualified research assistant delivered the NPS to the control group using a guide book for consistent delivery of the program. The research assistants were trained by the researcher and completed the required research module in human subjects protection at each hospital. The researcher monitored the research

assistants by holding two regular meetings per group and reviewing recorded field notes. No deviations in protocol or other difficulties with the control group were noted.

The qualitative research portion was conducted in order to enhance the quantitative results. As noted, this study used a multimethod design, which is “the conduct of two or more research methods, each conducted rigorously and complete in itself, in one project. The results are then triangulated to form a comprehensive whole” (Morse, 2003, p. 190). Results of qualitative research must be “credible, transferable, confirmable and dependable” (Gennaro, 2008). The criteria of credibility, transferability, confirmability and dependability were addressed for the qualitative portion of this study using the work of Anfara, Brown, & Mangione (2002) as a guide.

Credibility was assured by following a set protocol and standards devised beforehand (Appendix D). Credibility was enhanced through triangulation of findings. Transferability was assured by random sampling of the study population, and by having the two founders of Mid-Life Directions review the findings for congruency with their experiences with other workshop participants. Dependability was addressed by creating an audit trail, having a code-recode strategy, and providing for the examination of 25% of the written reflections and their thematic analysis by an expert in thematic analysis. A discussion of any differences by the researcher and the second expert was conducted in order to reach consensus. Meaning, structure and order were brought to the data through code mapping and use of the study framework to organize themes, as determined by the researcher and confirmed by the thematic analysis expert. Detailed records of the choices made during this process were kept concurrently by the researcher and recorded in the

field notes. Finally confirmability was assured by having an expert in thematic analysis check the final themes and provide feedback on the interpretation. An audit trail was kept by the researcher in the field notes which identified the analytical decisions made during data collection and data analysis. All processes were monitored by the researcher's dissertation committee.

Protecting the Participants

The Institutional Review Board (IRB) for Protection of Human Subjects at each hospital granted approval for the study. The Boston College IRB entered into an Authorization Agreement with each of the designated hospital IRBs after successful approval of the study at the designated sites. Terms of the agreement were that both parties agreed that Boston College would rely on the designated hospital's IRB for review and continued oversight of human subjects' research for the study.

Risks to participants.

Human subjects' involvement and characteristics. This study included men and women who had completed active primary treatment for cancer and were transitioning to survivorship. The inclusion criteria for the study were: 1) the person was between 40 and 64 years of age, 2) the person had completed active primary treatment for cancer within the past 18 months, 3) the person was diagnosed with a solid tumor, stages I, II or III, including lymphomas, 4) the person could speak, write and read English, and 5) the person was able to give informed consent. Exclusion criteria were: 1) the person had been diagnosed with stage IV disease, and 2) the person was diagnosed with dementia or

another medical condition that impaired his or her ability to participate in the study procedures according to the judgment of the nursing or medical staff.

Source of materials. Data obtained from participants included demographic data, informed consent, HHI and QOL-CS instruments (questionnaires), and for the treatment group, written reflections. All study data were coded with an allocation number to maintain participant confidentiality and anonymity. Data continue to be maintained in locked files in the office of the researcher. All protected health information will be destroyed by the researcher after 7 years. Only the researcher and the members of the dissertation committee have access to these files as well as any auditors of Institutional Review Board (IRB) approval committees.

Potential risks. Participants may have found the questionnaires and procedures to be tedious or stressful. The time commitment over six sessions may have been inconvenient. Workshop content and rating scales may have involved the disclosure of sensitive and personal information that may have been uncomfortable for some participants. There was a risk of a breach of confidentiality by group members regarding sensitive and personal information disclosed during the study. This risk was minimized by obtaining a verbal agreement from all group members that all information expressed in the group be held in confidentiality by all group members. In addition there was a psychiatric advance practice nurse on call in case a participant required immediate attention due to emotional upset. The services of the psychiatric advance practice nurse were not utilized since no emotional upset occurred during the study.

Adequacy of protection against risk.

Recruitment and informed consent. Participants were recruited from ambulatory Cancer Centers at two hospitals in the northeastern United States by means of the Tumor Registry at the site. Lists of eligible participants created by the Tumor Registry, and all other lists containing any of the participants' confidential information were and continue to be kept in locked files in the office of the researcher.

During the screening session, study procedures were carefully explained to the participants. Questions were answered by the investigator. If a participant agreed to participate in the study, the consent form was signed by the participant and the investigator. The participant was reminded that he/she could withdraw from the study at any time. The participant was given a copy of the informed consent form. Consent was reviewed again with the participants, prior to and throughout the intervention. The original informed consent was and continues to be kept in the folder for each participant in the locked file in the office of the researcher.

Protection against risk. Information regarding clinical history was kept in locked files. Participants with psychiatric disorders which might interfere with informed consent procedures (e.g., psychotic disorders) as determined by their practitioner/physician were not included in this study. Participants were monitored for symptoms of depression including active suicidal ideation by the researcher by questioning participants as appropriate. Referral to a mental healthcare provider was made available, although never needed to be utilized. Individuals who experienced the study procedures as stressful were free to withdraw and this was made known during the consent procedure. The only

adverse event during the study involved a complaint by one participant at the first site about the perceived disclosure of protected health information to the researcher without consent. This was resolved by the IRB and implemented by the researcher through changes in letterhead and opt-out procedures, as discussed earlier in this chapter.

Confidentiality and anonymity were strictly maintained. Group members were reminded to maintain the anonymity of other participants and maintain the confidentiality of all group sharing. Participants were identified by the use of consecutive numbers in the data, starting with number 101. Study information was stored in separate locked files from computerized deidentified data. Secure filing cabinets are available in the office of the researcher and are under the supervision of the dissertation chair.

Potential benefits of the proposed research to the participants and others.

There was minimal risk of serious psychological or physical side effects from this study. Although there were no known benefits of the intervention, participants reported benefit from the intervention by experiencing increased hope and better quality of life.

Importance of the Knowledge to be Gained

Hope and quality of life are important aspects of caring for persons with cancer. Although the process of maintaining hope and supporting quality of life is important, nursing interventions to support this population remain poorly defined. Results of this study contributed further knowledge regarding ways to support hope in patients in midlife who have completed active primary treatment for cancer. This is important

knowledge for nurses who serve this population in order to provide appropriate nursing care.

Chapter 4

Findings

Chapter 4

Findings

In this chapter I describe the findings of a study to examine the effects of a psycho-educational group intervention, the Mid-Life Directions (MLD) Workshop, on hope and quality of life in midlife cancer survivors. In particular, this study compared the outcomes of the MLD Workshop, which served as the treatment group, and the Nutrition Program for Survivors (NPS), which served as the control group. The outcome measures for both groups were hope and quality of life. Descriptive statistics are reported for the quantitative data from the demographic form, the Herth Hope Index (HHI) and Quality of Life Instrument, Patient/Cancer Survivor Version (QOL-CS). Statistical testing of each hypothesis follows. All statistics were computed using the software package Statistical Software for the Social Sciences (SPSS[®]) version 18.0. Qualitative data from the written reflections of the treatment group are reported using themes which are organized around the study framework categories and other categories that emerged.

Access and Retention

Between August 2010 and July 2011, 94 potential participants who completed active primary treatment for cancer at one of two acute care hospitals in the northeastern United States were sent letters of invitation to participate in the study. Forty-five were from hospital A and 49 from hospital B. Of those invited, 52 (55.3%) declined to participate, 2 (2.1%) did not meet inclusion criteria, 4 (4.3%) did not respond, and 3 (3.2%) could not be contacted. Reasons for declining to participate were lack of time

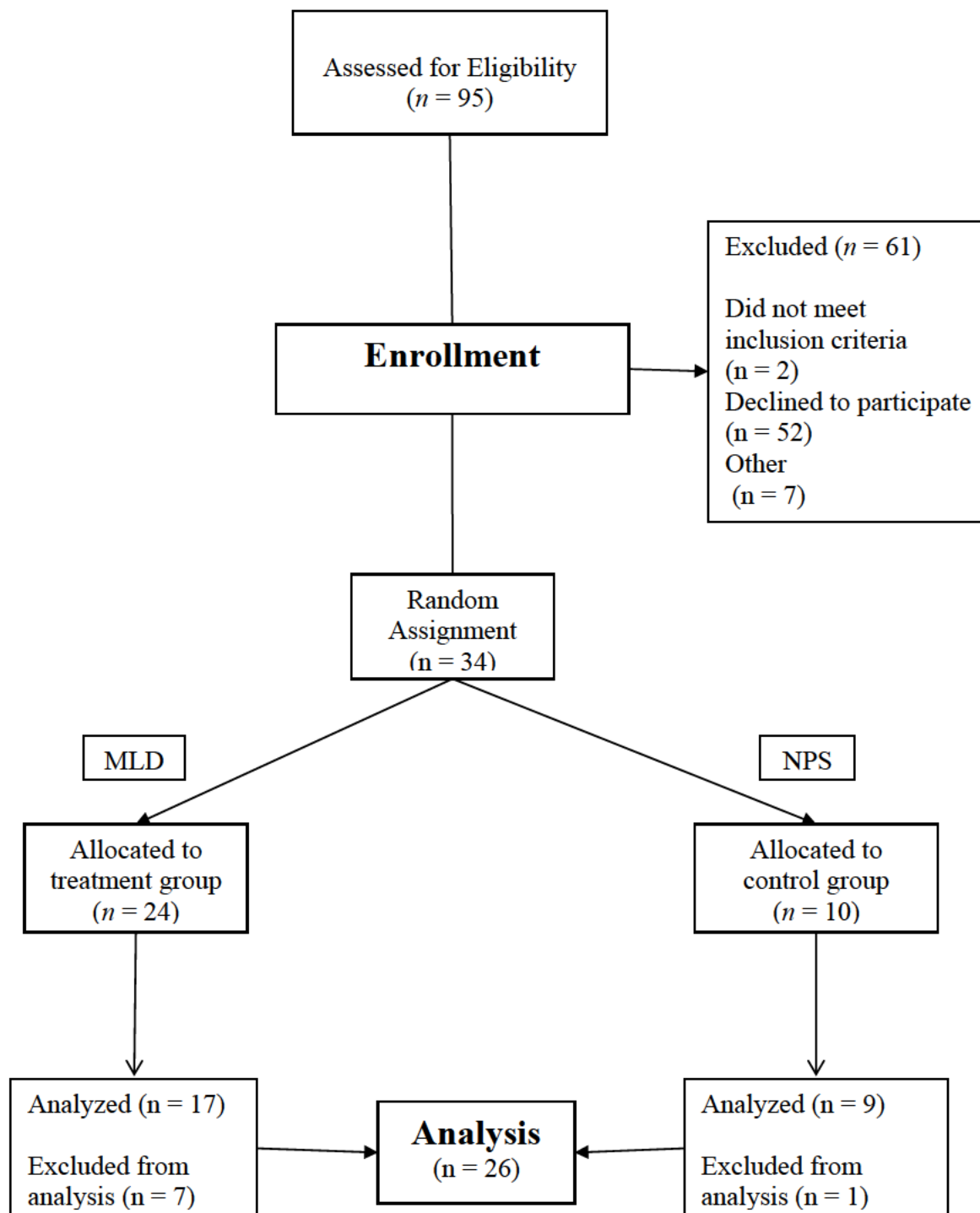
related to work, length of the study and/or family responsibilities (n = 28), lack of interest (n = 21), personal illness (n = 2) and fatigue (n = 1). The remaining 33 (35.1%) gave informed consent and were randomly assigned, with 3 exceptions to be described later, to either the treatment or the control group. One participant requested and was permitted to attend the MLD group one month after completing the NPS group, bringing the total number of participants to 34, with 24 (70.6%) in the treatment group and 10 (29.4%) in the control group.

Random assignment was made by means of a table of random numbers, assigning approximately twice the number of participants to the treatment group as to the control group (Dumville, Hahn, Miles & Torgerson, 2006). The larger number of participants in the treatment group was selected based on the practical issue of limited accessing of participants in a reasonable length of time. Random assignment was not possible for 3 cases. One participant's work schedule would not allow attendance at the treatment group to which the participant was randomly assigned. This participant was then assigned to the control group because it did not interfere with the participant's work. Two other participants were not able to meet for the informed consent procedure until after the control group sessions had begun. They were assigned to the treatment group because it was the only group offered subsequent to their informed consent process. When considering the participant who crossed over to the treatment group, after random assignment to and completion of the control group, then the total number of participants who were not randomized is 4, 3 in the treatment group and 1 in the control group. All 4

completed at least 4 sessions in their assigned groups and their data became part of the final analysis.

Ultimately data from 8 participants were excluded from the final analysis for the following reasons: 1 participant never formally withdrew, but attended fewer than 4 sessions due to illness; and 7 participants withdrew from the study; 3 due to family illness, 1 due to personal illness, 1 for reasons of travel distance, and 2 for personal reasons. Of those who withdrew, 4 attended only one session, and 3 attended none. The final analysis was performed using data from the 26 participants who completed at least 4 of the 6 sessions in their assigned groups. (See Figure 5)

Figure 5

Eligibility, Enrollment and Follow-up of Study Participants

Description of the Participants

After giving informed consent demographic data and clinical characteristics were collected from each participant via the demographic form (Appendix A). Findings are presented for the sample as a whole as well as for the treatment and control groups. Lastly those who were randomly assigned but lost to follow-up are described.

Sample description. The sample consisted of 26 patients with a mean age of 54.31 years (SD = 7.058, range, 40-65 years) and with the following diagnoses: breast cancer (n = 19, 73.1%), colorectal cancer (n = 4, 15.4%), lung cancer (n = 2, 7.7%), and malignant melanoma (n = 1, 3.8%). Disease stages I (38.5%), II (38.5%) and III (23.1%) were represented. The mean time since completion of treatment was 11.5 months (SD = 6.667, range, 0-28 months). There were more females (88.5%) than males. The majority of participants identified as non-Hispanic (96.2%) and white (100%) and most had some college courses or a college degree (88.5%). Table 8 presents the demographic characteristics for continuous variables for the 26 participants and by group, and Table 9 presents the categorical variables.

Table 8

Demographic Characteristics for Age and Months Post Treatment by Group with t-test

Characteristics	Total Sample N = 26	MLD (Treatment) Group n = 17	NPS (Control) Group n = 9	<i>p</i>
	Mean (SD)	Mean (SD)	Mean (SD)	
Age (years)	54.31 (7.058)	55.59 (7.323)	51.89 (6.194)	0.21
range	40-65	40-65	42-62	
Months post treatment	11.15 (6.667)	12.76 (6.842)	8.11 (5.419)	0.09
range	0-28	0-28	2-16	

Note. MLD = Mid-Life Directions, NPS = Nutrition Program for Survivors.

The treatment and control groups were similar in most measured characteristics. Continuous variables were compared using t-tests for age ($t = 1.288$, $df = 24$, $p = .21$) and months post treatment ($t = 1.763$, $df = 24$, $p = .09$) revealing no significant differences between groups. Significance level was set at $p < .05$ (two-tailed).

Categorical variables were compared using chi-squared tests. No significant differences ($p < .05$) between groups were found except that there were significantly more participants ($\chi = 1.385$, $df = 1$, $p = .01$) who had been treated with chemotherapy in the control group 9/9 (100%) than in the treatment group 9/17 (52.9%).

Table 9

Demographic Characteristics for Categorical Variables by Group with Chi-squared Test

Characteristics	Total Sample N = 26	MLD Group n = 17	NPS Group n = 9	χ^2	p
	N (%)	n (%)	n (%)		
Gender				0.348 df = 1	0.23
Male	3 (11.5)	1 (5.9)	2 (22.2)		
Female	23 (88.5)	16 (94.1)	7 (77.8)		
Race				N/A	N/A
Black	0 (0)	0	0		
White	26 (100)	17 (100)	9 (100)		
Ethnicity				0.125 df = 1	0.48
Hispanic	1 (3.8)	1 (5.9)	0 (0)		
Non-Hispanic	25 (96.2)	16 (94.1)	9 (100)		
Education				0.113 df = 4	0.78
High school	3 (11.5)	2 (11.8)	1 (11.1)		
Some college	8 (30.8)	4 (23.5)	4 (44.4)		
Associate's degree	3 (11.5)	2 (11.8)	1 (11.1)		
Bachelor's degree	10 (38.5)	7 (41.2)	3 (33.3)		
Master's degree	2 (7.7)	2 (11.8)	0 (0)		
Household income				0.261 df = 6	0.37
Less than \$30,000	2 (7.7)	0 (0)	2 (22.2)		
\$30,000-\$39,999	1 (3.8)	1 (5.9)	0 (0)		
\$50,000-\$59,999	5 (19.2)	4 (23.5)	1 (11.1)		
\$60,000-\$69,999	3 (11.5)	2 (11.8)	1 (11.1)		
\$80,000-\$89,999	1 (3.8)	0 (0)	1 (11.1)		
\$90,000 or greater	10 (38.5)	7 (41.2)	3 (33.3)		
Prefer not to answer	4 (15.4)	3 (17.6)	1 (11.1)		

Demographic Characteristics for Categorical Variables by Group with Chi-squared Test

Characteristics	Total Sample N = 26	MLD Group n = 17	NPS Group n = 9	χ^2	p
	N (%)	n (%)	n (%)		
Religious affiliation				0.109 df = 4	0.79
Catholic	16 (61.5)	10 (58.8)	6 (66.7)		
Christian	5 (19.2)	3 (17.6)	2 (22.2)		
Jewish	2 (7.7)	2 (11.8)	0 (0)		
Other religion	1 (3.8)	1 (5.9)	0 (0)		
None	2 (7.7)	1 (5.9)	1 (11.1)		
Type of cancer				0.40 df = 3	0.16
Breast	19 (73.1)	14 (82.4)	5 (55.6)		
Colorectal	4 (15.4)	2 (11.8)	2 (22.2)		
Lung	2 (7.7)	0 (0)	2 (22.2)		
Melanoma	1 (3.8)	1 (5.9)	0 (0)		
Treatment with surgery	25 (96.2)	17 (100)	8 (88.9)	0.445 df = 1	0.17
Treatment with radiation	18 (69.2)	13 (76.5)	5 (55.6)	0.274 df = 1	0.29
Treatment with chemotherapy	18 (69.2)	9 (52.9)	9 (100)	1.385 df = 1	0.01*
Other treatment	4 (15.4)	4 (23.5)	9 (100)	0.566 df = 1	0.12
Disease stage				0.192 df = 2	0.46
Stage I	10 (38.5)	8 (47.1)	2 (22.2)		
Stage II	10 (38.5)	6 (35.3)	4 (44.4)		
Stage III	6 (23.1)	3 (17.6)	3 (33.3)		

* $p < .05$ (two-tailed)

Note. MLD = Mid-Life Directions, NPS = Nutrition Program for Survivors.

Participants randomly assigned but lost to follow-up. A comparison was made between those who participated in the study and completed at least 4 of the 6 sessions (n = 26, 76.5%) and those who did not (n = 8, 23.5%) using t-tests for continuous variables

and chi-squared tests for categorical variables. Significant differences ($p < .05$) were found in the categories of race ($\chi = 10.694$, $df = 1$, $p = .001$, Fisher's exact = 0.009) and religious affiliation ($\chi = 15.342$, $df = 4$, $p = .002$). Those lost to follow-up were more likely to be self-identified as African American or Black ($n = 3$, 37.5%) and as having no religious affiliation ($n = 5$, 62.5%).

Treatment Fidelity

The treatment group was offered 4 times. Each of the 17 participants attended one of the 4 MLD groups for 6 sessions each. The control group was offered 2 times. Each of the 9 participants attended one of the 2 NPS groups for 6 sessions each. Two MLD groups were conducted at hospital A and two at B. One NPS group was conducted at each hospital (see Table 10).

Table 10

Number of Participants in Treatment and Control Groups by Hospital

	MLD Treatment Group		NPS Control Group	
	Assigned	Completed	Assigned	Completed
Hospital A	6	3	3	3
	3	3		
Hospital B	5	3	7	6
	10	8		
Totals	24	17	10	9

Note. MLD = Mid-Life Directions, NPS = Nutrition Program for Survivors.

Each of the interventions was delivered as intended and described below. All sessions began on time and ended on time. Although a psychiatric nurse practitioner was available in case of emotional upset, no adverse events occurred.

Treatment group. Each treatment group workshop was given by the researcher who is a certified Mid-Life Directions (MLD) consultant. An attendance record for each session was maintained by the researcher. Content for the sessions was presented using the guide book, assuring consistent delivery of the workshop. Participants received standard MLD Workshop workbooks which they used during the sessions and which they kept. Field notes were documented by the researcher after each session. A written reflection was completed by all treatment group participants during the last session of the workshop after completing the Herth Hope Index (HHI) and the Quality of Life Instrument (QOL-CS). All instruments were administered by the researcher, who allowed for sufficient time and provided a quiet atmosphere for their completion.

Control group. Each control group program was delivered by a certified professional in the role of research assistant (RA). The first Nutrition Program for Survivors (NPS) at hospital A was given by a certified nutritionist. At hospital B the NPS was given by a registered dietitian. Prior to giving the NPS sessions, each RA successfully completed the training modules for the human research curriculum required by the Institutional Review Board of each hospital. In addition the researcher provided a personal 30-minute session to each RA covering the following information: 1) overall research plan, 2) informed consent, 3) human subjects' protection principles, and 4)

documentation of field notes. A guide book with the content of the NPS sessions based on the American Society Guidelines for Nutrition & Physical Activity after Treatment (2009) was given to each RA in order to guide the session content. Each RA prepared their presentations using the guide book.

An attendance record for each session was maintained by the researcher. Content for the sessions was presented by the RA using the guide book, assuring consistent delivery of the workshop. Handouts were provided to the participants from the American Cancer Society and other materials deemed appropriate by the RA for the group. Field notes were documented by the RA after each session. The RA was monitored by the researcher who was present outside the conference rooms during the sessions. Researcher and RA met briefly after each session to examine adherence to the research protocols and standards. Guidance was given to each RA by the researcher as needed concerning the documentation of field notes and the appropriateness of handouts. The Herth Hope Index (HHI) and the Quality of Life Instrument (QOL-CS) were completed by all control group participants during the last session of the program. All instruments were administered by the researcher during the final 30 minutes of the last session. Sufficient time and a quiet atmosphere were provided for their completion. The researcher retained copies of the handouts given to participants at each session and stored them along with the field notes as study data.

Statistics and Quantitative Data Analysis

Cronbach's alpha coefficients were calculated for each of the standardized instruments used in the study. The Herth Hope Index (HHI) is reported to be reliable

(test-retest $r = 0.91$, $p < .05$) with Cronbach's alpha coefficient of 0.97 (Herth, 1992). In this study, Cronbach's alpha scores were $r = 0.90$ (pre-intervention) and $r = 0.88$ (post-intervention).

The Quality of Life Instrument, Cancer Patient/Cancer Survivor Version (QOL-CS) has reported overall test-retest reliability of 0.89 and internal consistency with Cronbach's alpha $r = 0.93$ (Ferrell, Hassey Dow & Grant, 1995). In this study, Cronbach's alpha scores were $r = 0.89$ (pre-intervention) and $r = 0.88$ (post-intervention). Both the HHI and the QOL-CS tools, therefore, are considered to have satisfactory reliability in this study.

Comparison of the pre-intervention mean scores for the HHI and QOL-CS instruments were made using independent samples t -test analysis in order to determine if the groups were equal regarding level of hope and quality of life prior to any intervention. In regard to the measure of hope, using the HHI, the two groups were not significantly different ($t = 1.44$, $df = 24$, $p = .16$) pre-intervention. In regard to the measure of quality of life, using the QOL-CS, the two groups were significantly different ($t = 2.47$, $df = 24$, $p = .02$) pre-intervention, with the mean score for the treatment group being significantly higher than the mean score for the control group.

Hypothesis testing. Descriptive and inferential statistics from SPSS[®] 18 were used in the analysis of data in order to test the 4 hypotheses. Individual and group total scores were calculated for the HHI and QOL-CS pre-intervention and post-intervention. Differences between and within groups were analyzed to determine significance with t -

tests for independent and paired samples. Significance level was set at $p < .05$ (two-tailed).

Hypothesis 1. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have a higher level of hope.

This hypothesis was tested by comparing the means of the post-intervention scores on the Herth Hope Index (HHI) for the treatment and the control groups using independent samples t -test analysis. Table 11 shows the HHI mean score for the MLD group as 41.00 (SD = 3.86, range, 35-47) and for the NPS group as 40.89 (SD = 5.09, range, 33-48).

Table 11

Herth Hope Index Scores Post-intervention by Group

Group	n	Mean	Standard deviation	Range
Mid-Life Directions	17	41.00	3.86	35-47
Nutrition Program	9	40.89	5.09	33-48

Note. n = number of participants in group

Table 12 displays results of the independent samples t -test of Herth Hope Index scores for differences between groups. While not significantly different ($t = 0.063$, $df = 24$, $p = .95$) the MLD mean score is higher than the NPS mean score. It should be noted that the control group has a higher standard deviation (SD = 5.09) than the treatment group (SD = 3.86), indicating more variability in the control group scores.

Table 12

Independent Samples t-Test of Herth Hope Index Scores for Differences between Groups

Time	<i>t</i>	df	Significance
Pre-intervention	1.44	24	.16
Post-intervention	.063	24	.95

Note. df = degrees of freedom

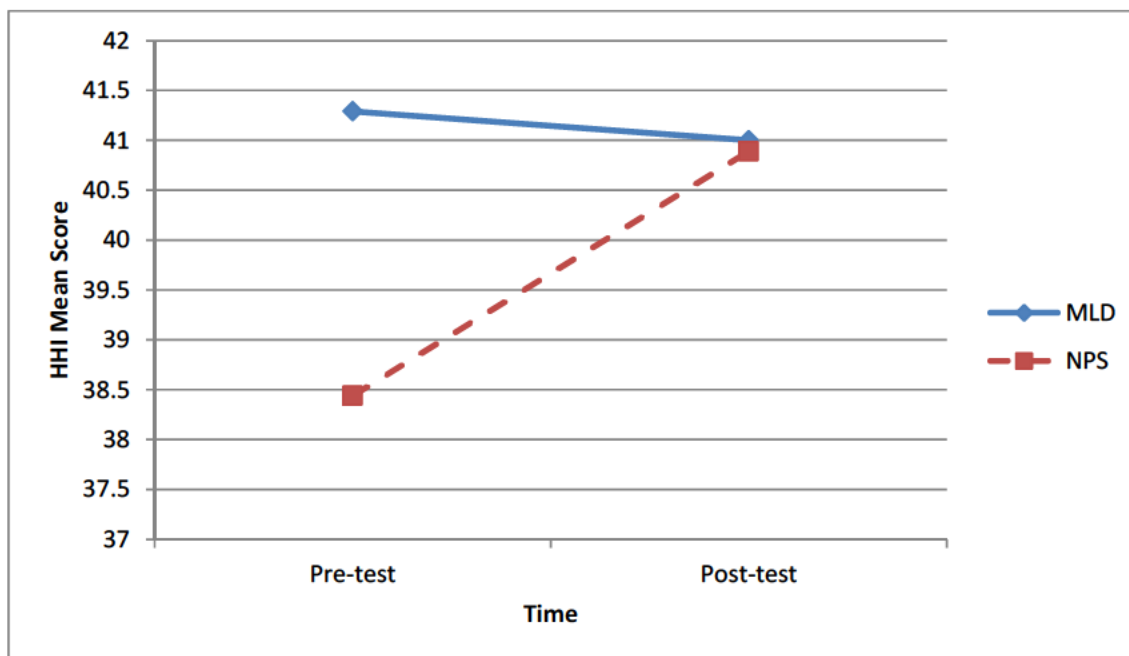
Hypothesis 2. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have greater gains in level of hope from pre-intervention to post-intervention.

This hypothesis was tested by comparing the HHI pre-intervention and post-intervention scores for the MLD and NPS groups using paired sample *t*-test analysis.

The MLD group had a loss of 0.29 points on average, with pre-intervention mean score of 41.29 points (SD = 4.327, range, 34-47) to post-intervention mean score of 41.00 points (SD = 3.857, range, 35-47). The NPS group had a gain of 2.45 points on average, with pre-intervention mean score of 38.44 points (SD = 5.615, range, 30-48) to post-intervention mean score of 40.89 points (SD = 5.085, range, 33-48) (see Figure 6).

Figure 6

Herth Hope Index (HHI)



Note. MLD = Mid-Life Directions, NPS = Nutrition Program for Survivors.

It is noted once again that the control group has consistently higher standard deviations than the treatment group, indicating more variability in the control group scores.

Paired sample *t*-test analysis of the HHI pre-intervention and post-intervention scores for the MLD and NPS groups showed a significant difference pre-intervention to post-intervention for the NPS group ($t = -2.35$, $df = 8$, $p = .047$). The MLD group showed no significant difference in scores pre-intervention to post-intervention ($t = 0.38$, $df = 16$, $p = .71$) (see Table 13).

Table 13

Paired Samples t-Test of Herth Hope Index Scores for Changes Pre-intervention to Post-intervention by Group

Group	<i>t</i>	df	Significance
Mid-Life Directions	.38	16	.71
Nutrition Program	2.35	8	.047*

Note. df = degrees of freedom, *p < .05

Hypothesis 2 was not supported. Rather, the opposite was supported, that is, the control group, when compared to the treatment group, had significantly greater gains in level of hope ($p = .047$) from pre-intervention to post-intervention. However, the standard deviation in the MLD group is less than that of the NPS group, indicating that the MLD group, when compared to the NPS group, is becoming more homogeneous over time.

Hypothesis 3. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have a higher level of quality of life.

This hypothesis was tested by comparing the means of the post-intervention scores on the Quality of Life Instrument, Cancer Patient/Cancer Survivor Version (QOL-CS) for the treatment and the control groups using independent samples *t*-test analysis. Table 14 shows the QOL-CS mean post-intervention score for the MLD group as 274.47 (SD = 32.90, range, 198-319) and for the NPS group as 257.44 (SD = 51.30, range, 184-356).

Table 14

Quality of Life (QOL) Scores Post-intervention by Group

Group	n	Mean	Standard deviation	Range
Mid-Life Directions	17	274.47	32.90	198-319
Nutrition Program	9	257.44	51.30	184-356

Note. n = number of participants in group

Table 15 displays results of the independent samples t-test of Quality of Life scores for differences between groups. While not significantly different ($t = 1.03$, $df = 24$, $p = .31$) the MLD mean score is higher than the NPS mean score.

Table 15

Independent Samples t-Test of Quality of Life (QOL) Scores for Differences between Groups

Time	t	df	Significance
Pre-intervention	2.473	24	.02*
Post-intervention	1.03	24	.31

Note. df = degrees of freedom, * $p < .05$

Two additional findings should be noted. One is that the QOL-CS pre-intervention mean scores are significantly different ($t = 2.473$, $df = 24$, $p = .02$). MLD mean scores pre-intervention 275.24 (SD = 37.65, range, 191-328) are higher than NPS mean scores pre-intervention 234.89 (SD = 43.15, range, 172-302). The other finding is that the

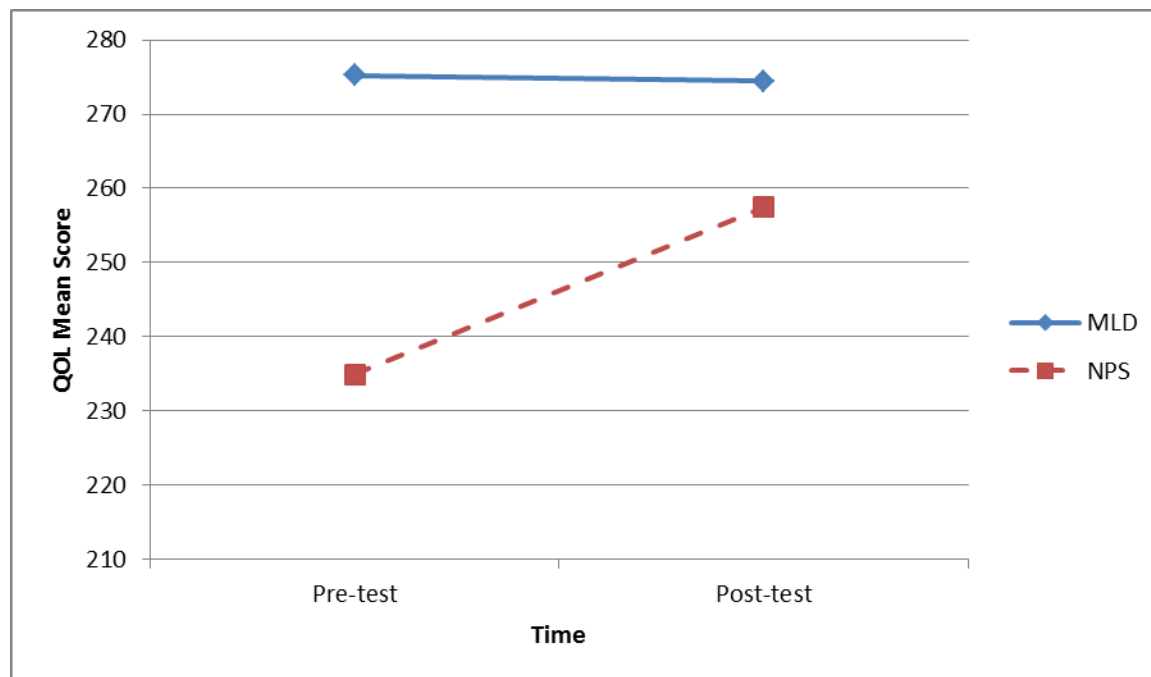
standard deviations pre-intervention to post-intervention are narrowing for the MLD group (37.65 to 32.90) and widening for the NPS group (43.15 to 51.30).

Hypothesis 4. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have greater gains in level of quality of life from pre-intervention to post-intervention.

This hypothesis was tested by comparing the QOL pre-intervention and post-intervention scores for the MLD and NPS groups using paired sample *t*-test analysis. The MLD group had a loss of 0.76 points on average, with pre-intervention mean score of 275.23 points (SD = 37.65, range, 191-328) to post-intervention mean score of 274.47 points (SD = 32.90, range, 198-319). The NPS group had a gain of 22.55 points on average, with pre-intervention mean score of 234.89 points (SD = 43.15, range, 172-302) to post-intervention mean score of 257.44 points (SD = 51.30, range, 184-356), (see Figure 7).

Figure 7

Quality of Life (QOL)



Note. MLD = Mid-Life Directions, NPS = Nutrition Program for Survivors.

It should also be noted that standard deviations narrow for the MLD group pre-intervention to post-intervention, while the NPS group standard deviations widen, indicating greater convergence and less variability in scores for the MLD group.

Paired sample *t*-test analysis of the QOL pre-intervention and post-intervention scores for the MLD and NPS groups showed no significant difference pre-intervention to post-intervention for the NPS group ($t = -2.15$, $df = 8$, $p = .06$). The MLD group also showed no significant difference in scores pre-intervention to post-intervention ($t = 0.09$, $df = 16$, $p = .93$) (see Table 16).

Table 16

Paired Samples t-Test of Quality of Life Scores for Changes Pre-intervention to Post-intervention by Group

Group	<i>t</i>	df	Significance
Mid-Life Directions	0.09	16	.93
Nutrition Program	-2.15	8	.06

Note. df = degrees of freedom

Hypothesis 4 was not supported. The control group, although non-significant, had greater gains in quality of life scores pre-intervention to post-intervention when compared to the treatment group.

Scatter plots of the pre-intervention and post-intervention scores for each participant by group demonstrated the convergence noted in the MLD group and the divergence in the NPS group in the measures of hope and quality of life over time. Figures 8 and 9 show the HHI score plots and Figures 10 and 11 the QOL-CS score plots, with the x-axis representing the pre-intervention scores and the y-axis representing the post-intervention scores for each participant. In this case visuals are informative related to the coalescing of groups and is supported by decreasing standard deviations.

Figure 8

Herth Hope Index (HHI) Pre-intervention and Post-intervention per Participant for MLD Group

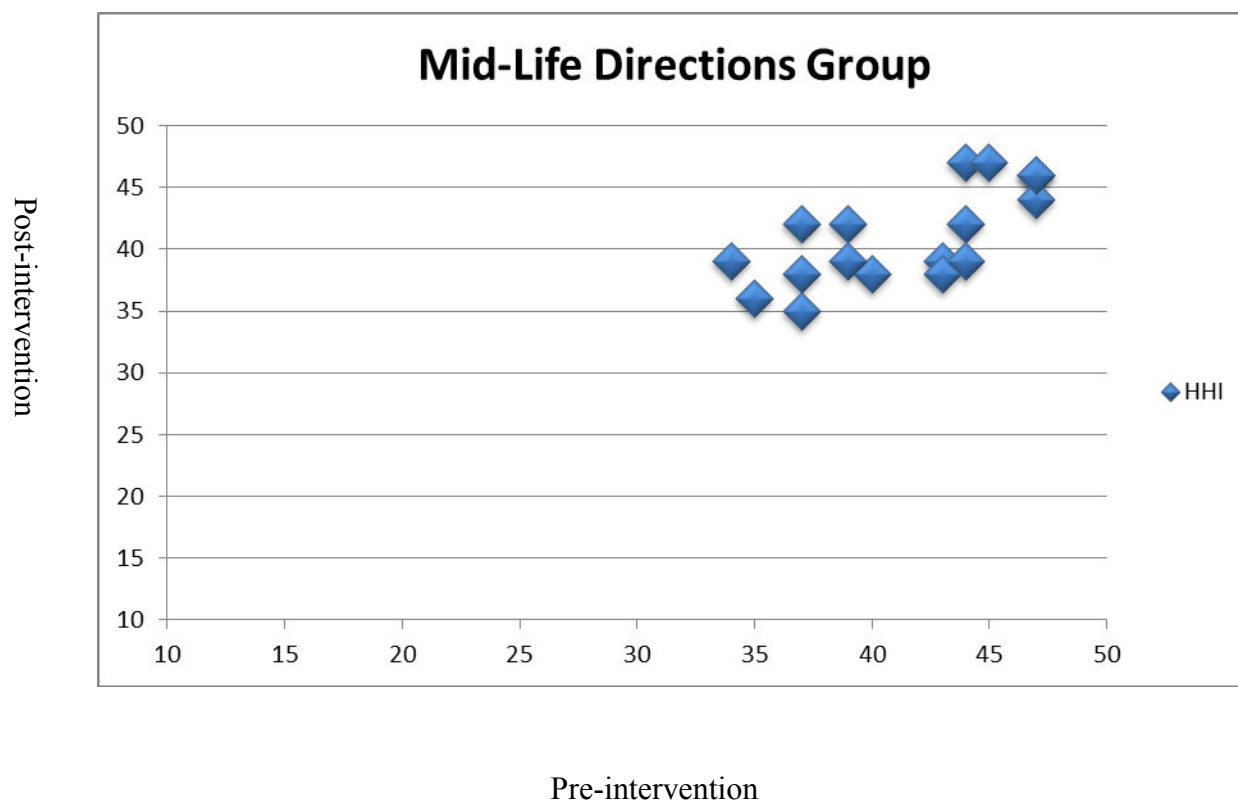


Figure 9

Herth Hope Index (HHI) Pre-intervention and Post-intervention per Participant for NPS Group

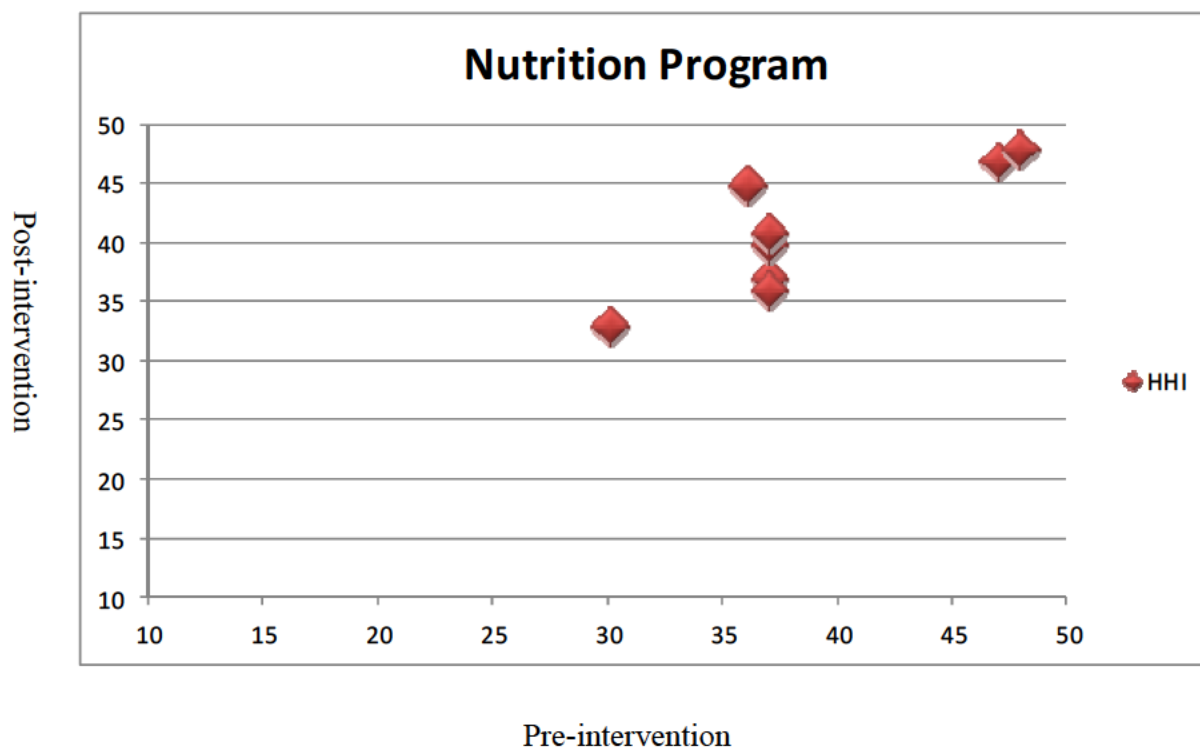


Figure 10

Quality of Life (QOL) Pre-intervention and Post-intervention per Participant for MLD Group

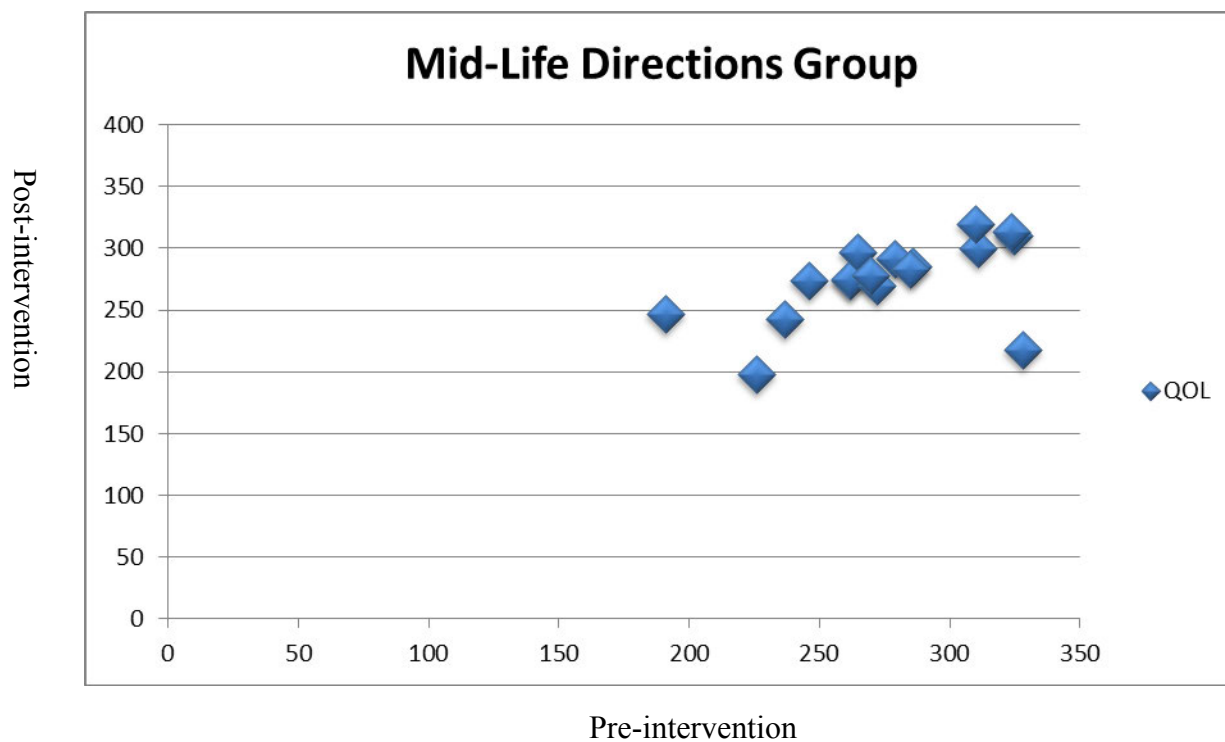
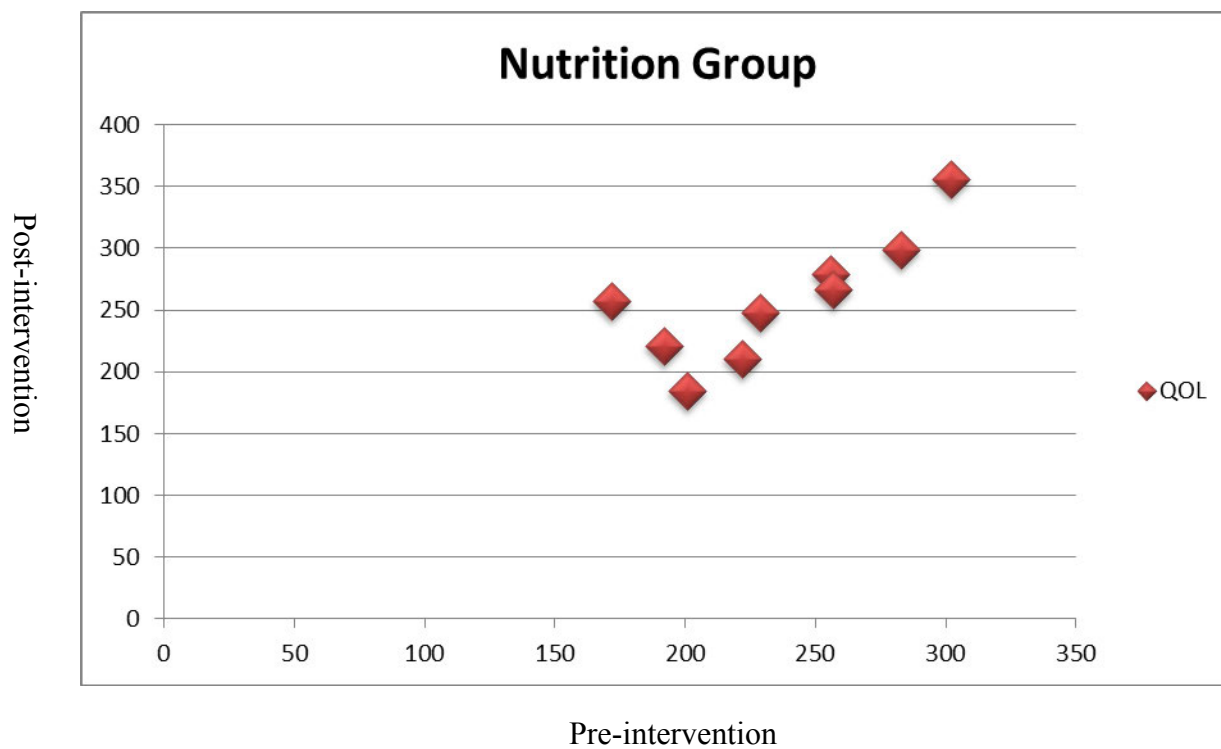


Figure 11

Quality of Life (QOL) Pre-intervention and Post-intervention per Participant for NPS Group



Summary of quantitative data analysis. In summary, the two groups, treatment and control, had no significant demographic differences pre-intervention except in regard to treatment with chemotherapy. Significantly more ($p = .01$) control group members ($n = 9/9$, 100%) received chemotherapy as a treatment modality than treatment group members ($n = 9/17$, 52.9%). In regard to the measure of hope, using the Herth Hope Index (HHI), the two groups, treatment and control, were similar in the HHI measure pre-intervention. In regard to the measure of quality of life, using the Quality of Life Instrument, Cancer Survivor version (QOL-CS), the two groups were significantly different ($p = .02$) pre-intervention; the treatment group scores were higher on average than the control group scores.

Measures of hope (HHI) and quality of life (QOL-CS) pre-intervention and post-intervention were used to test the four hypotheses. The first two hypotheses refer to hope and the second two to quality of life.

Hypothesis 1. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have a higher level of hope. This hypothesis was rejected since there was no significant difference between groups post-intervention.

Hypothesis 2. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have greater gains in level of hope from pre-intervention to post-intervention. This hypothesis was also rejected. In fact, the opposite was found to be supported. A significant difference ($p = .047$) was found in the NPS group, which had significantly greater gains in level of hope pre-intervention to post-intervention than the MLD group.

Hypothesis 3. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have a higher level of quality of life. This hypothesis was rejected because there was no significant difference between groups post-intervention. However, it is noted that the groups were significantly different in the QOL-CS measure pre-intervention.

Hypothesis 4. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have greater gains in level of quality of life from pre-intervention to post-intervention. This hypothesis was rejected since there were no significant differences between groups. Neither group had a significant increase in quality of life scores pre-intervention to post-intervention.

In summary, all four hypotheses were rejected. One significant finding was that the NPS group had significantly greater gains in level of hope pre-intervention to post-intervention ($p = .047$). The NPS group also had greater, though non-significant, gains in quality of life pre-intervention to post-intervention ($p = .06$). Of note was the convergence of scores for participants in the treatment group over time, while the control group scores became more divergent over time.

Qualitative Data Analysis

Qualitative data were collected from the treatment group via written reflections (Appendix D). Each of the 17 MLD participants created a reflection during the last session regarding their personal experience of participating in the workshop. They were asked to include how the workshop was helpful and how it was not helpful. As noted, all reflections were created after the HHI and QOL-CS post-interventions were completed.

Each written reflection consisted of one to two hand-written pages. The researcher typed them into Word documents and analyzed them using Patton's thematic analysis (Flemming, 1997; Patton, 2002). First the main qualitative points and topics were identified. From these main points and topics, themes were identified and numbered according to frequency of occurrence. Themes were then organized using study framework categories and other categories that emerged.

Themes. Each experience of the MLD Workshop was unique to the individual. However several common themes emerged concerning their experiences (see Table 17). These six themes explained how the workshop helped the participants adapt to survivorship. As noted, each participant had completed active primary treatment for cancer between 0 and 28 months ago. Selected quotes from the individual participants, using pseudonyms which they chose for themselves, were used to illustrate the themes.

Table 17

Themes Related to the Mid-Life Directions Workshop Experience

Themes with their Descriptions	
Theme 1	Examining what is A. Using journaling, music, a time line and other exercises B. Exploring self through a personality test C. Allowing time for self D. Learning new skills
Theme 2	Feeling connected A. Joining a group of cancer survivors B. Learning from others C. Sharing with others D. Knowing I'm not alone
Theme 3	Accepting what is, even the painful A. Overcoming obstacles B. Sorting through feelings C. Realizing how the cancer affected me D. Accepting that I'm a cancer survivor
Theme 4	Embracing one's life experiences with gratitude A. Seeing my experiences as part of midlife development B. Reinterpreting some life experiences C. Making spiritual connections D. Gaining perspective
Theme 5	Exploring new possibilities A. Being open to change B. Using new skills C. Wanting to live life fully D. Opening new doors
Theme 6	Moving forward with enthusiasm A. Setting goals B. Making changes C. Feeling free / feeling joyful D. Feeling hopeful, excited, energized

The Experience of Participating in a Mid-Life Directions Workshop

The following section describes the participants' experiences of the Mid-Life Directions Workshop. What it was like for them will be further described according to the six themes, noted above, which emerged as a common pattern. Having completed active primary treatment for cancer, the task before them was adaptation to survivorship. Because they had been recruited to be in midlife and so were between the ages of 40 and 65, this transition was set in the context of the midlife journey.

Theme 1: Examining what is. Participants described how they experienced the workshop and how they responded to the various exercises. The words *enjoyed* and *fun* come up often as well as the words *challenge* and *difficult* when describing their experiences. Specific tools were mentioned as especially helpful, such as journaling, music, the time line and personality test. Allowing time for self was also an important part of the experience. Learning new skills was indicated as helpful in dealing with their current life journey.

Using journaling, music, a time line and other exercises. Without a doubt, journaling was experienced as helpful. LexiSue says, "I especially enjoyed the journaling," as did many other participants. Barbara wrote, "I enjoyed the music and how it relaxes you." Berkeley mentions the engaging experience of "thoughtful concepts, metaphors, prose and group interaction for me to reflect on," and Chris adds, "I enjoyed the songs, poetry, reflections and some of the difficult writing exercises which forced me to think about me." Irene says, "The exercises were fun, reflective, and brought me back to my thinking self."

Exploring self through a personality test. The personality test was the Grey Wheelwright Survey, which was completed and self-scored with guidance during class time. Based on Jungian personality theory, the survey was used to help identify the participant's dominant personality type, as well as the less developed, shadow side of the personality. Since it provided a map to growth and understanding of the self and others, especially during midlife, many participants found it helpful. Kelly says, "I found the personality test to be very insightful. It really brought to the surface an area of interpersonal relationships that I have long struggled with and [it] should help me to grow in this area." Chris says, "Learning about my personality type and attempting to learn about midlife direction has propelled me forward." JeJibee enjoyed the "fun of seeing the objective personality experiences be a reflection of how I see myself." She adds, "seeing myself *as is* is OK and needn't be positive or negative."

Allowing time for self. Many participants had to make a concerted effort to give themselves permission to spend time on themselves. Midlife frequently involves advancing a career, raising children and caring for aging parents. Taking time for self seemed like such a luxury to them and one which they could ill afford. Chris writes, "The next hurdle for me was giving myself permission to forget my hectic pace of life and place this on a priority 'time for me.' As a result, life didn't fall apart." In this same vein Sasha says, "To me, this workshop has been such a luxury. To spend time not only thinking, but thinking about me." LexiSuse said the workshop "has also made me realize that it's OK to put yourself first, and that it's important to set goals." Blondie adds, "I also enjoyed taking two hours per week just to do something for me." One participant,

Murphy, sums it up this way, “This class has reinforced the concept that it is alright and important to think of myself first sometimes and to pursue the many things that I did not have time for.” This is a very important midlife insight.

Learning new skills. A number of participants commented on the skills that they learned. Rachel, for example, says, “This workshop has provided me with an understanding of where I am and has provided me with the tools to get where I want to be.” Berkeley writes, “This workshop is not necessarily something I was seeking, but it has great value. It was a terrific experience just to do my best to be honest and to participate as fully as possible.” Kelly says, “While I don’t feel I have all the answers after just 3 weeks [6 sessions], I feel I have some more resources to help me explore where I have been and where I am going. I am thankful for that.”

This doesn’t mean that all the participants found the exercises to be easy. Because they were developed for the growth of people during midlife, they at times were experienced as a challenge. Sasha explains,

Many of these exercises were a challenge to me, and before I began them, I was kind of dreading them, thinking that I would have no ideas, nothing to say or write. However, the thoughts and words flowed even though I may not have exactly, perfectly dialogued or followed the instructions.

Once participants engaged in the given exercises, it seems they were able to benefit from them. For example, the *Chapters of My Life* exercise asks participants to divide their lives into chapters of their own choosing, and then write in detail about the one which appeals

to them at the time. This assists them to get in touch with their own life stories, which may have been forgotten in the rush of everyday life.

Theme 2: Feeling connected. Being with other cancer survivors was a powerful experience for most participants. Some expressed initial uncertainty and fear at the prospect of being with others who had survived cancer. Many participants expressed that they had learned a lot from others, would treasure what others had said, and were able to share things with the group that family and friends might not understand. Some expressed how encouraging it was to know they were not alone in the experience of diagnosis, treatment and now survivorship.

Joining a group of cancer survivors. Being in the group evoked various responses in the beginning. Irene states, “Being in a group was initially a little scary,” but then goes on to say how she enjoyed the group interaction. Chris recalls,

The first obstacle was being in a group of other breast cancer survivors. I was initially afraid that we would be spending the time discussing our “cancer” story. It was tough working through the range of emotions knowing that others were at various stages.

However, Chris ends her reflection by saying, “And lastly it was enjoyable sharing our week with a group.”

Other participants underscore the benefits of being in a group. Barbara says, “I enjoyed coming to the classes [and] meeting new people that have been affected by cancer.” Kelly says, “Spending time sharing with the group was very valuable to me.”

Annie says, “I’m sad tonight that this workshop is coming to an end . . .” One reason is that she “developed good, healthy connections with the other participants.”

Learning from others. Often there is nothing to compare with hearing how peers have dealt with similar experiences. This was no different for the workshop participants who learned from one another during the workshop. Jackie says, “I also enjoyed sharing time and listening to people who have gone through similar experiences. Some of their stories were inspiring and insightful.”

Each participant’s experience was individual. Some chose to write about what affected them personally. Herseygirl says, “They think I’m beautiful – imagine that!! I pray (in time) I will also think I’m beautiful.” Berkeley recalls, “It was moving to hear others voice their experiences and share painful moments. I will treasure those expressions.” It was medications that interested Barbara, who says, “It’s been nice to hear other people talk about their concerns about medication and how they are dealing with it.” Rachel sums it up well by saying, “I learned from those who chose to share and hope to incorporate these ‘learnings’ as I move forward.”

Sharing with others. The experience of sharing with others was expressed well by Rachel, who wrote, “None of us were looking for a ‘support group,’ but we were open to sharing our individual experiences and supporting one another.” Herseygirl reflects on how the workshop was good for her. She explains, “I could talk of personal things that, till this point, I could only think in my head.” She then goes on to say how she appreciates the others in the group for the manner in which they received what she shared. Prior to this she believed, “There are some things better left unsaid.” She found

sharing her experience with others to be a pleasant surprise. Chris calls the sharing “enjoyable” as did other participants.

Knowing I’m not alone. Various experiences of being connected and not alone were expressed by the participants. Alex writes, “I feel *connected* rather than disconnected to human history and the life process.” Irene talks about “meeting very nice people” and being less fearful as a result. Herseygirl says, “The others in my group are very dear to me now, and we share a special bond that even I didn’t think I could ever have.” The connections forged during the workshop were carried forward by some. At the end of the workshop Annie says, “Hopefully we can continue our journeys together in some form.”

Theme 3: Accepting what is, even the painful. The workshop helped participants not only to understand where they had been, but also to accept where they were at the present time. Once again this sometimes involved overcoming obstacles and sorting through painful feelings. What often came to awareness was a realization of how the cancer diagnosis and treatment, often endured stoically at the time, actually affected them now. The experience of cancer, although different for everyone, had certain commonalities. In addition, cancer was viewed within the developmental stage of midlife, and its relationship to other life events was evaluated by each participant. Writing and sometimes talking about their life experiences assisted participants to reflect on what being a cancer survivor meant for them individually.

Overcoming obstacles. One of the obstacles to be overcome by participants was just getting to the workshop sessions. Irene writes, “Initially I was reluctant about

coming, especially since I do not drive anymore at night. . . . Also I figured, why now? I'm OK. Other than neuropathy, I'm my old self." She adds, "What I learned is that I'm not my old self." Herseygirl says that the workshop "made me realize I need to deal with some aspects of my cancer that I had suppressed." Barbara says, "I don't want to talk too much about it [being affected by cancer] because I don't want to burden people." She also says, "Just the fact of making you look at yourself and who you are is most difficult." However, once engaged, participants benefitted greatly from the sessions, according to their own testimonies, as will be discussed shortly.

Sorting through feelings. All participants chose for themselves what to dialogue or write about. Never was there any coercion. The exercises were presented as invitations to explore their lives. However, because midlife is a time to discover where one finds oneself in life, and to know that the past does influence the present, there were exercises to assist participants to explore the past and reinterpret it from a midlife adult perspective. This exploration sometimes brought feelings that may have been forgotten to awareness.

Kelly expresses her experience this way, "This program has helped me to sort through some of the feelings I have been experiencing now that my treatment is behind me and I look to the future." Rachel writes, "This workshop has helped me to understand what I've been feeling. I've sensed the changes and reflections taking place, but not only didn't understand them, but didn't know how to work with them." Barbara focuses on how painful it was to look at her past saying, "The biggest part of these classes is that it made me go back into my past, which was a very painful life."

LexiSue says, “This workshop has helped me with finding new ways of expressing my feelings – be it anger or excitement, etc.” Berkeley states, “I suppose the class has been a kind of unexpected gift. Unexpected, a little discomfoting, but I welcome its unfolding.”

Realizing how the cancer affected me. Participants were at different places in their understanding of how cancer affected them. The discovery of a changed relationship to life after their cancer experience was expressed by some. Jackie says, “We always think, ‘Life goes on’ and I guess I always thought things should be the same. I’ve learned that as you grow to midlife, and especially after you go through a traumatic event, that life does change.” The same was true for Irene. After stating that she’s not her old self anymore, Irene explains,

Having gone through treatment, meeting so many people – in treatment – who were so much sicker than I – I guess I am fortunate and grateful – bad as it was – for the positive things it gave me. The workshop helped me realize the changes that have taken place in my life.

Saltairnut puts it this way, “I did not realize before participation in this workshop just how strongly my diagnosis has affected my life.” Alex also comments on how the cancer experience changed him. He says,

This class has helped me to formalize some of the disparate events that have occurred since I was diagnosed with cancer. I struggled to understand why the life

process was becoming clearer to me after cancer. I felt a calmness and sense of purpose unlike at any other time of my life.

Accepting that I'm a cancer survivor. Moving past treatment and into survivorship requires a change in outlook. Some participants talked about this experience. Blondie says,

This workshop has aided in putting my post-cancer/survivor status in a brighter, more positive light. Surviving is, of course, a wonderful thing on its own, but still sort of came with the 'baggage' of the disease at times. I feel like this workshop helped put the cancer experience or portion of my life in the right place in my life.

Murphy talks about her understanding of surviving cancer this way, "My cancer experience will always affect who I am. The fact that I am a survivor allows me to move forward to what I can become." Later in the reflection she affirms, "I survived, as I will for many, many more years."

Theme 4: Embracing one's life experiences. After coming to a deeper understanding of the cancer experience and how it fits into one's life, moving forward requires embracing what is. This does not mean liking what may have happened, but rather knowing that it has taught some lesson or brought some growth into one's life. Appreciating the gifts of even the worst experience assists the person to embrace all of life and move on with greater wisdom. By means of the workshop experience the participants were invited to "use conscious awareness and choice to create human and environmental integration" (Roy, 2009, p. 26).

Several phases of this process of integration emerged in the reflections. Some participants expressed an understanding of their experiences in the context of midlife development. Others explained how they were able to reinterpret their life experiences or make spiritual connections. Many expressed the experience of gaining perspective in a way that expanded their former view of life.

Seeing my experiences as part of midlife development. Various understandings of midlife development were expressed. Jackie says, “For the most part I am happy with my life, but this workshop has given me insight into looking within myself, learning and understanding that changes in my life or the way I view or feel about things may be viewed as midlife changes.” This understanding often helps pull the cancer experience out of a dominant position and into the normal pattern of life. Kelly says, “It’s been good to know that my feeling of ‘now what?’ is very common at this point in life regardless of whether or not the cancer had occurred.”

Alex speaks about how he had been feeling even before the cancer, describing it as typical of the midlife journey. He saw cancer as adding to his midlife experience and pushing him further along his life journey. He says, “The illness thrust me out of the midlife fog that after this seminar I know can be characteristic of midlife – loss of faith, disappointment with humanity, fatigue, loss of direction.”

Reinterpreting some life experiences. Some participants expressed a reinterpretation of what life has given them. For example, Philomena talks about a friend whom she thought she didn’t need, but who she now sees as a much needed support. She says, “My best friend came out of one of the worst times in my life and has been there for

me in every difficult time I've had since. She was someone I thought I didn't need in my life."

After saying that she did not realize how strongly cancer affected her life, Saltairnut acclaims, "I am blessed that most of the changes that have occurred have helped me to become a stronger more positive person." This is an insight that did not come during cancer diagnosis and treatment, but as a reinterpretation of these events afterwards.

Murphy talks about changing her opinion of cancer from being an end to being a beginning. She says, "The workshop has opened a door for me to realize that my cancer diagnosis is not an end to my dreams and desires, but a stepping stone to explore new opportunities and experiences that lie ahead of me." This is a clear example of reinterpretation.

Making spiritual connections. Some participants spoke of the workshop as including a spiritual experience. Others spoke of connecting what they learned with an experience of God as a higher power who is guiding them.

Sasha explains her experience this way:

I have enjoyed the time each Tuesday to sit, be quiet, listen, think and reflect.

This is the one thing that I like about attending religious services, strangely.

While I do not feel much like a spiritual person, setting myself in the midst of a spiritual setting really is a comfort to me. In this frame of mind I find I can

remove myself from the daily routine and dig deeper into myself. Peace and quiet!

Blondie says, “Although I couldn’t attend all of the Tuesday nights, due to work and illness, it still felt good to plan and dedicate time towards something that is spiritually enriching. . .”

On a more directly religious theme, Herseygirl writes,

I’m trying to picture myself as a ‘blob’ of clay on the Potter’s (God’s) wheel. God uses his hands to shape me into a lovely vase in which he will place a lovely bouquet of my favorite flowers – carnations. Then I will truly be beautiful!

Philomena, who was quoted earlier as having a best friend whom she at first felt she didn’t need, says that this friend “was in God’s plan to be there all along.” While Philomena speaks of recognizing God’s plan, Barbara reports that she is still seeking clarity, saying, “I have always been a very spiritual person, and God has seen me through many tough times in my life, so I do believe that I have this cancer for a reason, even though I haven’t figured out why.” Alex writes, “The workshop really resonates with my inner being,” expressing his connection with the spiritual aspects of life.

Gaining perspective. Many participants wrote about how the workshop helped them gain some perspective in their lives. Each experience was individual, yet illustrates this change in perspective.

Kelly talks her about changes in her life as a result of both a divorce and the cancer diagnosis. She says,

I know this process started for me shortly before my diagnosis as I was just divorced the year before but had not had a chance to deal with this question before I got sick. My divorce and subsequent illness have really put things in

perspective for me, and I expect I am feeling the need to *choreograph* the second half of my life earlier and more strongly than I might have otherwise.

Sasha speaks about seeing herself in a more positive light now, and knowing it will make a difference as she moves forward. She says:

I am coming to realize that I can be a kind, loving, giving person as well as a person who devotes time and energy to her own needs, whims and desires. I need to continue to remind myself of this as I know this will make a tremendous, positive difference in my life.

Another example is that of Blondie. She explains that after doing the time line activity, which showed so many aspects and events in her lifetime, she was able to see the cancer experience from a different perspective.

I realized that I had sometimes been defining or remembering things that I had experienced related to my cancer – pre or post – before treatment or during or after treatment. This has been an interesting discovery. So recognizing this about myself has enlightened me and shown me that I can talk about things or plan things with or without the benefit of being a cancer patient/survivor.

Finally Philomena's experience is also one of gaining a new perspective on her life. She says,

I've re-examined what I want for the second half of my life, not what others have wanted of me or expected of me. . . . I've been just moving along for so long walking in other people's shoes that I forgot what my own shoes felt like, and that maybe others should try to walk in mine for a while.

Theme 5: Exploring new possibilities. Having entered into the workshop activities and having taken time to reflect on the rich experiences of their lives, many participants were able to look to the future by exploring new possibilities. They wrote about their openness to change, how they were using the new skills they had learned, and wanting to live life fully. All of this opened new doors into the future.

Being open to change. Philomena says it directly, “I am more open to change myself in order to change other aspects of my life. If I understand myself better, I feel I can understand others better.” Irene reports, “I learned about my new improved self, met very nice people, am less fearful of going forward and making changes, and more able to stand up for myself.” Also looking to the future, Sasha says, “I am in the midst of change, and I am anticipating more significant changes in the near future. This workshop has underscored the fact that I need to continue to work on how I am going to deal with these changes . . .”

Using new skills. Participants learned a variety of skills which they could continue to use in the future. Some wrote about the ones they would use. Kelly speaks about the personality test which provided an insight which she says she will use to “help me to grow in this area [of interpersonal relationships].” The values prioritization exercise, in which the participant made 10 or more choices from a list of values and then wrote a sentence describing why they chose each one, was seen by JeJibee as an important new skill. She says,

This has been a validation to shift priorities in life choices, allowing my place in the decision process to move from secondary to primary, and not see this as a

negative or flaw, but as a worthwhile avenue to pursue – benefitting myself and those I interact with.

Other skills which the participants mentioned as important for them were reflection, use of the imagination and music. Jackie says, “All in all, I really think I am looking more inside myself, which is so different for me. It’s nice looking at things that way.” Herseygirl talks about moving forward by picturing herself as clay in the hands of the potter, as noted earlier. And Rachel utilizes a reference to music and the imagination in her reflection by starting off this way, “Close your eyes – listen to Pachabel Cannon in D. It’s like standing at ocean’s edge and watching the sun come up over the horizon to start a new day.”

Wanting to live life fully. Some participants, in looking to the future, expressed a desire to live life fully. Sasha says that she will “work on keeping myself healthy so that I can continue to live a full and meaningful life.” Barbara says the class “has shown me how blessed I am and [I] feel that I have come a long way, and my friends and some family members have never given up on me, and I will continue to be there for them.” She also talks about what she wants to give to her grandchildren, evidence of wanting to live life fully. Finally Blondie says, “. . . even though I do sometimes feel nervous about reoccurrence of this disease, I confidently acknowledge that life is for living and that there is only so much control one can impose on that future.” Life is for living, and these participants clearly want to live it fully.

Opening new doors. Some participants felt that doors were opened to them by the workshop. Philomena speaks of the doors to her heart and mind, saying, “It really made

me open my mind and my heart to what's in me." Annie speaks of opening the door to new friends saying, "hopefully we can continue our journeys together in some form." Saltairnut speaks generally by saying, "Thank you . . . for opening a door for me." Murhphy speaks of another door by writing, "The workshop has opened the door for me to realize that my cancer diagnosis is not an end to my dreams and desires, but a stepping stone to explore new opportunities and experiences that lie ahead of me."

Theme 6: Moving forward with enthusiasm. Many participants write about their future for which they have set goals. They speak about the changes which they are or will be making. Feeling free, joyful, hopeful, excited and energized are mentioned.

Setting goals. Goal setting was part of the workshop. Participants were told to be creative in setting goals and that they could change their goals whenever they liked. Chris sounds excited as she reports, "Somewhere along the line I now have goals!" Saltairnut says, "My new mantra is 'Don't sweat the small stuff.'" However she shows that she knows that every person is unique by adding, "With that said, I do understand that 'small stuff' is different for everyone." LexiSue says simply that the workshop has made her realize "that it's important to set goals."

Barbara has a specific goal which she shares: "I want to be around for my children and grandchildren. I want to show them that life can be wonderful even when you have been dealt a bad hand." Sasha tells us that there are changes in her life and states, "I am going to deal with these changes and work on keeping myself healthy."

Making changes. While all participants were empowered by the workshop to make the changes that they desired, a few shared which changes they would make or

already had made. Chris says, “This has since propelled me to take time for other interests in my life like reading books and taking a 2-hour computer class.” Saltairnut proclaims, “I will never question another’s pain.”

Barbara mentions some specific changes for her life. The first is about music. After explaining how she enjoyed the relaxing music played during the workshop she says, “I listen to more upbeat music most of the time because of my daughter. I will now be getting a few meditation tapes.” Regarding other changes she says, “I am making more time for myself and making my husband do more around the house.”

Feeling free and feeling joyful. There were some spontaneous expressions of feeling free and feeling joyful as a result of the work done during the workshop and how it affected the participants. JeJibee says, “It’s been freeing, but not as a revolutionary, just as a thinking, valued adult.” Annie also mentions that the experience of attending the workshop was freeing for her, saying, “Sharing some deep rooted thoughts and feelings, be it with myself through journaling or sharing with the other workshop participants, has been *freeing*.”

Blondie shares her joy by saying that she “really enjoyed marking these events for the future [on the time line] – they were joyous and celebratory.” Murphy writes, “I am more . . . joyful . . . than when I first started.”

Rachel mentions joy as she once again uses an allusion to Pachabel’s Cannon to close her reflection. She writes, “Now close your eyes – listen to Pachabel’s Cannon in D and feel the joy rise from your heart as a new day begins.”

Feeling hopeful, excited and energized. Sometimes expressions of hope, being excited or feeling energized were stated explicitly. Four participants mentioned feeling hopeful. Irene says, “This workshop helped me realize the changes that have taken place in my life – and given me much hope for the future.” Alex proclaims, “This clarity of being is very exciting and hopeful.” Annie simply concludes her reflection by writing, “This program was wonderful. I am hopeful! Thank you.” Murphy says, I am more hopeful . . . and energized than when I first started. Thank you.” Lastly, Annie’s enthusiasm practically jumps off the page when she exclaims, “There’s so much to uncover and discover at this stage of my life, and I’m so excited to continue this life journey.”

Summary of qualitative data analysis. All group members reported benefitting from the MLD Workshop in their written reflections. Six themes emerged: 1) examining what is, 2) feeling connected, 3) accepting what is, even the painful, 4) embracing one’s life experiences, 5) exploring new possibilities, and 6) moving forward with enthusiasm.

Chapter 5

Discussion

Chapter 5

Discussion

In this chapter I will discuss the findings of this study. The original hypotheses will be examined through the lens of the research framework in order to explain the convergence and divergence of results from the quantitative and qualitative findings. Possible rationale for statistically non-significant findings will be explored. Similarities and differences between these results and the work of others will be examined. Limitations of the study will be noted. Finally, implications for clinical practice, research, policy and theory will be discussed.

Original Hypotheses

The original hypotheses of this study were not supported by the quantitative measure of hope, using the Herth Hope Index (HHI), nor by the quantitative measure of quality of life, using the City of Hope Quality of Life Instrument, Patient/Cancer Survivor Version (QOL-CS). The hypotheses were:

1. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have a higher level of hope.
2. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have greater gains in level of hope from pre-intervention to post-intervention.
3. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have a higher level of quality of life.

4. After participating in a MLD Workshop, the treatment group, when compared to the control group, will have greater gains in level of quality of life from pre-intervention to post-intervention.

The statistical findings related to the hypotheses were disappointing likely due to small sample size. The treatment group ($n = 17$) received the Mid-Life Directions (MLD) Workshop, while the control group ($n = 9$) received a Nutrition Program for Survivors (NPS). Each program was given in six sessions. One finding was that the NPS group had significantly greater gains in level of hope pre-intervention to post-intervention ($p = .047$). The NPS group also had greater gains in quality of life pre-intervention to post-intervention that tended toward significance ($p = .06$). Again the comparison is $n = 17$ versus $n = 9$. The treatment group had a higher raw HHI mean score pre-intervention than the control group, but this was not statistically significant. The treatment group also had a higher QOL-CS mean score pre-intervention than the control group and this did reach significance ($p = .02$).

Qualitative data for the treatment group were collected via written reflections. Themes derived from these Reflections supported an expansion of hope and improved quality of life for the treatment group post-intervention. Therefore, there is qualitative evidence to support a positive effect on hope and quality of life in the treatment group. In contrast, the evidence is seen in the quantitative results with the control group. These results, however, are considered within the limits of the small sample size.

Before discussing the findings further, some discussion of the small sample size is warranted. Power analysis was used to determine an appropriate sample size for this

study, which was 98 participants, evenly divided between the treatment and control groups. A 25% attrition rate was predicted, resulting in an ideal sample of 122 participants. In an attempt to reach the desired sample size, two hospitals were included in the study, with two treatment groups and one control group at each site. As with any study, history is an important factor in conducting a study as well as affecting validity. History means the effect of trends or events external to the study occurring concurrently with the study (Polit & Beck, 2006). It may be noted that this research was conducted in an era of hospital mergers and buy-outs in this geographic area. In particular the first hospital used was a private hospital purchased by a for-profit financial corporation. This occurred just as participant accrual began, and the process was greatly impacted by the event. Secondly, the major source for referral of potential subjects in this area seemed to be over-subscribed, and there was an 11-month wait for beginning discussion of use of their sites. With the advice of the dissertation committee an effort was made to continue the design of the randomized trial as much as possible. Wherever deviations were made, these are identified and discussed. A prudent decision was made to stop efforts to accrue subjects after 22 months.

Similarities of the findings with the work of others will be explored. In the qualitative portion of this study, as with previous research, hope was found to be an important component of quality of life and a key factor in coping with illness (Ersek, 2006; Ferrell, Hassey-Dow & Grant, 1995; Felder, 2004). Similar to other studies in the cancer population, changes in levels of hope and quality of life were closely aligned (Herth, 2000; Duggleby et al., 2007). This study also supported hope as it has been

described in the nursing literature, that is, multidimensional and dynamic (Cutcliffe & Herth, 2002; Dufault & Martoccio, 1985) and changing over time (Reb, 2007; MacLeod & Carter, 1999).

Contrary to recent studies measuring hope in cancer patients using the HHI, the participants in this study had relatively high HHI mean scores pre-intervention. The MLD group's HHI mean score was 41.29 (SD = 4.3, range 34-47). The NPS group's HHI mean score was 38.44 (SD = 5.6, range 30-48). In a study of 194 community-based cancer patients, Rustoen, Cooper & Miaskowski (2010) report a HHI mean score of 36.1 (SD = 5.3, range 20-48). In a study of 160 outpatients with cancer and fatigue, Schjolberg, Dodd, Henriksen & Rustoen (2011) report a HHI mean score of 38.9 (SD = 5.4). And in a study of 182 cancer patients receiving chemotherapy, Shun, Hsiao & Lai (2011) report an HHI mean score of 35.18 (SD = 4.74, range 23-48). Lower pre-intervention HHI scores were reported as well in studies of interventions to support hope in patients experiencing cancer. Duggleby et al. (2007) reported a pre-intervention HHI mean score of 36.81 (SD = 4.17), and Herth (2000) reported a pre-intervention HHI mean score of 34.30. The MLD group's pre-intervention score was higher than any of those reported in the literature.

It is possible that a larger sample would have resulted in HHI baseline scores similar to those reported by others for cancer populations. Had the accrual of an adequate sample size as determined by power analysis ($n = 98$) been achieved, then the sample's HHI scores may have been similar to those reported in other studies. It is possible that because the groups were uneven in size to start, this affected the scores. Evidence

suggests that an adequate sample size, evenly distributed between groups, may correct this deficiency (Polit & Beck, 2006).

In comparing this study to other intervention studies to support hope using the HHI (Duggleby et al., 2007; Herth, 2000), both prior studies had resulted in a significant increase in hope post-intervention. For Duggleby et al., the HHI mean score post-intervention was 38.32. (SD = 4.26). For Herth it was 43.1 at 2 weeks post-intervention, 41.9 at 3 months, 40.8 at 6 months and 39.7 at 9 months. For this study the HHI mean scores post-intervention were MLD = 41.00 and NPS = 40.89. As noted, this is interpreted within the context of the small sample size of the current study ($n = 26$). However the possibility of a ceiling effect with the HHI scale needs to be considered as a possible reason for lack of increase in the HHI score of the MLD group post-intervention. With a starting score of 41.29 and a maximum score of 48 for the instrument, the HHI scale offered the MLD group limited ability for scores to increase. There is some evidence to support the use of mixed methods to overcome the limits imposed by an instrument's possible ceiling effect (Andrew, Salamonson, Everett, Halcomb & Davidson, 2011). Indeed, the qualitative portion of this study via the written reflections did reveal a robust hope post-intervention for the MLD group.

Another possible reason for the lack of increase in the treatment group's HHI score could be the changing nature of hope itself. As noted, there is evidence to support that hope changes over time (Reb, 2007; MacLeod & Carter, 1999; Duggleby et al., 2007; Herth, 2000). Consequently, the changing nature of hope calls into question the validity of positing a hypothesis predicting an increase in hope without taking into consideration

the current level of hope in the participants being studied and what a change in hope might mean. It also raises questions concerning the concept of hope. What is appropriate hope? What is false hope? What is hopelessness? How do these relate to the HHI scale values?

It is possible that the HHI scores post-intervention might indicate appropriate hope, which is not false hope and not hopelessness. While each HHI score represents the individual's hope at a given time, the mean scores clustered around 41 on the scale for both the treatment and control groups. This could be evidence of appropriate hope for this group of survivors, since both groups found the interventions helpful. This possibility seems to be supported by the other hope intervention studies (Duggleby et al., 2007; Herth, 2000) whose post-intervention HHI scores were 38.32 and 43.1 respectively.

It is possible that the HHI does not measure the concept of hope adequately. There is evidence that the HHI measures four dimensions of hope – experiential, spiritual/transcendent, relational and rational thought processes – as delineated in the Hope Process Framework (Farran, Herth & Popovich, 1995; Herth, 1991). Indeed the HHI has demonstrated reliability and validity in the cancer population (Herth, 1991; Herth, 1992). However there is evidence to support another viewpoint as well. This position represents a paradigm shift to multiple ways of knowing. The work of Elliot & Olver (2007), for example, advocates looking upon hope as both a verb and a noun, suggesting the limits of objective knowing. “Most of the research on hope is interwoven with an objectivist epistemology/ontology that relegates meaning to the objective reality” (Dorcy, 2010, p. 88). The logic of objective knowing, which underlies traditional

scientific practice, has been critiqued as demoting “whole realms of human experience” to being “non-existent and unimportant” (Cook-Greuter, 2006, p. 20). Therefore using multiple ways of knowing, such as multimethod research, may be indicated when measuring hope in midlife cancer survivors. The use of multiple ways of knowing in the development of nursing knowledge has been advocated since the seminal work of Carper (1978) describing patterns of knowing as empirics, ethics, personal knowing and aesthetics. Chin and Kramer (2008) include a fifth pattern, that of emancipatory knowing, based on their synthesis of nursing scholarship. The work of Roy (2009) in particular, using the universal cosmic imperative as a perspective, provides the philosophical basis for “new insights and multiple approaches to developing knowledge for nursing practice” (Roy, 2007, p. 9).

In addition, hope as a life force (Dufault & Martocchio, 1985) can be conceptualized as developmentally linked. The work of Erik & Joan Erikson supports hope as grounded in human development. The Stages of Psychosocial Development portray hope as the first strength to emerge in infancy, and to continuously expand along with the other strengths throughout the life span (Erikson, 1963, 1988). Putting together these elements of development and multiple ways of knowing, the logic of objective knowing can be viewed as limited (Shea, 2005), that is, necessary but not sufficient for an understanding of hope in midlife and beyond (Brewi & Brennan, 2004). Therefore, it is possible that using the HHI along with qualitative methods to measure hope may be needed for research with midlife and older adults. It is also possible that measuring other concepts along with hope may give a more nuanced picture of what hope means for the

hoping person. There is some evidence for measuring other constructs along with hope with intervention studies. Some measures utilized include: sense of meaning, sense of dignity, peace, purpose and spiritual well-being (Breitbart et al., 2009; Chochinov, Hack, Hassard, Kristjanson, McClement & Harlos, 2005). Nursing intervention studies to increase hope have measured quality of life along with hope (Herth, 2000; Duggleby et al., 2007; Rustoen, Wiklund, Hanestad & Moum, 1998).

Triangulation of Quantitative and Qualitative Findings

In order to understand the findings of this study better, linkages were made between qualitative and quantitative findings. This triangulation of data for the treatment group resulted in an illuminative and important evaluation of the Mid-Life Directions (MLD) Workshop in the study sample. It highlights clinical rather than statistical significance. Areas of convergence and divergence are examined with both the qualitative and quantitative results. Patton suggests, “Areas of divergence open windows to better understanding the multifaceted, complex nature of a phenomenon” (Patton, 2002, p. 559). In this study the quantitative measure of hope using the Herth Hope Index (HHI) did not reveal an increased level of hope in the treatment group, while the qualitative measure through the written reflections did. This area of divergence will be examined more closely to help explain how the MLD Workshop affected hope in a way that was clinically significant, yet not statistically significant.

As noted in the results section, there were several participants who made direct statements about hope. In order to explore these further, the participants’ statements were compared with their HHI scores. Surprisingly, all four participants who described

themselves as hopeful had either a decrease or no change in their HHI scores pre-intervention to post-intervention (see Table 18). The scores would indicate lower hope levels or no change in hope post-intervention. Yet these participants reported a lively hope, as evidenced by their written reflections. These four participants illustrate the clinical significance of the effect of MLD workshop on hope.

Table 18

Hope Expressions and Herth Hope Index (HHI) Scores for Four Treatment Group

Participants

Name	Comments	HHI scores		
		Pre-intervention	Post-intervention	Change
Alex	“This clarity of being is very exciting and hopeful.”	47	46	-1
Annie	“This program was wonderful. I am hopeful! Thank you.”	44	39	-5
Irene	“This workshop helped me realize the changes that have taken place in my life – and given me much hope for the future.”	39	39	0
Murphy	“I am more hopeful . . . and energized than when I first started. Thank you.”	47	44	-3

The specific items on the HHI were examined for changes for these four participants. All of the changes in scores were from a rating of 4 to 3 or vice versa. Both ratings (3 and 4) are on the higher end of the scale, indicating higher hope. None of the changes involved the lower ratings of 1 or 2, which would indicate lower hope. For example, two participants rated item #8 “I have deep inner strength” as 3 (agree) post-intervention, down from 4 (strongly agree) pre-intervention. Two participants rated #4 “I can see possibilities in the midst of difficulties” from a 4 to a 3 post-intervention. Two participants changed their rating on #11 “I believe that each day has potential,” one from 4 to 3, the other from 3 to 4. What does this indicate?

It is possible that the new knowledge and skills that were learned through the personality test, the time line, and other activities, provided the participant with a new perspective on life. This midlife perspective, while exciting and filled with potential for growth, also may be the source of uncertainty regarding what one is going to do with this new knowledge and how it relates to what one already knows. “Healthy people keep growing and this transformation includes the pain of leaving behind and the awkwardness of moving toward the unknown” (Hermes, 2010, p. 119). This can be seen in comments such as that of participant Kelly who says, “While I don’t feel I have all the answers . . . I feel I have some more resources to help me explore where I have been and where I am going.” In the same vein Alex says, “The illness thrust me out of the midlife fog that after this seminar I know can be characteristic of midlife – loss of faith, disappointment with humanity, fatigue, loss of direction.”

Shea (2005) describes the process of imaging as the “linking of the self with all manner of events and experiences” (p. 9). He calls it a “continuous, developing, bodily process, an ongoing organizing and reorganizing of perceiving and knowing” (Shea, p. 9). Connecting this process of imaging with Erikson’s work, he says this ongoing reconfiguration of one’s perspective on life “is prompted by physical maturation, the complexity of events, and the experiences of conflict and desire” (Shea, p. 9). The experience of diagnosis and treatment for cancer can prompt this change of perspective on life as previously described (Institute of Medicine, 2005). Because hope involves a personally meaningful and realistically possible future good, the use of imaging is central to the process of maintain hope. This provides one explanation of why HHI scores could remain relatively unchanged following an intervention that resulted in changes in hope that may be clinically significant as seen in participants’ written reflections. Perhaps what was adequate hope in a former stage of psychosocial development becomes challenged hope in a newly entered stage. Midlife when combined with the cancer experience can initiate one “into a new journey, the journey of the Spirit, the journey of the Self, of the second half of life, the journey of the personality, the search for God, the appropriation of wisdom” (Brewi & Brennan, 1999, p. 227). Who can embark on such a journey and not feel that hope needs to grow?

As discussed, given the small sample size for the treatment group in this study (n = 17) the HHI results are not generalizable. However, the qualitative results are more dependable since saturation was reached with the written reflections. They reveal the clinical rather than the statistical significance of the intervention, the MLD Workshop.

That is, individuals benefitted in ways they could express, but which could not show statistical significance for a small group on a paper and pencil test from which statistical scores compared were based on the average of group scores (Hayat, 2010).

The written reflection results will be discussed next through the lens of the study framework in order to provide a possible explanation for this area of divergence about hope being relatively unchanged pre-intervention to post-intervention as measured by the HHI, yet expanding as evidenced in the participants' written reflections. In this way some clarity will be achieved regarding the complex nature of hope for participants in this study. Erikson's stages of psychosocial development will be utilized first.

Erikson's Stages of Psychosocial Development

Erikson's stages of psychosocial development (Erikson, 1963) provide a framework for changes in hope throughout the lifespan. The focus in this study was on the adulthood (midlife) developmental stage. For Erikson, hope is the first strength to emerge as a result of the tension of trust versus mistrust in infancy. Hope then expands throughout the lifespan to eventually extend between presumption and despair in the eighth developmental stage, that of old age (Erikson, 1997).

In midlife, the seventh developmental stage, hope expands within the specific developmental tension of generativity versus stagnation, which produces the adaptive strength of care. For the person in midlife, the task is to care for one's productivity and progeny in a way that is both self-giving and selfless, while avoiding the stagnation of self-absorption. For the cancer survivor, this task also can relate to quality of life. This

study partially supports concurrent increases in hope and quality of life, as do other studies of adults with cancer (Duggleby, 2007; Herth, 2000).

The definition guiding this study states “Hope is a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant” (Dufault & Martocchio, 1985, p. 380). As the person moves from early adulthood to midlife, the realistically possible and personally significant future good, defined by the person, expands from the context of intimacy versus isolation to that of generativity versus stagnation (Erikson, 1963, 1997). Part of the struggle involves learning to be *generative* without *overextension*. This can be seen in the participants’ written reflections, particularly in the *Allowing Time for Self* section of theme 1. This is illustrated by participant Murphy, who writes, “This class has reinforced the concept that it is alright and important to think of myself first sometimes and to pursue the many things that I did not have time for.” Self-knowledge is foundational to generativity. Philomena says it succinctly, “If I understand myself better, I feel I can understand others better.”

Another part of the tension of generativity versus stagnation involves recognizing *stagnation*. Jackie says, “We always think, ‘Life goes on’ and I guess I always thought things should be the same. I’ve learned that as you grow to midlife, and especially after you go through a traumatic event, that life does change.” So *stagnation* is interrupted by cancer, and an opportunity for growth presents itself.

As a result of this midlife tension, *care* develops and becomes strong. This comes across clearly in the words of Barbara who says, “I want to be around for my children and

grandchildren. I want to show them that life can be wonderful even when you have been dealt a bad hand.” This participant’s words clearly illustrate that “the essentials of . . . generativity are a feeling of contributing something of value and finding a way of integrating past strengths and weaknesses” (Welchman, 2000, p.145). Erikson’s notion of midlife involving the tension of *generativity versus stagnation* and producing *care* came across strongly in the study participants’ written reflections. How this leads to an expansion of hope will be examined next through the Hope Process Framework, which was also a part of the framework for this study.

The Hope Process Framework

Hope can be seen expanding along with the other strengths already developed, and particularly with *care* in the context of midlife. The Hope Process Framework of Farran, Herth & Popovich (1995) identifies four major attributes of hope which are used to describe hope within the MLD Workshop. The attributes include experiential, spiritual/transcendent, relational and rational thought processes. Based on this framework for hope, the HHI measures the following hope dimensions: 1) temporality and future, 2) positive readiness and expectancy, and 3) interconnectedness. Additionally, the study framework predicted outcomes in the areas of experiential and rational thought processes as a new relationship to time and future; in the spiritual / transcendent process as positive readiness and expectancy; and in the relational process as interconnectedness. These processes and dimensions of hope and their outcomes will be discussed for their manifestation in the participants’ written reflections.

Experiential and rational thought processes: New relationship to time and future. The cognitive-temporal dimension has been described as “the perception that a positive, desired outcome is realistically probable in the near or distant future” (Farran, Herth & Popovich, 1995, p. 62).

These processes and this outcome were seen clearly in participants’ reflections. For example, Sasha writes,

I am in the midst of change and I am anticipating more significant changes in the near future. This workshop has underscored the fact that I need to continue to work on how I am going to deal with these changes and work on keeping myself healthy so that I can continue to live a full and meaningful life.

For Sasha, her new relationship to time and future involves the experiential and rational thought processes of anticipating changes and being able to deal with them. This allows her to perceive that the desired outcome of a full and meaningful life is realistically possible in the near future.

Spiritual/transcendent process: Positive readiness and expectancy. The affective-behavioral dimension has been described as “a feeling of confidence with initiation of plans to affect the desired outcome” (Farran, Herth & Popovich, 1995, p. 62).

This process and outcome were identifiable in many participants’ written reflections. A good example is Irene, who writes about the workshop, “I learned about my new, improved self, met very nice people, am less fearful of going forward and making changes, and more able to stand up for myself.” In these words, Irene expresses her positive readiness and expectancy about moving forward and initiating plans,

expressed as making changes, and affecting the desired outcome by being assertive in standing up for herself.

Relational process: Interconnectedness. The affiliative-contextual dimension has been described as “the recognition of interdependence and interconnectedness between self and others and between self and spirit” (Farran, Herth & Popovich, 1995, p. 62).

This process and outcome were identified as well in participants’ written reflections. Most participants expressed the importance of being connected with one or more of the following: other cancer survivors, their families, their God and/or the universe. Alex, for example, says, “I feel connected rather than disconnected to human history and the life process.” These words express his recognition of interconnectedness between himself and others through human history, as well as between self and spirit when mentioning the life process. Herseygirl writes, “The others in my group are very dear to me now, and we share a special bond . . .” Her words describe her feeling of connection with the other participants in the workshop who are also cancer survivors. Saltairnut expresses her interdependence by saying, “Perhaps the strength and humor I show can be helpful to those who still struggle every day.” Jackie adds, “I also enjoyed sharing time and listening to people who have gone through similar experiences. Some of their stories were inspiring and insightful.” Thus the recognition of interconnectedness among participants, others, and spirit was expressed strongly.

In summary, the Hope Process Framework helped to explain how an expansion of hope was evident in the study participants’ written reflections. The study framework’s

outcomes regarding hope were seen as predicted in three areas: 1) in experiential and rational thought processes as a new relationship to time and future; 2) in the spiritual / transcendent process as positive readiness and expectancy; and 3) in the relational process as interconnectedness.

Thus far the quantitative measure of hope via the written reflections provides evidence worthy of note to support an expansion of hope in the study participants. The multidimensional structure of hope, as delineated in the hope Process Framework is supported. Erikson's stages of Psychosocial Development give some understanding of the dynamic of hope. The Roy Adaptation Model will be examined next in order to shed further light on the dynamic process by which hope expanded in the midlife cancer survivors in this study.

The Roy Adaptation Model

The MLD Workshop provided the participants with an opportunity to adapt to the psychological growth and development appropriate in midlife. According to the Roy Adaptation Model (RAM), the role of the nurse involves the promotion of positive adaptation which is "the process and outcome whereby thinking and feeling people, as individuals or in groups, use conscious awareness and choice to create human and environmental integration" (Roy, 2009, p. 26). The MLD Workshop offered participants an invitation to human integration. For these midlife participants in the post-treatment phase of cancer, the workshop provided an opportunity to gain new knowledge and skills which could have served to help them to integrate the personal experience of illness into

life as a cancer survivor. According to the model, this would be done by promoting positive adaptation through conscious awareness and choice.

The dynamic process by which hope expands in midlife can be further explained by the elements of adaptation as described in the RAM. The MLD Workshop first of all addresses what it means to be a *thinking and feeling person* in midlife. According to Jungian personality theory, every individual, while having a preference for one or the other, has both of the judging capacities of thinking and feeling (Jung, 1933; Brennan & Brewi, 2003). However in midlife, the underdeveloped function becomes more developed, that is thinking for the person who prefers to use feeling, and feeling for the person who prefers to use thinking. Therefore the person begins to *integrate* both thinking and feeling into their decision-making during midlife.

The MLD Workshop provided the participants with a self-scored personality survey, the Gray-Wheelwrights Survey (Mattoon & Davis, 1995) which helped them to identify the more developed and less developed parts of their personalities. The formerly hidden or unconscious elements in the personality can become conscious over time (Brennan & Brewi, 2003). The personality survey can serve as a guide to growth in midlife, a growth requiring integration of the less developed or shadow side of the personality. Participants found this part of the MLD Workshop to be enlightening. Participant Kelly expressed it this way, “I feel I have some more resources to help me explore where I have been and where I am going.” This can be viewed as an instance in midlife when *conscious awareness and choice* take on new meaning. The *thinking and feeling person* is able to use *conscious awareness and choice* on a new level. The shadow

or unconscious part of the personality gradually becomes conscious and is able to be *integrated* into the already developed personality in a way that would have been impossible during an earlier stage of life. This is intimately connected to hope.

According to the RAM, there are four adaptive modes which “are related to how human systems respond to stimuli from the environment” (Roy, 2009, p.89). For the individual, these modes are the physiologic mode, the self-concept mode, the role function mode and the interdependence mode. The model is based on an interactive and holistic understanding of the self in the four adaptive modes. This study focused on hope within the context of the self-concept mode. The self-concept mode involves making choices when facing changes in one’s health and therefore applies to the person transitioning from cancer treatment to survivorship. Self-concept is defined as “the composite of beliefs and feelings that one holds about oneself at a given time” (Roy, p. 323). For the adult in the post-treatment phase of cancer, the self-concept mode is utilized to adapt to the challenges of life after cancer diagnosis and treatment. “Adaptation in this mode affects the other three modes because people act out of who they are” (Roy, p. 321).

According to the model the self-concept mode includes the personal self and the physical self, with the basic processes of the developing self, the perceiving self and the focusing self. The focusing self is the process used to explain hope in this framework. The focusing self is defined as

the process of being in touch with the physical and personal self in a way that surfaces hope, energy, continuity, meaning, purpose, and pride to be an individual

self within the whole community; awareness of self, consciousness and meaning are transformed in person and environment integration, which the person focuses on by way of thinking and feeling. (Roy, 2009, p. 322)

The person uses the focusing self “to maintain consistency and unity in the midst of many changes” (Roy, p. 331). This process can explain how the cancer survivor is aware of the changes imposed by the diagnosis and treatment of cancer and how the cancer survivor finds the hope to transform the situation into healthy survivorship.

In the self-concept mode, “the person uses thinking and feeling to move from awareness of self to higher consciousness and meaning” (Roy, 2009, p. 347). The MLD Workshop engaged the participants in the process of revisiting their past experiences through activities such as the *Time Line* and *Chapters of My Life* exercises. These journaling sessions provided participants with the opportunity to revisit and reinterpret life events as desired from the adult midlife perspective and to move to *higher consciousness and meaning*. Many participants gave voice to the outcomes of their engagement in this process. Participant Murphy expresses her learning this way, “The workshop has opened the door for me to realize that my cancer diagnosis is not an end to my dreams and desires, but a stepping stone to explore new opportunities and experiences that lie ahead of me.” This is consistent with the findings of other research which found that hope is focused not only on a cure of disease, but changed and redefined by the patient over time (Reb, 2007; MacLeod & Carter, 1999). Reb found that women with stage III or IV ovarian cancer worked through three stages, shock, aftershock and rebuilding. These women used hope, which changed over time, to find meaning, support

and control in order to transform their experience of facing the death sentence. “Hope has the ability to be fluid in its expectations, and in the event that the desired object or outcome does not occur, hope can still be present” (Farran, Herth & Popovich, 1995, p. 6).

Roy says that “consciousness of person and environment meanings is an element of person and environment integration” (Roy, 2009, p. 347). The linking of the self with events and experiences is a continuous, developmental process (Shea, 2005). The perceiving functions of sensing and intuiting are more fully developed and owned in midlife (Jung, 1933; Brennan & Brewi, 2003). As with the judging functions of thinking and feeling, the midlife adult is able to *integrate* whichever of the two perceiving functions is less developed, sensing or intuiting, into the personality. The MLD Workshop exposed participants to a variety of sensing and intuiting ways of perceiving their person and environment meanings. Workshop exercises involved: exploring peak/depth experiences, the creation of a mandala as a symbol of the self, creative listening and sharing, engaging in music meditation, writing a dialogue with a wisdom figure, and using the imagination to envision the future. The investigator worked to provide a supportive environment for participants while engaged in these exercises and while drawing meaning from their life experiences.

Roy states, “The situation of illness itself will be a stimulus for changes in both the physical and personal self, especially self-consistency and self-ideal” (Roy, p. 347). As viewed with the RAM, participants used the focusing self “to maintain consistency

and unity in the midst of many changes” (Roy, p. 331). Participant JeJibee, for example, says

[The workshop] has been a validation to shift priorities in life choices, allowing my place in the decision process to move from secondary to primary, and not see this as a negative or flaw, but as a worthwhile avenue to pursue – benefitting myself and those I interact with. It’s been freeing, but not as a revolutionary, just as a thinking valued adult. Thank you.

Thus through the experiences of the MLD Workshop, participants were provided with the opportunity to adapt to the challenges of life after their cancer diagnosis and treatment by creating a new normal for themselves through *person and environmental integration*.

According to the model, the participants used conscious awareness and choice to work with the changes in the physical and personal self and maintain self-consistency and self-ideal during survivorship in a developmentally appropriate way.

This is consistent with the finding that the post-treatment phase is a time when the individual is open to change (Allen, Savadatti & Levy, 2009). During focus groups with 47 women with breast cancer to explore their experiences and needs when transitioning to life after treatment, Allen et al. found that “the completion of treatment is in many ways a welcome milestone, but our results show that this is, indeed, a time of great hardship, uncertainty, and isolation for many women” (p.76). They conclude that “this period may represent an opportune time to capitalize on women’s motivation to pursue behavioral goals related to health” (p.77). These findings are also consistent with findings that midlife adults may have greater needs than younger or older adults. A recent study of

the needs of 307 adult cancer survivors found that midlife survivors (ages 40-64) reported significantly greater needs and distress in all areas measured – physical, social, emotional, spiritual and other (Schlairet, Heddon & Griffis, 2010). The midlife participants also expressed a desire for greater numbers of educational topics than either the young adult or older adult participants.

The MLD Workshop encouraged participants to search out possibilities and envision how the future might be for them as cancer survivors. There were exercises involving imagining one's preferred future and planning goals and objectives for the near future. This use of imaging can allow the participants to find coherence in life's experiences and realize meaning (Shea, 2005). "This process of imaging refuses to be held bound by the past or the present. It searches out possibilities, it envisions how the future might be, and it is intimately connected, as Erikson's work suggests, with the foundational virtue of hope" (Shea, p. 9).

Participants envisioned the future in various ways. Theme 6, *Moving forward with enthusiasm*, was expressive of this imaging of the future. As mentioned earlier in this chapter, five participants mentioned feeling hopeful. Others spoke of feeling joyful. Participant Blondie says that she "really enjoyed marking these events for the future [on the time line] – they were joyous and celebratory." Still others spoke of feeling free, excited and energized. Murphy writes, "I am more hopeful, joyful and energized than when I first started."

It seems that once the *integration* of person and environment meanings began occurring, the outcome was a surfacing of "hope, energy, continuity, meaning, purpose,

and pride to be an individual self within the whole community” as predicted by the RAM (Roy, 2009, p. 322). Particular outcomes which surfaced in the written reflections were feeling free, feeling joyful, and feeling hopeful, excited and energized. These results support the RAM concept of adaptation in the self-concept mode. In addition, it explains how this occurred in a sample of midlife cancer patients who had completed active primary treatment were transitioning to survivorship, and were provided with a workshop that focused on their specific midlife transitions.

Hope is related to quality of life, which by definition is located in the concept of integrated adaptation in the RAM. Quality of life will be discussed in light of the study findings.

Quality of Life

The City of Hope Quality of Life (QOL) Model for Cancer Survivors (Ferrell, Hassey-Dow & Grant, 1995) defines QOL as a multidimensional construct with four dynamic domains – physical well-being, psychological well-being, spiritual well-being and social well-being. Findings in this study using the Quality of Life Instrument, Cancer Patient/Cancer Survivor Version (QOL-CS) based on this model showed no significant change in QOL pre-intervention to post-intervention for either the treatment or the control group. The treatment group’s mean QOL-CS score was significantly higher than the control group’s pre-intervention ($p = .02$). This baseline difference in QOL scores does not allow for between-group inferences to be drawn on post-intervention scores. Possible reasons for this difference have been discussed earlier in this chapter related to small sample size and uneven group size. It is also possible that because there were more

participants in the control group (100%) who had been treated with chemotherapy, this affected the baseline QOL-CS scores. There is evidence to support the negative effects of chemotherapy on quality of life even into survivorship (Reid-Arndt, Hseih & Perry, 2010).

Consistent with the literature, changes in QOL-CS scores mirrored the HHI scores (Esbensen et al., 2006; Vellone et al., 2006). This would make sense because in the City of Hope QOL model, hope is named as part of the spiritual well-being domain of the model.

Predicted outcomes for the study were identified in the written reflections of the treatment group participants. These outcomes were in the four domains of QOL:

- *Physical well-being* – Adopting changes to minimize negative impact of disease
- *Psychological well-being* – Coping with emotions surrounding illness and treatment
- *Spiritual well-being* – Owning peak/depth experiences
- *Social well-being* – Balancing the polarities of generativity vs. stagnation to express caring

Because all of these outcomes are identifiable in the written reflections, as previously discussed earlier in this chapter, it is evident that the qualitative analysis showed an improved QOL in these four domains. This is consistent with other intervention studies (Dirksen & Epstein, 2008; Meneses et al., 2007). Dirksen & Epstein provided an insomnia intervention to 72 breast cancer survivors within 3 months of treatment in a

randomized trial, which resulted in improved QOL for the treatment group. Meneses et al. provided a Breast Cancer Education Intervention to 256 cancer survivors within one year of treatment in a clinical trial which resulted in improved QOL for the treatment group that was durable over time.

Limitations

The results of this study indicate clinical rather than statistical significance for the effectiveness of the MLD workshop in the treatment group. Despite non-significant statistical findings for the hypotheses, which predicted treatment group increases in hope and QOL, the written reflections revealed clear improvements in both variables. The control group showed an increase in hope scores via the HHI that reached significance. I will now explore the study limitations.

The first limitation has to do with the small sample size. As noted an appropriate sample size for this study determined by power analysis was 98 participants, evenly divided between the treatment and control groups. A 25% attrition rate was predicted, resulting in an ideal sample of 122 participants. In an attempt to reach the desired sample size, two hospitals were included in the study, with two treatment groups and one control group at each site. Despite these attempts, the sample size was too small for a randomized trial ($n = 26$) using the quantitative measures of hope and quality of life. The study extended over 22 months with factors external to the study impacting accrual of subjects, as noted earlier in this chapter.

The second limitation is related to uneven groups. Because of the difficulty in accrual early in the study, the treatment group was assigned approximately twice the

number of control group participants (treatment group, $n = 17$; control group, $n = 9$). The larger number of participants in the treatment group was selected based on the practical issue of limited accessing of participants in a reasonable length of time. This resulted in a treatment group where saturation was achieved with the qualitative measures of hope and quality of life via written reflections. However equal group size was not achieved.

The third limitation was with randomization. Randomization was attempted and achieved with some exceptions as noted. The four exceptions were made for the following reasons. One was due to the participant's work schedule, which conflicted with the assigned group's meeting days. Two were due to the participant's inability to meet for the informed consent procedure until after the assigned group sessions had begun. One was due to cross over to the treatment group, upon participant request, once the control group was attended. The exceptions were proportionally divided between the two groups, two in the treatment group, one in the control group, and one who attended both groups. This last participant was assigned to the control group, and after completion, attended the treatment group. Three weeks elapsed between the completion of one group and the start of the other.

The fourth limitation involved a lack of diversity in the sample. Despite attempts to accrue a demographically diverse sample, the final sample consisted mainly of female Caucasian breast cancer survivors. All three of the Black or African American participants did not participate in at least 4 of the 6 sessions, and therefore were excluded from the final analysis. Meeting the needs of a more diverse sample would be desirable in future studies. Suggestions for accruing Black or African American participants might be

partnering with a local church serving this population, securing the support of local community leaders, and training a person of color to deliver the intervention (Gehlert, Sohmer, Sacks, Mininger, McClintock & Olopade, 2008).

There was also a lack of participants with prostate cancer and lymphomas in the study. These survivors may not receive routine follow-up care at established Cancer Centers from which this study sample was drawn. It is possible that partnering with urologists, surgeons and other providers of care for these survivors might increase referrals and participation from this group of survivors.

Implications for Clinical Practice

It is the duty of the nurse to relieve patient suffering. “Our ability to relieve pain should be the litmus test of our value as health-care professionals. It is the core of our contract with society and the mandate of our privilege to be nurses” (Ferrell & Coyle, 2008, p.52). The challenges of the cancer patient transitioning to survivorship are well documented. The particular concerns of this population are the fear of recurrence, fear of death, worry, and physical symptoms such as fatigue, trouble sleeping, and trouble concentrating (Institute of Medicine, 2005). Concerns may also include an altered sense of health and life itself, difficulties making life decisions, and other existential and spiritual issues (Institute of Medicine, 2005). Consistent with the psychological literature, midlife is an opportune time to address the transition to a new phase of life (Brewi & Brennan, 2004). It is a particularly significant time for the person in the post-treatment phase of cancer transitioning to the role of cancer survivor (Allen, Savadatti & Levy, 2009).

Oncology nurses are in contact with patients through all stages of their disease and follow-up. This research study and that of others (Herth, 2000; Duggleby et al., 2007; Breitbart, 2002; Chocinov et al., 2005) underscore the imperative to see the cancer patient who is suffering not merely as a patient but also as a person. This broader, more nuanced view respects the person on all levels and as connected to their personal and environmental networks. Maintaining hope and quality of life are important to patients as persons, and therefore must be important to nurses as they care for these patients and influence their hope and quality of life.

Patton (2006) said, “Although everyone who does not die grows older, not everyone becomes wise. Growth is a choice rather than a necessity” (Patton, p. 306). Suffering presents an opportunity for growth in the cancer patient transitioning to survivorship that should not be wasted. The tragedy would be for nurses to waste the opportunity to relieve suffering in the cancer survivors with whom they interact. The intimacy of the nurse-patient relationship allows the nurse to provide individualized care that is sensitive to patients’ suffering and respectful of their complex personal and environmental concerns. While the patient care setting may have limited resources of time, personnel and finances, patient-centered cancer care is needed despite these constraints (Institute of Medicine, 2011). Evidence supports the need to educate nurses and other healthcare providers about the particular needs of cancer survivors. This is because survivorship care can occur in primary care and other settings as well as in Cancer Centers (Lewis, 2007).

While every person's experience of cancer is unique, research which documents the benefits of various interventions to support hope, meaning and quality of life is growing. Participants in this study, although involving a small sample, experienced enhanced hope from both the Nutrition Program for Survivors and the Mid-Life Directions Workshop offered in a group setting. Findings from this and other studies (Dirksen & Epstein, 2008; Meneses et al., 2007) suggest that recommending sources of support to patients may be beneficial to their growth and enhance their hope and quality of life. An opportune time to make such referrals might be during patient encounters for follow up after active primary treatment is completed and survivorship begins (Allen, Savadatti & Levy, 2009 Schlairet, Heddon & Griffis, 2010).

Implications for Research

Further study of the Nutrition Program for Survivors is recommended. This program could be implemented by a registered dietitian using the American Cancer Society Guidelines for Nutrition after Treatment (Kushi et al., 2006). The importance of promoting healthy behaviors during survivorship has been highlighted in the literature (Institute of Medicine, 2007; Schlairet, Heddon & Griffis, 2010). Nutrition after treatment has been identified as one component of survivorship care (Grant, Economou & Ferrell, 2010).

The Mid-Life Directions (MLD) Workshop merits further study with a larger sample. Some suggestions would be to use a large Cancer Center in order to accrue an adequate sample for a randomized repeated measures trial comparing the MLD group with a control group receiving usual care. Usual care would be defined as the protocol

used at the institution. Another suggestion might be to measure hope and quality of life with other measures, such as sense of purpose and sense of meaning. These may add to the evaluation of the outcomes of this new intervention.

A question being raised by this study is what a high level of hope means as measured on the Herth Hope Index (HHI) scale. Is a higher level of hope indicative of appropriate hope or of false hope, that is, a falsely inflated hope? Is it realistic or even desirable to find an increase in hope in a research study when the starting score for hope is already high? Perhaps hope should continue to be measured by both qualitative and quantitative means to understand the outcome more fully with a study such as the MLD Workshop, which attempts to bring hope to a developmental level appropriate in midlife.

Related to the question of what is appropriate hope and how it can be measured, is the issue of what happens to hope during midlife growth and development. How does hope expand within a new stage of development? Does abundant hope in a former stage of psychosocial development become challenged hope in a newly entered stage? Does it take time for the person to adapt to the new stage, and is this reflected in changing levels of hope? Are changes in hope scores, even decreased scores, healthy and a sign that the person is working to rebalance hope and redefine it to meet the challenges of the developmental task of the new stage?

In order to clarify the questions being raised by the present study, further research is indicated. However, in order to do so, a broader context of hope, as it expands within the tension of false hope and hopelessness can be utilized. In particular knowledge of the developmental stage of midlife might offer a more nuanced interpretation of hope in

multimethod studies of midlife in persons transitioning from active primary treatment to survivorship. Dorcy, for example, advocates for adopting a broader method of analysis and interpretation of hope in the human experience of suffering and despair, recommending that “further explorations into the meaning and performance of hope . . . be open to the complexities existing within the experience of human hopelessness” (Dorcy, 2010, p. 89). Since the time of Thomas Kuhn (1970), an awareness of what constitutes normal science, and the need for new approaches to research has grown. Erikson says that stressing the measurable aspects of science “can lead to a regimentation of ‘facts,’ often based on half-truths, which dominate thinking and planning” (Erikson, 1988, p.75). As noted, Cook-Greuter critiques the logic of objective knowing, which underlies traditional scientific practice, as demoting “whole realms of human experience” to being “non-existent and unimportant” (Cook-Greuter, 2006, p. 20). As a human life force, changing over the life span, hope requires recognition that quantitative, empirical methods are insufficient to measure hope. When researching hope, the limits of the logic of objective knowing, need to be recognized. Shea says that as we continue to develop as adults “we find ourselves relating to reality in ways that are more personally meaningful” and that “other ways of knowing that are more actively involving, more empathetic, and more interpersonally challenging become increasingly important to us” (Shea, 2005, p.18). As noted the nursing community has supported using multiple ways of knowing and integrating them in order to develop nursing knowledge (Carper, 1978; Chin & Kramer, 2008 Roy, 2009).

Implications for Policy

With the cancer survivorship population growing, the challenge for the healthcare team is to address the needs of this population in new ways. Opportunities abound to offer programs to meet the needs of these survivors. While the timing of such interventions is unknown, and may depend somewhat on individual needs, studies are beginning to support the time after active primary treatment for cancer as important (Allen, Savadatti & Levy, 2009; Flanagan, Winters, Habin & Cashavelly, 2012).

Survivorship care plans, now being developed and implemented, “need to include a broad spectrum of activities, from prevention and surveillance to treatment of specific long-term and late effects” (Grant, Economou & Ferrell, 2010, p. 711). The field of oncology healthcare providers has recognized the need to address survivors’ psychological well-being, spiritual well-being and social well-being (Institute of Medicine, 2007; Rustoen, Cooper & Miaskowski, 2010). All survivors, from the day of completing active primary treatment for cancer onward, deserve to have their comprehensive needs addressed (Lewis, 2006). Programs to address nutrition after treatment and adaptation to survivorship should be studied further and funded. An invitational symposium of stakeholders suggested, among other things, that clinical studies include a long-term survivorship component (Lewis, 2005). The National Cancer Institute (NCI) can include a survivorship component in grant-funded research to NCI-designated Cancer Centers. Policies providing for patient access to programs with proven efficacy need to be in place (Morgan, 2009).

Oncology nurses have always played a key role in coordinating patient care. Now is the time for policies that provide sufficient time for oncology nurses to address the needs of cancer survivors. A greater use of patient navigators has been suggested as helpful to not only coordinate care, but also to facilitate communication among providers (Lewis, 2007). Now is the time for oncology managers and administrators to engage other disciplines in the process of providing for healthy survivorship. Managers and administrators also need the support of boards and insurers to provide adequately for survivorship care. Health system values and structures can be modified to focus more on whole person care.

The interdisciplinary contributions of dietitians, physical therapists, social workers and spiritual counselors can be coordinated and supported with policies that address avenues of communication and opportunities to share patient assessments within the interdisciplinary team (Morgan, 2009). This can be a part of routine survivorship care; otherwise providers may be engaged with cancer survivors only in times of crisis when the need cannot be ignored. Yet nearly every patient experiences the cancer diagnosis and subsequent treatment as distressing to themselves and their families (Institute of Medicine, 2005). We will not neglect the opportunity to improve hope and quality of life in every survivor, even those who may not seem distressed. Policies need to help the various parts of the healthcare system work with seamless interface so that services can be provided without waste of valuable time in an effort to coordinate services through the various disciplines. “Turf battles must be set aside. Cancer

survivorship is not the domain of any one health care discipline or practice setting. It is everyone's concern" (Lewis, 2007, p. 95).

Implications for Theory

The ultimate goal of nursing is to facilitate "humanization, meaning, choice, quality of life, and healing" (Willis, Grace & Roy, 2008, p. E28). The MLD Workshop addresses this ultimate goal especially by facilitating humanization in midlife cancer survivors by means of addressing the needs of the cancer survivor as a human person. "Humanization in nursing practice provides the open space in which human beings have the potential to experience wholeness" (Willis, Grace & Roy, p. E34). The MLD Workshop may offer participants needed assistance during their transition from cancer patient to cancer survivor as midlife persons.

Implications for the Roy Adaptation Model. This study may contribute to a deeper understanding of the scientific assumptions of the Roy Adaptation Model (RAM) when they are applied to midlife cancer patients transitioning to survivorship. The following scientific assumptions (*italicized*) of the RAM (Roy, 2009) can be applied, based on data described earlier in the qualitative discussion, to the midlife cancer survivor in the following ways.

1. *Systems of matter and energy progress to higher levels of complex self-organization.* The person in midlife is challenged to mature from an early adult focus on ego development to the midlife focus on integration of the developed ego into a more complex whole. Integration of the cancer

experience into life as a survivor takes place as part of this midlife maturation process.

2. *Consciousness and meaning are constitutive of person and environment integration.* As consciousness expands it will include a broader understanding of the meaning of life's achievements and disappointments. The midlife cancer survivor integrates the experience of illness into a life of meaningful wholeness during survivorship.
3. *Awareness of self and environment is rooted in thinking and feeling.* The survivor integrates into the maturing personality the underdeveloped thinking function with the more developed feeling function, or vice versa. This higher level of self-awareness promotes a deeper understanding of the cancer experience as it unfolded and continues to unfold in the social context.
4. *Person and environment transformations are created in human consciousness.* From the standpoint of an expanded awareness of the self and one's life experiences, the midlife cancer survivor can transform the experience of illness into one of holistic wellness. The experience of illness and treatment are transformed so that they are no longer separate entities, but integrated into the self-concept.
5. *Integration of human and environment meanings results in adaptation.* When the meaning of the cancer experience emerges as beneficial to the

self and others, the midlife cancer survivor adapts to survivorship. (Butt, 2010, pp. 2600-2601)

Implications for Erikson's stages of psychosocial development. This study may also contribute to an enhanced understanding of Erikson's Stages of Psychosocial Development by viewing this work as a developmental theory of hope. As noted, the Stages of Psychosocial Development portray hope as the first strength to emerge in infancy, and to continuously expand along with the other strengths throughout the life span (Erikson, 1963, 1988). Joan Erikson in particular describes the process of hope expanding throughout all eight stages of development. She says, "Hope remains constant throughout life [so] that more sturdy resolutions of the basic confrontation may be realized" (Erikson, 1988, p. 75). She is referring to the first emergence of hope in infancy as a resolution of the confrontation between basic trust and basic mistrust.

Erikson speaks about the syntonic and dystonic poles of each stage as always incomplete and in need of re-balancing and expansion throughout the life cycle. These syntonic and dystonic poles are the particular tensions which comprise the tension of each stage, that is, basic trust vs. basic mistrust; autonomy vs. shame and doubt; initiative vs. guilt; industry vs. inadequacy; identity vs. role confusion; intimacy vs. isolation; generativity vs. stagnation; and integrity vs. despair (Erikson, 1963).

A resolution of the balance between the syntonic and dystonic poles is a consistent demand for everyone throughout the life cycle. No permanent achievement of a firm balance is possible while the unpredictable vicissitudes of

life, with all its changes, continues. Every new tension in the social matrix can modify the tension one way or the other. (Erikson, 1988, p. 77)

Erikson gives examples of how hope expands within each stage as that stage's strength emerges. In the seventh stage, that of adulthood (midlife), she speaks of hope and care within the context of generativity vs. stagnation.

The incorporation of the images of those benevolent persons who hover over the earliest, neediest period of one's life is mandatory for all productivity and creativity. The development of this strength, this quality of "caring for," is the generational task for species survival. Where the rudiments of caring have not been part of the learning experience of the infant, later relationships may be difficult or unfeeling. (Erikson, 1988, p. 87)

The need to constantly renew one's hope is evident in the person with cancer. The vicissitudes of life for the patient transitioning to the post-treatment phase have been documented by the Institute of Medicine and continue to be researched (Institute of Medicine, 2005; Schlairet, Heddon & Griffis, 2010; Allen, Savadatti & Levy, 2009). As noted the particular concerns of this population are the fear of recurrence, fear of death, worry, an altered sense of health and life itself, difficulties making life decisions, and other existential and spiritual issues (Institute of Medicine, 2005). Adults in midlife may have greater survivorship needs and more distress than older adults (Schlairet, Heddon & Griffis, 2010). These particular challenges, when they occur in midlife, can become part of the developmental tension of generativity vs. stagnation, calling forth care and an

expanded hope. Viewing hope within the context of Erikson's Stages of Psychosocial Development may help to broaden understanding of the dynamism of hope as a life force.

Conclusion

The purpose of this study was to test the MLD Workshop, a psycho-educational group intervention, for its effect on hope and quality of life in midlife cancer survivors. A control group received a Nutrition Program for Survivors. Both treatment and control groups received six sessions in group settings. The study included adults between 40 and 65 years of age in the post-treatment phase of cancer, diagnosed at stages I, II and III, transitioning from active primary treatment to survivorship.

The purpose of the MLD Workshop was to support hope and quality of life during the transition from cancer patient to cancer survivorship during midlife. The quantitative measures of hope and quality of life, measured pre- and post-intervention for both groups, revealed an increase in hope that reached significance ($p = .047$) and an increase in quality of life which did not reach statistical significance ($p = .06$) for the control group. The treatment group, while showing no significant changes pre- to post-intervention by means of the quantitative measures of hope and quality of life, did show positive effects on hope and quality of life by means of the qualitative measure, the written reflections. This highlights the clinical rather than statistical significance of the intervention being studied, the MLD workshop.

A thematic analysis of the written reflections of treatment group participants produced six themes: 1) examining what is, 2) feeling connected, 3) accepting what is, even the painful, 4) embracing one's life experiences, 5) exploring new possibilities, and

6) moving forward with enthusiasm. The study framework's outcomes regarding hope were seen as predicted in the MLD group in three areas: 1) in experiential & rational thought processes as a new relationship to time and future; 2) in the spiritual / transcendent process as positive readiness & expectancy; and 3) in the relational process as interconnectedness. Predicted outcomes for quality of life were seen in the four domains as follows: 1) *physical well-being* – adapting changes to minimize the negative impact of disease, 2) *psychological well-being* – coping with emotions surrounding illness and treatment, 3) *spiritual well-being* – owning peak/depth experiences, and 4) *social well-being* – balancing the polarities of generativity vs. stagnation to express caring.

The MLD Workshop, while resulting in relatively unchanged quantitative measures of hope and quality of life post-intervention, demonstrated positive effects on hope and quality of life as seen in the qualitative findings for this group of midlife cancer patients transitioning from active primary treatment to survivorship. The Nutrition Program for Survivors demonstrated positive effects on hope and quality of life in this population as measured quantitatively. The MLD workshop merits further study with a larger sample. The nutrition program also merits further study.

This study affirms previous research regarding the multidimensional life process of hope. It may broaden understanding of the dynamic life process of hope through the Roy Adaptation Model applied to Erikson's adult (midlife) stage of psychosocial development involving the tension of generativity versus stagnation. Finally, it provides

an increased understanding of interventions which nurses may be able to use to support hope in cancer survivors.

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Appendix A

Demographic Form

Name _____ Birth date _____
(month/day/year)

Check sex: Male _____ Female _____

Highest Level of Education

Some Elementary School _____

Completed Eighth Grade _____

Some High School _____

Completed High School / GED _____

Associate Degree _____

Bachelor's _____

Master's _____

Doctorate _____

Ethnicity (Select one category.)

Hispanic or Latino or Spanish origin _____

Not Hispanic or Latino _____

Racial Categories (Select all that apply.)

American Indian or Alaskan Native _____

Asian _____

Black or African American _____

Native Hawaiian or Other Pacific Islander _____

White _____

Income Range (Please check the range that most accurately reflects your income.)

Less than \$30,000 _____

\$30,000 to \$39,999 _____

\$40,000 to \$49,999 _____

\$50,000 to \$59,999 _____

\$60,000 to \$69,999 _____

\$70,000 to \$79,999 _____

\$80,000 to \$89,999 _____

\$90,000 or greater _____

Prefer not to answer _____

Religious affiliation

Agnostic _____

Atheist _____

Buddhist _____

Catholic _____

Christian _____ (please specify) _____

Hindu _____

Jewish _____

Muslim _____

Other religion _____

Type of cancer _____

Date of diagnosis _____

Stage of disease at time of diagnosis

I _____ II _____ III _____ IV _____

Type of cancer treatment received: Please check all that apply.

Surgery _____

Chemotherapy _____

Radiation therapy _____

Other _____

Date treatment was completed _____
(m _____ onth/day/year)

Appendix B

Herth Hope Index

Study

No. _____

HERTH HOPE INDEX

Listed below are a number of statements. Read each statement and place an [X] in the box that describes how much you agree with that statement right now.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I have a positive outlook toward life.				
2. I have short and/or long range goals.				
3. I feel all alone.				
4. I can see possibilities in the midst of difficulties.				
5. I have a faith that gives me comfort.				
6. I feel scared about my future.				
7. I can recall happy/joyful times.				
8. I have deep inner strength.				
9. I am able to give and receive caring/love.				
10. I have a sense of direction.				
11. I believe that each day has potential.				
12. I feel my life has value and worth.				

Appendix C

Quality of Life Instrument, Patient/Cancer Survivor Version

Study

No. _____

Quality of Life Scale/CANCER PATIENT/CANCER SURVIVOR

Directions: We are interested in knowing how your experience of having cancer affects your Quality of Life. Please answer all of the following questions based on your life **at this time**.

Please circle the number from 0 - 10 that best describe your experiences:

Physical Well Being

To what extent are the following a problem for you:

1. **Fatigue**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
2. **Appetite changes**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
3. **Aches or pain**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
4. **Sleep changes**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
5. **Constipation**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
6. **Nausea**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
7. **Menstrual changes or fertility**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
8. **Rate your overall physical health**
extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

Psychological Well Being Items

9. How difficult is it for you to **cope** today as a result of your disease and treatment?

not at all 0 1 2 3 4 5 6 7 8 9 10 **very difficult**
difficult

10. How good is your **quality of life**?

extremely 0 1 2 3 4 5 6 7 8 9 10 **excellent**
poor

11. How much **happiness** do you feel?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

12. Do you feel like you are **in control** of things in your life?

not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

13. How **satisfying** is your life?

not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

14. How is your present ability to **concentrate or to remember** things?

extremely 0 1 2 3 4 5 6 7 8 9 10 **excellent**
poor

15. How **useful** do you feel?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

16. Has your illness or treatment caused changes in your **appearance**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

17. Has your illness or treatment caused changes in your **self concept** (the way you see yourself)?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

How distressing were the following aspects of your illness and treatment?

18. Initial diagnosis

not at all 0 1 2 3 4 5 6 7 8 9 10 **very distressing**
distressing

19. Cancer treatments (i.e. chemotherapy, radiation, or surgery)

not at all 0 1 2 3 4 5 6 7 8 9 10 **very distressing**
distressing

20. Time since my treatment was completed

not at all 0 1 2 3 4 5 6 7 8 9 10 **very distressing**
distressing

21. How much anxiety do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

22. How much depression do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

To what extent are you fearful of:

23. Future diagnostic tests

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

24. A second cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

25. Recurrence of your cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

26. Spreading (metastasis) of your cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

Social Concerns

27. How distressing has illness been for your **family**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

28. Is the amount of **support** you receive from others sufficient to meet your needs?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

29. Is your continuing health care interfering with your **personal relationships**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

30. Is your **sexuality** impacted by your illness?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

31. To what degree has your illness and treatment interfered with your **employment**?

no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

32. To what degree has your illness and treatment interfered with your **activities at home**?

no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

33. How much **isolation** do you feel is caused by your illness or treatment?

none 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

34. How much **financial burden** have you incurred as a result of your illness and treatment?

none 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

Spiritual Well Being

35. How important to you is your participation in **religious activities** such as praying, going to church?

not at all 0 1 2 3 4 5 6 7 8 9 10 **very important**
important

36. How important to you are other **spiritual activities** such as meditation?

not at all 0 1 2 3 4 5 6 7 8 9 10 **very important**
important

37. How much has your **spiritual life** changed as a result of cancer diagnosis?

less 0 1 2 3 4 5 6 7 8 9 10 **more important**
important

38. How much **uncertainty** do you feel about your future?

not at all 0 1 2 3 4 5 6 7 8 9 10 **very uncertain**
uncertain

39. To what extent has your illness made **positive changes** in your life?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

40. Do you sense a **purpose/mission** for your life or a reason for being alive?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

41. How **hopeful** do you feel?

not at all 0 1 2 3 4 5 6 7 8 9 10 **very hopeful**
hopeful

Appendix D

Directions for the Written Reflection

The researcher will direct the participants as follows:

Now that you have completed your *Dialogue with Workshop* section in your workbook, I would like to ask you to write something that you would like to share as part of the research project. Think about creating a reflection about your personal experience of participating in the workshop. How was the workshop helpful and how was it not helpful? You can take as many pages as you like to write your response using prose, poetry, art, music or any other form of expression that will capture how the content affected you and what it means to you personally. You are asked to give yourself a pseudonym (a name that is not your name) and write it on the cover page with your actual name. The pseudonym and not your actual name will be used to identify anything you may express. Most of the report will be a summary of the experiences of the group members. No one will be able to identify any part of the report with you personally. Your personal identity will always be kept in strict confidence in accordance with the permission form which you signed when you began the program. You will have 20 minutes of quiet time to create your response. During this time you are free to remain in the room or go to a place of your choice. Please return to the room at _____.

The researcher will hand out the cover page and paper, leaving extra paper on a table for participants to take as desired. The researcher will not hold conversations with participants or otherwise disturb the silence during the allotted time period. At the end of

the 20-minute period, the researcher will collect the responses and give a 15 minute break before resuming the session. This will allow time for completion by all participants.

Cover for the Written Reflection

Pseudonym _____ Allocation # _____

Actual Name _____

Pseudonym _____ Allocation # _____

Written Reflection

What meaning has the workshop had for you personally? Use as many pages as you like to write your response in prose, poetry, art, music or any other form of expression that will capture how the content affected you and what it means to you personally.

Appendix E

Consent Forms

ST. ELIZABETH'S MEDICAL CENTER INFORMED CONSENT TO PARTICIPATE IN RESEARCH	St. Elizabeth's IRB Approval Expires: MAR 29 2011 IRB# QP 528 Release Date: 8/17/2010
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Subject's Name: _____ **Date:** _____

Home Address: _____

Home Telephone: _____ **Date of Birth:** _____

Research Study Title: Supporting Hope in Midlife Cancer Survivors: Intervention Workshop

Principal Investigator/Study Doctor: Clare Butt, RN, MSN, PhD(c)/ Leslie Martin, MD

Study Sponsor(s): None

About this Research Consent Form:

You are being asked to participate in a research study. A research study is the scientific method used to improve medical practice and patient care.

Do I have to participate in this study?

Your participation is voluntary. Taking part in this research study is totally your choice. You can choose whether or not to participate.

If you decide to participate, you can stop taking part in this research study at any time for any reason. If you are thinking about stopping or decide to stop, tell the principal investigator/study doctor. The principal investigator/study doctor will make sure that you stop the study safely and talk to you about follow-up care, if needed.

If you decide not to participate in this research study or stop being in this research study, it will not affect how you are treated at St. Elizabeth's Medical Center. Prior to deciding if you should participate in this research study, you should understand enough about the risks and benefits to make an informed decision. This process is called informed consent.

Please take your time to make your decision about taking part in this research study. You may discuss your decision with your family and friends. You can also discuss it with any other health care provider. Please read all of the information contained in this form

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carefully and ask any questions that you have about this research study. If words or sections are unclear to you, please ask for an explanation.

If you decide to take part in this research study, you will be asked to sign this form and you will be given a copy of the signed form to keep.

1. Invitation:

You are being invited to take part in a research study to find ways to improve the care of cancer survivors. This study will be done with persons in midlife, ages 40-64, who have completed initial treatment for cancer within the past 18 months. Your name was obtained through a review, by the physicians and staff of St. Elizabeth's Medical Center, of cancer patients treated at St. Elizabeth's. Your doctor has given us permission to contact you regarding this study.

2. Purpose: Why is this research study being done?

The purpose of this study is to evaluate what helps patients who have completed initial treatment for cancer to have hope and enjoy the best quality of life after treatment. The Mid-Life Directions Workshop will be compared to a Nutrition Program for Survivors for its effect on hope and quality of life. The Mid-Life Directions Workshop has been used for over 25 years by professional adult educators with persons in midlife. However it has never been evaluated for its effects on cancer survivors.

3. Procedures: What will happen if you take part in this research study?

After signing the consent form, you will be asked to answer some questions on a demographic form in order to find out if you can be in the research study. You are free to choose not to answer the question about income. The form will take about 5 minutes to complete. We will verify that:

- You are between 40 and 64 years of age
- You have a new diagnosis of a stage I, II or III solid tumor
- You do not have stage IV disease
- You have completed initial therapy within the past 18 months
- You are able to read, write and speak English
- You do not have a medical condition that impairs your ability to participate in the study

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If your answers to the questions show that you are eligible to participate in the study, you will be eligible to participate in the research study. If you do not meet the eligibility criteria, you will not be able to participate in the study.

After the above screening questions confirm that you are eligible to participate in the research study, you will be asked to complete two standardized questionnaires:

- The Herth Hope Index, which will take about 4 minutes, and
- The Quality of Life – Cancer Survivor Instrument, which will take about 10 minutes.

You will then be assigned by means of a table of random numbers to either the Mid-Life Directions Workshop (MLD) group or the Nutrition Program for Survivors (NPS) group. You will be told when the first session begins, where it will be held, and other details about parking and the location of the meeting rooms.

The MLD group will be facilitated by a certified Mid-Life Directions consultant for six weekly 2-hour sessions. If you are assigned to this group, you will be asked once again to complete the two standardized questionnaires during the last session of the workshop:

- The Herth Hope Index, and
- The Quality of Life – Cancer Survivor Instrument

In addition, you will be asked to write a written reflection of your opinion of the workshop during the last session.

The NPS group will be facilitated by a nutritionist for six weekly 1-hour sessions. If you are assigned to this group, you will be asked once again to complete the two standardized questionnaires during the last session of the program:

- The Herth Hope Index, and
- The Quality of Life – Cancer Survivor Instrument

At the end of the study, you will receive a small gift for participation. Once you complete the study, you will not be contacted further for this study.

4. Duration: How long will you be participating in this research study?

You will be in this research study for less than 7 months.

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5. Risks, Discomforts, Side Effects and Inconveniences: What are the risks involved with being enrolled in this study?

There are risks to taking part in any research study.

The commitment to participate in the workshop or program and respond to questionnaires and write a written reflection requires your time. The time of the workshop or program sessions may be inconvenient for you or you may have some discomfort in talking about your own experiences. There is a risk of a breach of confidentiality by group members regarding sensitive and personal information disclosed during the workshop or program. You may experience emotional distress. There may be unknown risks.

Safeguards will be in place to keep risks at a minimum. There will be a psychiatric advanced practice nurse on call in case you or another participant requires immediate attention due to emotional upset. A verbal agreement will be obtained from group members that all information expressed in the group will be held in confidentiality by all group members. This agreement will be reviewed periodically with the group, however confidentiality cannot be guaranteed for information shared within the group.

During the research study, you will be provided with any new information that may affect your health or willingness to participate. You may be asked to sign a new consent form that shows that you have been informed of new information relating to this research study.

6. Benefits: Are there benefits to taking part in this study?

Taking part in this research study may or may not benefit you. However, it is possible that you may experience increased levels of hope and improved quality of life. We will use the information learned from this research study to provide more information about helping cancer patients find the best quality of life after treatment.

7. Alternatives: What other choices do you have if you do not take part in this study?

Taking part in this research study is voluntary. Instead of being in this research study, you have the following options:

- Attend a Mid-Life Directions Workshop that might be offered in the Boston area.
- Request a nutritional consultation with a dietitian at St. Elizabeth's Medical Center.
- Plan your own program of self-development.
- Decide not to participate in this research study.
- Participate in another research study.

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8. Confidentiality: Will your medical information be kept private?

Confidential information contained in your medical record may not be given to anyone except to members of the research group and others who must be involved professionally to provide essential medical care. The study sponsor, the St. Elizabeth's Research/Human Subjects Committee (IRB), state and federal agencies protecting the welfare of the study participants may view study records.

9. Compensation: Will you be paid to participate in this research study?

You will receive the National Cancer Institute booklet, *Facing Forward: Life After Cancer Treatment*, for completing the study. You will not be paid a sum of money for your participation in the study.

10. In Case of Injury: What happens if you become injured because of taking part in this research study? – N/A

No injury related to the research study is expected.

11. Costs: What are the costs for taking part in this study?

There is no charge for participation in this study. You will receive a free workbook if you are assigned to the Mid-Life Directions Workshop group and free handouts if you are assigned to the Nutrition Program for Survivors group.

12. New Findings: New Information. – N/A

13. Number of Subjects enrolled at St. Elizabeth's Medical Center.

There may be up to 122 subjects at St. Elizabeth's Medical Center who are enrolled in this study.

14. Termination without Consent: - N/A

You can stop participating in the research study at any time. Leaving the research study will not affect your medical care. You can still get your medical care from St. Elizabeth's Medical Center or your study doctor.

If you chose not to participate, or if you are not eligible to participate, or if you withdraw from this research study, this will not affect your present or future care and will not cause any penalty or loss of benefits to which you are otherwise entitled.

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If you have any questions about the study or if you choose to withdraw from the study, please contact the research investigator or study staff below:

- Clare M. Butt, RN, MSN, PhD(c)
Principal Investigator
[REDACTED]
- Leslie Martin, MD
Study Doctor
[REDACTED]

15. Contacts:

If at any time during this research study, you feel that you have not been adequately informed as to the risks, benefits, alternative procedures, or your rights as a research subject, have a complaint about the research or feel under duress to participate against your wishes, or to continue with the study, you can contact a member of the Research/Human Subjects Committee (a group of people who review the research study to protect your rights), who will be available to speak with you during normal working hours (8:30 a.m. to 5:00 p.m.) at:

Institutional Review Board (IRB) Office

Telephone: [REDACTED]

Address: [REDACTED]

You may also contact the Principal Investigator or Representative at any time during this Research study for questions and answers regarding the Research study at:

- Clare M. Butt, RN, PhD(c)
Principal Investigator
[REDACTED]
- Dr. Leslie Martin, MD
Study Doctor
[REDACTED]

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Statement of Principal Investigator or Person Obtaining Consent

The subject has been informed of the nature and purpose of the procedures including any risks involved in the research study's performance. The subject has been asked if any questions have arisen regarding these procedures and these questions have been answered to the best of the investigator's ability. A signed copy of this informed consent has been provided to the subject.

Also, any new unforeseen information relevant to the patient that may develop during the course of this research activity will be provided to the subject and the Research/Human Subjects Committee (IRB). I will inform any referring physician(s) of any and all protocol changes, adverse events and/or safety reports.

Signature of Principal Investigator
or Person Obtaining Consent

Date

Printed Name

Statement and Signature of Subject

I have been informed about the procedures, risks, and benefits of this Research Study and agree to participate. I know that I am free to withdraw my consent and to quit the Research Study at any time. My decision not to participate in this Research Study or my decision at any time to withdraw from this Research Study will not cause me any penalty or loss of benefits that I am otherwise entitled to.

I have read or have had this form read to me and understand the terms of this Consent Form and I have had an opportunity to ask questions about the Study and to discuss the Study with my doctor and other health care providers and my family and friends.

I hereby consent to have my medical records relating to this research activity be made available to state and federal agencies (including but not limited to the Department of

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Health and Human Services' Food and Drug Administration (FDA)), which regulates medical research activity, including this research study. I understand that while every effort will be made to keep my identity confidential, there may be occasions when my identity must be made known to state and federal agencies at their request.

I understand that this research study has been reviewed and approved by the Research/Human Subjects Committee, the Institutional Review Board of St. Elizabeth's Medical Center.

Signature of Subject
or Subject's Legal Representative

Date

Printed Name

The subject has received a copy of this consent form.



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4. The persons who are authorized to use and disclose your protected health information are:
- All Investigators listed on page one of the Research Consent Form and others at St. Elizabeth's Medical Center who are participating in the conduct of the research protocol
- The Institutional Review Board
- Others: _____
5. The persons who are authorized to receive this information are:
- The Sponsor of this study: _____
- Federal or other governmental agencies as required for their research oversight and public health reporting in connection with this research study:
- OHRP FDA NIH Other: _____
- Others: _____
6. **Right to Refuse to Sign this Authorization.** I do not have to sign this Authorization. If I decide not to sign the Authorization, I will not be allowed to participate in this study or receive any research related treatment that is provided through the study. However, my decision not to sign this Authorization will not affect any other treatment, payment, or eligibility for benefits.
7. **Right to Revoke.** I understand that I may revoke this Authorization at any time by sending a written notice to Leslie Martin, MD and Clare Butt, RN, Division of Hematology/Oncology, St. Elizabeth's Medical Center, 736 Cambridge Street, Brighton, MA 02135. If you withdraw this Authorization, St. Elizabeth's Medical Center and its research staff may only use and disclose individual health information already collected for the study. No additional health information about you will be collected by or disclosed to the researcher for the purpose of this study. Revoking this Authorization will not affect your healthcare or your relationship with St. Elizabeth's Medical Center.
8. **Potential for Re-disclosure.** My individual health information disclosed under this Authorization may be subject to re-disclosure outside the research study and no longer protected. For example, researchers in other studies could use my individual health information collected for this study without contacting me if they get approval from an Institutional Review Board (IRB) and agree to keep my information confidential.



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I further understand that my health information may be disclosed as required by law and to representatives of government organizations, review boards, and other persons who are required to watch over the safety and effectiveness of medical products and therapies and the conduct of research.

9. Suspension of Access. I may not be allowed to review the information collected for this study, including information recorded in my medical record, until after the study is completed. When the study is over, I will have the right to access the information again.

10. Health Information from Other Institutions. N/A

11. Term. This Authorization shall expire upon completion of the study.

Access. I understand that I have the right to access my Protected Health Information, which is maintained by Caritas St. Elizabeth's Medical Center in the Caritas St. Elizabeth's Medical Center's Designated Record Set upon completion of the Authorization to Use and Disclose Protected Health Information. I also understand I have the right to view and/or have copied my Protected Health Information in its entirety or an abstract. Based on State and Federal Law, Caritas St. Elizabeth's Medical Center has a right to deny me access to all or portions of my Protected Health Information and must notify me in writing. I understand that Caritas St. Elizabeth's Medical Center may charge a reasonable cost based fee associated with copying my Protected Health Information.

I may contact the Correspondence Department at: [REDACTED]
 I may contact Caritas St. Elizabeth's Medical Center's Privacy Officer by mail at Caritas St. Elizabeth's Medical Center, 736 Cambridge Street, Boston, MA 02135, or by telephone at [REDACTED]

I have read and understand the terms of this Authorization and I have had an opportunity to ask questions about the use and disclosure of my health information. By my signature below, I hereby, knowingly and voluntarily, authorize Caritas St. Elizabeth's Medical Center to use or disclose my health information in the manner described above. I will receive a copy of this Authorization form after I sign it.

12. _____ 13. _____
 Signature of Patient Date

Printed Name of Patient _____ Witness _____ I.D. Verification _____

If the patient is a minor or is otherwise unable to sign this Authorization, obtain the following signatures:

12. _____ 13. _____
 Signature of Personal Representative Date

Printed name of Patient Representative _____ 14. _____
 Relationship to patient or authority to act for patient



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Cape Cod Healthcare

INFORMED CONSENT TO PARTICIPATE IN RESEARCH

Subject's Name: _____ **Date:** _____

Home Address: _____

Home Telephone: _____ **Date of Birth:** _____

Research Study Title: Supporting Hope in Midlife Cancer Survivors: Intervention Workshop

Principal Investigator/Study Doctor: Clare Butt, RN, MSN, PhD(c)

Study Sponsor(s): Alpha Chi Chapter of Sigma Theta Tau International

About this Research Consent Form:

You are being asked to participate in a research study. A research study is the scientific method used to improve medical practice and patient care.

Do I have to participate in this study?

Your participation is voluntary. Taking part in this research study is totally your choice. You can choose whether or not to participate.

If you decide to participate, you can stop taking part in this research study at any time for any reason. If you are thinking about stopping or decide to stop, tell the principal investigator. The principal investigator will make sure that you stop the study safely and talk to you about follow-up care, if needed.

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If you decide not to participate in this research study or stop being in this research study, it will not affect how you are treated at Cape Cod Hospital. Prior to deciding if you should participate in this research study, you should understand enough about the risks and benefits to make an informed decision. This process is called informed consent.

Please take your time to make your decision about taking part in this research study. You may discuss your decision with your family and friends. You can also discuss it with any other health care provider. Please read all of the information contained in this form carefully and ask any questions that you have about this research study. If words or sections are unclear to you, please ask for an explanation.

If you decide to take part in this research study, you will be asked to sign this form and you will be given a copy of the signed form to keep.

1. Invitation:

You are being invited to take part in a research study to find ways to improve the care of cancer survivors. This study will be done with persons in midlife, ages 40-64, who have completed initial treatment for cancer within the past 18 months. Your name was obtained through a review, by the physicians and staff of Cape Cod Hospital, of cancer patients treated at Cape Cod Hospital. Your doctor has given us permission to contact you regarding this study.

2. Purpose: Why is this research study being done?

The purpose of this study is to evaluate what helps patients who have completed initial treatment for cancer to have hope and enjoy the best quality of life after treatment. The Mid-Life Directions Workshop will be compared to a Nutrition Program for Survivors for its effect on hope and quality of life. The Mid-Life Directions Workshop has been used for over 25 years by professional adult educators with persons in midlife. However it has never been evaluated for its effects on cancer survivors.

3. Procedures: What will happen if you take part in this research study?

After signing the consent form, you will be asked to answer some questions on a demographic form in order to find out if you can be in the research study. You are free to choose not to answer the question about income. The form will take about 5 minutes to complete. We will verify that:

- You are between 40 and 64 years of age
- You have a new diagnosis of a stage I, II or III solid tumor, including lymphomas

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- You do not have stage IV disease
- You have completed initial therapy within the past 18 months
- You are able to read, write and speak English
- You do not have a medical condition that impairs your ability to participate in the study

If your answers to the questions show that you are eligible to participate in the study, you will be eligible to participate in the research study. If you do not meet the eligibility criteria, you will not be able to participate in the study.

After the above screening questions confirm that you are eligible to participate in the research study, you will be asked to complete two standardized questionnaires:

- The Herth Hope Index, which will take about 4 minutes, and
- The Quality of Life – Cancer Survivor Instrument, which will take about 10 minutes.

You will then be assigned by means of a table of random numbers to either the Mid-Life Directions Workshop (MLD) group or the Nutrition Program for Survivors (NPS) group. You will be told when the first session begins, where it will be held, and other details about parking and the location of the meeting rooms.

The MLD group will be facilitated by a certified Mid-Life Directions consultant for six 2-hour sessions. If you are assigned to this group, you will be asked once again to complete the two standardized questionnaires during the last session of the workshop:

- The Herth Hope Index, and
- The Quality of Life – Cancer Survivor Instrument

In addition, you will be asked to write a written reflection of your opinion of the workshop during the last session.

The NPS group will be facilitated by a nutritionist for six 1-hour sessions. If you are assigned to this group, you will be asked once again to complete the two standardized questionnaires during the last session of the program:

- The Herth Hope Index, and
- The Quality of Life – Cancer Survivor Instrument

At the end of the study, you will receive a small gift for participation. Once you complete the study, you will not be contacted further for this study.

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4. Duration: How long will you be participating in this research study?

You will be in this research study for less than 3 months.

5. Risks, Discomforts, Side Effects and Inconveniences: What are the risks involved with being enrolled in this study?

There are risks to taking part in any research study.

The commitment to participate in the workshop or program and respond to questionnaires and write a written reflection requires your time. The time of the workshop or program sessions may be inconvenient for you or you may have some discomfort in talking about your own experiences. There is a risk of a breach of confidentiality by group members regarding sensitive and personal information disclosed during the workshop or program. You may experience emotional distress. There may be unknown risks.

Safeguards will be in place to keep risks at a minimum. There will be a psychiatric advanced practice nurse on call in case you or another participant requires immediate attention due to emotional upset. A verbal agreement will be obtained from group members that all information expressed in the group will be held in confidentiality by all group members. This agreement will be reviewed periodically with the group, however confidentiality cannot be guaranteed for information shared within the group.

During the research study, you will be provided with any new information that may affect your health or willingness to participate. You may be asked to sign a new consent form that shows that you have been informed of new information relating to this research study.

6. Benefits: Are there benefits to taking part in this study?

Taking part in this research study may or may not benefit you. However, it is possible that you may experience an increased level of hope and improved quality of life. We will use the information learned from this research study to provide more information about helping cancer patients find the best quality of life after treatment.

7. Alternatives: What other choices do you have if you do not take part in this study?

Taking part in this research study is voluntary. Instead of being in this research study, you have the following options:

- Attend a Mid-Life Directions Workshop that might be offered in the Boston area.
- Request a nutritional consultation with a dietitian at Cape Cod Hospital.
- Plan your own program of self-development.

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- Decide not to participate in this research study.
- Participate in another research study.

8. Confidentiality: Will your medical information be kept private?

Confidential information contained in your medical record may not be given to anyone except to members of the research group and others who must be involved professionally to provide essential medical care. The study sponsor, the Cape Cod Healthcare Institutional Review Board (a group of people who review the research study to protect your rights) state and federal agencies protecting the welfare of the study participants may view study records.

9. Compensation: Will you be paid to participate in this research study?

You will receive the National Cancer Institute booklet, *Facing Forward: Life After Cancer Treatment*, for completing the study. You will not be paid a sum of money for your participation in the study.

10. In Case of Injury: What happens if you become injured because of taking part in this research study? – N/A

No injury related to the research study is expected.

11. Costs: What are the costs for taking part in this study?

There is no charge for participation in this study. You will receive a free workbook if you are assigned to the Mid-Life Directions Workshop group and free handouts if you are assigned to the Nutrition Program for Survivors group.

12. New Findings: New Information. – N/A

13. Number of Subjects enrolled at Cape Cod Hospital.

There may be up to 110 subjects at Cape Cod Hospital who are enrolled in this study.

14. Termination without Consent: - N/A

You can stop participating in the research study at any time. Leaving the research study will not affect your medical care. You can still get your medical care from Cape Cod Hospital or your study doctor.

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If you chose not to participate, or if you are not eligible to participate, or if you withdraw from this research study, this will not affect your present or future care and will not cause any penalty or loss of benefits to which you are otherwise entitled.

If you have any questions about the study or if you choose to withdraw from the study, please contact the research investigator or study staff below:

- Clare M. Butt, RN, MSN, PhD(c)
Principal Investigator
[REDACTED]
- Jeff Gaudet, LICSW
Cape Cod Hospital, Davenport Mugar Cancer Center
[REDACTED]

15. Contacts:

If at any time during this research study, you feel that you have not been adequately informed as to the risks, benefits, alternative procedures, or your rights as a research subject, have a complaint about the research or feel under duress to participate against your wishes, or to continue with the study, you can contact a member of the Cape Cod Healthcare Institutional Review Board (a group of people who review the research study to protect your rights), who will be available to speak with you during normal working hours (8:30 a.m. to 5:00 p.m.) at:

Cape Cod Healthcare Institutional Review Board

Chairman: Spiros Thomas, R.Ph., MBA
Telephone: [REDACTED]
Address: [REDACTED]

You may also contact the Principal Investigator or Representative at any time during this Research study for questions and answers regarding the Research study at:

- Clare M. Butt, RN, PhD(c)
Principal Investigator, [REDACTED]

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Statement of Principal Investigator or Person Obtaining Consent

The subject has been informed of the nature and purpose of the procedures including any risks involved in the research study's performance. The subject has been asked if any questions have arisen regarding these procedures and these questions have been answered to the best of the investigator's ability. A signed copy of this informed consent has been provided to the subject.

Also, any new unforeseen information relevant to the patient that may develop during the course of this research activity will be provided to the subject and the Cape Cod Healthcare Institutional Review Board. I will inform any referring physician(s) of any and all protocol changes, adverse events and/or safety reports.


Signature of Principal Investigator or Person Obtaining Consent	Date	Printed Name
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Statement and Signature of Subject

I have been informed about the procedures, risks, and benefits of this Research Study and agree to participate. I know that I am free to withdraw my consent and to quit the Research Study at any time. My decision not to participate in this Research Study or my decision at any time to withdraw from this Research Study will not cause me any penalty or loss of benefits that I am otherwise entitled to.

I have read or have had this form read to me and understand the terms of this Consent Form and I have had an opportunity to ask questions about the Study and to discuss the Study with my doctor and other health care providers and my family and friends.

I hereby consent to have my medical records relating to this research activity be made available to state and federal agencies (including but not limited to the Department of Health and Human Services) which regulates research activity, including this research


C.C.H.C.
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study. I understand that while every effort will be made to keep my identity confidential, there may be occasions when my identity must be made known to state and federal agencies at their request.

I understand that this research study has been reviewed and approved by the Cape Cod Healthcare Institutional Review Board

Signature of Subject

Date

Printed Name

- The subject has received a copy of this consent form.



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Uses and Disclosures of Protected Health Information for Research Purposes

Protocol Number:

Principal/Overall Investigator: Clare M. Butt, RN, MSN, PhD(c)

Protocol Title: Supporting Hope in Midlife Cancer Survivors: Intervention Workshop

AUTHORIZATION TO USE OR RELEASE INDIVIDUAL HEALTH INFORMATION FOR RESEARCH PURPOSES

Federal law requires Cape Cod Healthcare, Inc. ("CCHC") and its affiliated hospitals, researchers and other health care providers to protect the privacy of information that identified you and relates to your past, present or future physical and mental health and conditions ("protected health information"). If you decide to become a subject in the research described in the attached informed consent form, your protected health information will be used and shared with others as explained below.

If you agree to the described uses within CCHC and the sharing of your protected health information outside of CCHC, then after reading this entire document, please sign your name at the end of the line provided. If you have questions, you may ask the research staff who are reviewing the informed consent form with you or you can contact the researcher listed under Study Contacts in the attached consent form.

1. What protected health information about me will be used or shared with others during this research?

- √ Existing medical records
- √ New health information created from study-related tests, procedures, visit, and/or questionnaires, as described in the attached consent form.

2. Why will protected health information about me be used or shared with others?

The main reasons include:

- √ To conduct and oversee the research described in the attached consent form;
- √ To ensure the research meets legal, institutional, and accreditation requirements; and
- √ To conduct public health activities (including reporting of adverse events or situations where you or others may be at risk of harm).

C.C.H.C.
INST. REVIEW BOARD
VALID THROUGH: 7/1/12



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3. Who will use or share protected health information about me?

- a. CCHC and its affiliated researchers and entities participating in the research, as described in the informed consent form will use and share your protected health information. In addition CCHC's review board that oversees all research activities within CCHC and its affiliated staff who have a need to access this information to carry out their responsibilities (for example, the quality improvement staff may access your protected health information as part of their work to improve the quality of care delivered across the CCHC system) will be able to use and share your protected health information.
- b. All reasonable efforts will be made to protect the confidentiality of your protected health information, which may also be shared with the following others for the reasons noted above:

Outside individuals or entities that have a need to access this information to perform functions on behalf of CCHC and its affiliates (for example, data storage companies, insurance companies, or legal advisors when necessary).

- The sponsor of the study, its subcontractors, and its agents: Alpha Chi Chapter of Sigma Theta Tau International
- Other researchers and medical centers participating in the research
- Federal and state agencies (for example, the Department of Health and Human Services, the Food and Drug Administration, the National Institutes of Health, and/or the Office for Human Research Protections), or other domestic or foreign government bodies if required by law and/or necessary for oversight purposes.
- Hospital accrediting agencies
- A data and safety monitor assigned to oversee this research

We recognized that some of those who receive protected health information may not have to satisfy the privacy requirements that we do and may re-disclose it, so we share this information only if necessary, and we use all reasonable efforts to request that those who receive it take steps to protect your privacy.

4. For how long will protected health information about me be used or shared with others?

Your protected health information that is being used or shared for this research will be kept for seven years and then destroyed.

5. Statement of privacy rights:

- a. You have the right to withdraw your permission at any time and for any reason for the researchers and participating CCHC entities to use or share your protected health information. We will not be able to withdraw all of the information that already

C.C.H.C.
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has been used or shared with others to carry out the research or any information that already has been used or shared with others to carry out related activities such as oversight, or that is needed to ensure the quality of the study. If you withdraw your permission, you cannot participate further in the research. If you want to withdraw your permission, you must do so in writing by contacting the researcher listed as the Study Contact on the attached informed consent form; and the Cape Cod Healthcare Privacy Office, at 88 Lewis Bay Road, Hyannis, MA 02601.

- b. You have the right to request access to your protected health information that is used or shared during this research and that relates to your treatment or payment for your treatment; but you may access this information only after the study is completed. To request this information, please contact the researcher listed under Study Contacts on the informed consent form.

SIGNATURES:

Print Name of Subject

Date of Birth

Signature of Subject

Date

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Appendix F

Permissions and Letters of Support

[Back to Inbox](#)











back reply reply all forward delete flag next unread save sender print

From: "Herth, Kaye A" [REDACTED]

[view source](#)

Subject: RE: Request for Permission to use HHI

Date: Tue, 3 Jun 2008 07:14:27 -0500

To: "Clare Butt" [REDACTED]

Dear Clare,

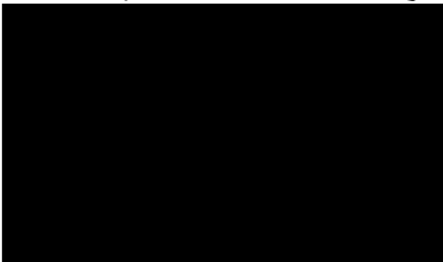
I appreciate your interest in the Herth Hope Index (HHI). I have attached a copy of the Herth Hope Index (HHI) and the longer Herth Hope Scale (HHS), scoring instructions, and several reference lists I have compiled on hope.

You have my permission to use either the HHI or HHS in your doctoral research project. If either the HHI or HHS is used, I would appreciate your sending me a summary of your findings when your project is completed. There is no charge connected with the use of the HHI or HHS.

If I can be of any further assistance please don't hesitate to contact me. Best wishes in your doctoral study and with your research project involving persons with cancer in the post treatment phase of the disease.

Dr. Kaye Herth

Kaye A. Herth, Ph.D., R.N., F.A.A.N.
Dean, College of Allied Health and Nursing



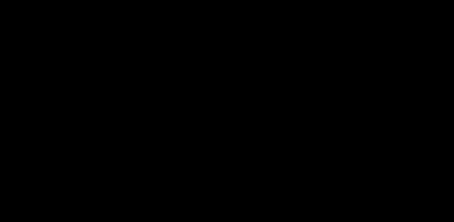
Dear Kaye,

Let me introduce myself. I am a PhD Doctoral student at Boston College School of Nursing, and have completed my first year of study. I have read your research and scholarly work on hope, and congratulate you for your success in increasing hope in your intervention study. I have a sample copy of your Herth Hope Index from the City of Hope palliative care website.

I am very interested in using your Herth Hope Index for my research with persons with cancer in the post treatment phase of the disease. Would you give me permission to do so? Please let me know what is involved.

I look forward to hearing from you. Thank you for your attention to my request.

Clare Butt, RN, MSN, AOCN
PhD Doctoral Student &
Research Fellow
Center for Nursing Research
Wm. F. Connell School of Nursing
Boston College





**NATIONAL MEDICAL CENTER AND
BECKMAN RESEARCH INSTITUTE**

Quality of Life Patient/Cancer Survivor Version

Dear Colleague:

The Quality of Life Instrument (CANCER PATIENT/CANCER SURVIVOR VERSION) is a forty one-item ordinal scale that measures the Quality of Life of a cancer patient. This tool can be useful in clinical practice as well as for research. This instrument can be administered by mail or in person. The instrument originated in our pain research and has been recently adapted for use in long term cancer survivors. A Hispanic version of this questionnaire is also included.

Directions: The patient is asked to read each question and decide if he/she agrees with the statement or disagrees. The patient is then asked to circle a number to indicate the degree to which he/she agrees or disagrees with the statement according to the word anchors on each end of the scale.

The scoring should be based on a scale of 0 = worst outcome to 10 = best outcome. Several items have reverse anchors and therefore when you code the items you will need to reverse the scores of those items. For example, if a subject circles "3" on such an item, $(10-3 = 7)$ thus you would record a score of 7. The items to be reversed are: 1-7, 9, 16-27, & 29-34 and 38. Subscales can be created for analysis purposes by adding all of the items within a subscale and creating a mean score.

You are welcome to use this instrument in your research/clinical practice to gain information about Quality of Life of patients. You have permission to duplicate this tool.

The QOL instrument is based on previous versions of the QOL instrument by researchers at the City of Hope National Medical Center (Grant, Padilla, and Ferrell). This instrument was revised in cancer survivorship studies and includes 41 items representing the four domains of quality of life including physical well being, psychological well being, social well being and spiritual well being. A study was conducted in 1995 to evaluate the psychometrics of this revised instrument as a mail survey to the membership of the National Coalition for Cancer Survivorship. This survey included a Demographic tool, the QOL tool and the FACT-G tool developed by Cella. Psychometric analysis was performed on 686 respondents including measures of reliability and validity. Two measures of reliability included re-test and internal consistency. In order to perform test re-test reliability, a randomly selected sample of 150 subjects who completed the initial QOL survey were asked to repeat this tool approximately two weeks later. 110 of the 150 subjects responded for an overall response of 73%. Of the 110 respondents, only those with complete data sets on all variables were used (N=70). The overall QOL-CS tool test re-test reliability was .89 with subscales of physical $r=.88$, psychological $r=.88$, social $r=.81$, spiritual $r=.90$. The second measure of reliability was

computation of internal consistency using Cronbach's alpha co-efficient as a measure of agreement between items and subscales. Analysis revealed an overall $r=.93$. Subscale alphas ranged from $r=.71$ for spiritual well being, $r=.77$ for physical, $r=.81$ for social, and $r=.89$ for psychological. Several measures of validity were used to determine the extent to which the instrument measured the concept of QOL in cancer survivors. The first method of content validity was based on a panel of QOL researchers and nurses with expertise in oncology. The second measure used stepwise multiple regression to determine factors most predictive of overall QOL in cancer survivors. Seventeen variables were found to be statistically significant accounting for 91% of the variance in overall QOL. Variables accounting for the greatest percentage were control, aches and pain, uncertainty, satisfaction, future, appearance and fatigue. The fourth measure of validity used Pearson's correlations to estimate the relationships between the subscales of the QOL-CS and the subscales of the established FACT-G tool. There was moderate to strong correlation between associated scales including QOL-CS Physical to FACT Physical ($r=.74$), QOL-CS Psych to FACT Emotional ($r=.65$), QOL Social to FACT Social ($r=.44$). The overall QOL-CS correlation with the FACT-G was $.78$. Additional measures of validity included correlations of individual items of the QOL-CS tool, Factor Analysis, and Construct Validity discriminating known groups of cancer survivors. This psychometric data is reported in reference #1 and 2.

Good luck with your research!!

Betty R. Ferrell, RN, PhD, FAAN
Research Scientist

Marcia Grant, DNSc, FAAN
Research Scientist
Director Nursing Research & Education

City of Hope National Medical Center
1500 E. Duarte Road
Duarte, CA 91010



Dr. Anne Brennan, csj
Dr. Janice Brewi, csj

November 2, 2009

Clare Butt, PhD (c)

Dear Clare,

We completely support your proposal to provide the Mid-Life Directions Workshop to cancer survivors as part of the research for your doctoral dissertation. Having discussed your research plan with you over the past two years, we are confident that, as a certified Mid-Life Directions consultant, you are able to provide the workshop within the study in a way that is consistent with the mission of Mid-Life Directions. As authors of the material and founders and directors of Mid-Life Directions, we give you our permission to use our copyrighted workshop material for your dissertation research.

We look forward to hearing further about how your research progresses. We wish you every success as you continue to pursue your doctoral degree.

Sincerely,

Anne Brennan, csj, STD

Founders, Directors

Janice Brewi, csj, STD