

Hope in Patients With Cancer Transitioning to Survivorship: The Mid-Life Directions Workshop as a Supportive Intervention

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An estimated 1.6 million people were diagnosed with cancer in 2011 in the United States (American Cancer Society, 2011). Of those newly diagnosed, many were 40–64 years old and in the developmental stage of midlife. Midlife is the time when a person is engaged in caring for a family, advancing a career, and tending to the needs of aging parents (Helson & Soto, 2005). Cancer diagnoses and treatments interrupt the roles in the family and workplace. In addition, the cancer experience may change the way the patient views his or her life and future. After active primary treatment is completed, many patients find themselves lost in the transition to survivorship (Hewitt, Greenfield, & Stovall, 2005).

The article will describe the background and needs of patients with cancer transitioning to survivorship, a theoretical framework for addressing those needs, and a promising new clinical intervention, the Mid-Life Directions workshop (MLD), which is directed at this population. Each session of the workshop is presented with its goal, topics, and processes, as well as benefits for cancer survivors. Finally, because the workshop has not been formally tested among people with cancer, the opportunity to design a research study is discussed.

Survivorship begins at the time of a cancer diagnosis and continues through the balance of life. However, many patients only begin to focus on survivorship after active primary treatment is completed. Therefore, for purposes of the article, survivorship will refer to the time after active primary treatment is completed. The Institute of Medicine (IOM) has detailed the unmet needs of patients transitioning to survivorship (Hewitt et al., 2005). Physical symptoms, such as pain, fatigue and sleep disturbance, as well as psychological symptoms, such as depressed mood and distress, are common in post-treatment survivors. Fear of recurrence or death, difficulty making decisions, and a changed relation-

Purpose/Objectives: To describe the Mid-Life Directions workshop as an intervention to support hope and quality of life in midlife cancer survivors.

Data Sources: Published articles and books.

Data Synthesis: The Mid-Life Directions workshop assists survivors to integrate the cancer experience through conscious awareness and choice, and transition to survivorship with an increased level of adaptation. Quality of life and hope are enhanced through new information and skills allowing participants to direct their lives into a preferred future.

Conclusions: The midlife cancer survivor is challenged to face the fear of recurrence, death, and the crisis of meaning in a developmentally appropriate way. The task of midlife is to navigate the tension of generativity versus stagnation for care to emerge as the predominant strength. The Mid-Life Directions workshop provides the cancer survivor the opportunity to reevaluate goals, reprioritize values, and find one's own answers to these challenges to adapt to life as a cancer survivor.

Implications for Nursing: This clinically relevant intervention merits formal study. Facilitator preparation, mode of delivery, and other elements for possible research are discussed.

ship with time characterize that transition. Importantly, midlife cancer survivors appear to be vulnerable to higher levels of distress (Brant et al., 2011). The IOM called for interventions to improve the quality of life (QOL) of cancer survivors (Hewitt et al., 2005).

The period following cancer diagnosis and active primary treatment is a time when the patient is open to change (Allen, Savadatti, & Levy, 2009). However, once active primary treatment is complete, the transition back to life becomes a challenge. Life may have remained the same, but the cancer survivor is forever changed (Grant, Economou, & Ferrell, 2010). How the

individual wishes to live as a survivor will be personal, but also developmentally influenced. Recent studies indicated that the needs of midlife patients with cancer are greater than those of young or older adults (Brant et al., 2011; Schlariet, Heddon, & Griffis, 2010). Therefore, interventions should be developed specifically to address the QOL of those in midlife.

In recent years, survivorship care has become the focus of the interdisciplinary cancer community, with recommendations issued by the American Cancer Society, the American Society of Clinical Oncology, the Association of Community Cancer Centers, the Centers for Disease Control and Prevention, the National Cancer Institute, and the Office of Cancer Survivorship (Grant et al., 2010). The IOM, in particular, has defined the components of survivorship care to include prevention and detection, surveillance, interventions for consequences of cancer and treatment, and coordination (Hewitt et al., 2005). Although the needs of patients with cancer transitioning to survivorship are assessed individually and the survivorship care plan needs to involve the contributions of many disciplines and departments, the focus of this article will be on the role of the nurse as part of the interdisciplinary team.

QOL has been conceptualized in various ways (Ferrens & Powers, 1985; Ferrell, Hassey-Dow, & Grant, 1995). Regardless of the model, the multiple dimensions are meant to encompass all aspects of life—physical, emotional, spiritual, social, and financial. For post-treatment cancer survivors, QOL is affected by the sequelae resulting from treatment effects, which carry over into this phase.

Hope has been 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). Many scholars agree that hope is complex and multidimensional (Clukey, 2007; Cutcliffe & Herth, 2002; Miller, 2007). Hope is described too often in the literature as focused only on a cure of disease; however, it encompasses other dimensions, changes with life experiences, and can be redefined by the patient over time (MacLeod & Carter, 1999; Reb, 2007). Hope is important during times of transition and is an integral part of a person’s QOL.

Many factors affect how a person navigates life’s transitions, but the developmental factor may be the most influential, especially during midlife (Brewi & Brennan, 2004; Jung, 1933). Like the transition to survivorship, midlife is a time of change that calls for a new approach to life. During midlife, the time to build identity is more or less complete; an individual knows how to function effectively in the workplace, with one’s family, and among friends. However, a new restlessness

often begins to manifest. It may be in the form of a job loss, a first major illness, or the death of a parent; it also may take the form of an achievement such as a job promotion or new responsibilities with older relatives. The precipitating event may cause a crisis of feelings, which is characterized by loneliness, and necessitates new meaning, values, and goals in the person’s life (Anderson, 2008; O’Collins, 1995). For those diagnosed with cancer during midlife, the diagnosis likely becomes the precipitating event for the midlife crisis and transition.

Theoretical Framework

According to Erikson (1963, 1997), a person in midlife is negotiating the developmental crisis of generativity versus stagnation. Generativity involves the task of caring for productivity and progeny in a way that is self-giving and selfless, while avoiding the stagnation of self-absorption. For the cancer survivor, this task also can relate to QOL. During the transition from patient with cancer to cancer survivor in midlife, questions may arise, such as: What do I have to give to the next generation when I am feeling fatigued, unsure of my future, and financially depleted? Will I become a burden to my family if cancer recurs? From a hopeful perspective, the patient may ask, what is personally meaningful and realistically possible for me now?

Jung (1933) recognized that the second half of life, although psychologically distinct, is an extension of and continuous with the developments achieved in the first half of life, which consists of the stages of childhood and of youth, and is characterized by psychological growth and development influenced primarily by the environment. During the second half of life, however, growth and development proceed primarily from within the person.

During midlife, a person’s underdeveloped personality traits will manifest, integrating into the more complete self that the person is becoming. As part of the healthy maturation process, the *shadow* side (i.e., the suppressed and underdeveloped aspects of the personality) of the individual will need to be acknowledged and integrated. In this way, the midlife person develops a more mature and less one-sided personality. For the patient with cancer transitioning to survivorship, that involves reevaluating the experience of cancer diagnosis and treatment from the perspective of post-treatment and experiencing the fullness of the present journey with all its emotions, hopes, and fears.

The way a person with cancer experiences the transition from cancer survivor is influenced by his or her developmental stage. Therefore, interventions that provide a developmentally focused approach to support hope and improve QOL should be considered for this population.

The MLD workshop is an intervention that promotes adapting to normal developmental changes occurring during midlife. In the Roy Adaptation Model (RAM), Roy (2009) defined 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” (p. 26). 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, 2009 p. 27). Therefore, nurses promote the integrated adaptive process 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).

In the RAM, the role of nurses is to promote adaptation of patients under their care. As an adaptive system, the person in midlife uses conscious awareness and choice to integrate the experience of the cancer diagnosis and treatment into life as a cancer survivor. Nursing interventions need to provide midlife survivors with the information and skills that will allow the individuals to expand their awareness of options and, therefore, integrate human and environment for successful adaptation during cancer survivorship.

Some of the RAM’s scientific assumptions (Roy, 2009) can be applied to cancer survivors in midlife.

- *Systems of matter and energy progress to higher levels of complex self-organization.* People in midlife are challenged to mature from an early-adult focus on ego development to the midlife focus on integrating that 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.
- *Consciousness and meaning are constitutive of person and environment integration.* As consciousness expands, it includes 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.
- *Awareness of self and environment is rooted in thinking and feeling.* Although both thinking and feeling functions are present in the first half of life, one function usually is preferred and more fully developed. The survivor integrates into the maturing personality the underdeveloped thinking function with the more developed feeling function, or vice versa. The higher level of self-awareness promotes a deeper understanding of the cancer experience in the social context.
- *Person and environment transformations are created in human consciousness.* From the standpoint of an expanded awareness of the self and one’s life experi-

ences, 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.

- *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).

The MLD workshop can provide an environment where the patient with cancer is able to find his or her own answers to the questions raised by the transition to cancer survivor. By supporting hope and offering new information and skills in a reflective and communal manner, the MLD Workshop has the potential to assist patients with improving their QOL. According to Roy (2009), “People constantly redefine and transform stimuli, their knowledge base, and the goals of activity” (p. 275). Therefore how people respond to life events determines the effects of those events on hope and QOL. Considering that physical symptoms are well-controlled and other aspects of the survivorship care plan are addressed, the MLD workshop may be one way to provide psychological and spiritual support to cancer survivors as part of the overall care plan following active primary treatment.

Workshop Description

Brewi and Brennan (2004) developed the MLD workshop for personal and spiritual growth, but it also can be used as an intervention. Since the 1980s, Brewi and Brennan have conducted MLD workshops internationally to foster psychological and spiritual growth in the second half of life. In addition, they have trained and certified MLD consultants to conduct workshops in their own areas of work and residence. Although the workshop has never been studied formally, positive feedback from participants has verified its value and supported its continued development (Brewi & Brennan, 1999).

The workshop consists of six two-hour group sessions. The main goal of the workshop for midlife cancer survivors is to assist in integrating the cancer experience through conscious awareness and choice and making the transition to survivorship with an increased level of adaptation, resulting in increased hope and improved QOL. Each session of the workshop contributes to that goal. An MLD workbook is given to all participants so they can enter into each session’s themes and activities.

Session 1: The Life Cycle

The first session of the workshop begins with an overview of its goals and objectives. All personal

information expressed in the group is expected to be held in confidentiality by all participants, and each participant is expected to attend all sessions. The goal of session 1 is to promote understanding of normal psychological growth and development as they relate to personal experiences. Topics for this session include 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 includes the processes of creative listening to presentations and other participants, guided imagery, music meditation, and journaling about their life story. In session 1, midlife cancer survivors place the experience of diagnosis and treatment for cancer into the context of their significant happenings, events, turning points, and life transitions. Survivors can review their life as it unfolded and examine the meaning it might have currently.

Session 2: Understanding Personality Type and Midlife Growth

The goal of this session is to assist the participant with connecting new information to prior experiences. Topics include 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 Gray-Wheelwrights Survey (Mattoon & Davis, 1995) was used to delineate the individual's personality type and outline the chapters of his or her life. Using the survey results, the participant is guided to identify the reasonably well-developed aspects of his or her personality, as well as the lesser-developed aspects, and acknowledge and include those aspects as appropriate into the expanding personality in midlife and beyond. That new information is connected to the individual's life story through journaling, music meditation, and small group sharing. In session 2, midlife 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 and Depth Experiences, Myths, and Symbols

The goal of this session is to support coping with the emotions surrounding the experience of illness and treatment and to explore changes in individual hope and QOL. Topics include an exploration of myths and

symbols as being at the heart of the process of individuation; the role of myths and symbols in relating to great archetypal, life-giving realities; mandalas as expressions of the self; and peak and depth experiences as sources of meaning, decisions, and integration. Processes used during this session are the consideration and exploration of the participant's peak and depth experiences, music meditation, creation of a mandala collage, and small group sharing of the collages created. In session 3, midlife cancer survivors are provided the opportunity to bring into consciousness their unconscious hopes and dreams for the future.

Session 4: Aligning Outer Values and Inner Life

The goal of this session is to foster the use of the imagination to envision new hope and QOL, as well as adopting changes to minimize the negative effects of the disease. Topics addressed during this session include the need for inwardness and interiority to live the second half of life well; the danger of becoming cynical with the end of naiveté; the recovery of wonder by examining present experiences; and identifying the shift of values at midlife. The processes involved identifying and prioritizing values and their current meaning. Participants also examine a typical day, week, and year in light of those values. Finally, they redesign a day, week, and year to correspond to their current values as identified and prioritized. Other activities include an extended contemplative experience while listening to music and an explanation of how bearing the tension of opposites results in healthy integration and peace within. For example, when the tension between competition and accommodation is balanced, effective collaboration can result. In session 4, the survivor can more closely align his or her inner and outer experiences through values clarification and reimagining a preferred life.

Session 5: Integrating the Inner and Outer Journeys

The goal of session 5 is to promote the integration of the cancer diagnosis and treatment into the individual's self-concept. Topics include the importance of being true to oneself in midlife, which can facilitate growth, and being open to continual growth; in addition, the midlife crisis and transition, which usually are precipitated by an inner life or outer life catalyst, such as cancer, are discussed. Processes employed during the session include participation in a ritual of renewal, a written dialogue with a wisdom figure (i.e., someone valued as a source of inspiration), and creative listening and sharing. In session 5, the cancer survivor is set on a path to greater understanding of what the person hopes for now and a consideration of what QOL might be desired in the future.

Session 6: Imagining One's Preferred Future

The goal of this session is to launch the participant into acceptance of responsibility for maintaining hope and QOL. Topics include an understanding of the second half of life as increasing self-knowledge, understanding personal psychology, developing an inner life, and continuing generativity in one's outer life. Participants project their futures by remembering their past life experiences and imagining their future. In session 6, hope is supported by allowing the survivors to consider what is realistically possible and personally meaningful now, and QOL is enhanced by increasing awareness of their life story and learning new skills to direct themselves toward a preferred future.

Potential for Research

The MLD workshop process is well-established; however, it has not been tested formally among people with cancer. The workshop has the potential to assist transition of patients with cancer at midlife survivorship, while increasing hope and improving QOL; therefore, permission was obtained from the MLD founders for a certified MLD consultant to provide the workshop to cancer survivors in the context of a formal research study. Each consultant is trained and certified in a three-week intensive program. Qualified trainees must have the minimum of a master's degree, completed the training program, and been monitored in the successful delivery of their first five workshops. Although MLD consultants are from various disciplines, the researcher in the proposed study ideally would hold a master's degree in nursing and be certified in oncology nursing.

When administered to a group, the intervention is preferable for 8–12 participants, but it can be delivered to larger or smaller groups. Participants ideally attend all six sessions of the workshop, but at least four must be attended to provide dependable study data.

The population to be studied would be people in midlife who have completed active primary treatment for cancer. Potential participants should be assessed for appropriateness and allowed to decide on their readiness to participate in the workshop. Suggested inclusion and exclusion criteria are listed in Figure 1.

Research instruments recommended for the proposed study are the Herth Hope Index (Herth, 1992), and the Quality of Life Instrument, Cancer Patient/Cancer Survivor Version (Ferrell, Hassey-Dow, & Grant, 1995). The instruments have demonstrated reliability and validity in the study population (Ferrell et al., 1995; Herth, 1991). To enhance understanding of quantitative results, participants could provide a written response postintervention to the question, "What meaning has

Inclusion Criteria

- Aged 40–64 years
- Completed active primary treatment for cancer within the prior 18 months
- Diagnosed with a solid tumor, including lymphomas, stages I, II, or III
- Able to speak, write, and read English

Exclusion Criteria

- Diagnosed with stage IV disease
- Diagnosed with dementia or another medical condition that impairs the ability to participate in the study procedures

Figure 1. Suggested Participant Inclusion and Exclusion Criteria

the workshop had for you personally?" Quantitative measures should be performed pre- and postintervention.

The workshop should be conducted in a room that allows for privacy and has space for participants to move into various groups (i.e., table and chairs; chairs in a circle; groupings of two or three; and place to spread out for reflection, journaling, and artistic creation). The workshop should be located conveniently for survivors and should vary according to the manner in which services are offered within a given locale.

Potential confounding variables may be high levels of distress, unmet social needs, or physical symptoms such as pain, fatigue, or other distressing symptoms that are controlled poorly. The population also may be employed outside the home and caring for children and older relatives, all of which may limit their availability for participation in the workshop. Other challenges to the conduct of the proposed study may be associated with costs for the facilitator, workbooks for participants, and parking or other transportation fees. Remaining questions include whether the workshop does what it proposes and whether the costs involved would be covered by insurance or other funding sources. If the questions are answered favorably, the workshop could be considered as an option for the survivorship care plan.

A study of this promising new intervention is needed to determine its effect on hope and QOL. It presents an opportunity to research one means of addressing the pressing needs of midlife patients with cancer transitioning to survivorship. In the words of Roy (2009), "Life can be regarded as successive patterns of choice that lead to the feeling of fulfillment, with resulting happiness that comes to a life centered on meaning and purpose" (p. 278). As the number of survivors grows, interventions, such as the MLD workshop, are needed to increase hope and QOL.

Conclusion

The task of midlife is to navigate the tension of generativity versus stagnation for care to emerge as the predominant strength. Midlife cancer survivors are challenged to face the fear of recurrence, the fear of death, and the crisis of meaning in a developmentally appropriate way. Therefore, how do cancer survivors care for what they have produced by love, necessity, or accident while suffering fatigue, facing possible recurrence and the prospect of a shortened life span? How do they avoid the stagnation of having nothing to give the next generation, feeling like a burden to their family, and sometimes being unable to be productive in the work setting?

The MLD workshop provides new information and skills to help survivors bear this tension creatively. It gives cancer survivors the opportunity to reevaluate goals, reprioritize values, and find answers to challenges adapting to life as survivors. The MLD workshop assists participants in using conscious awareness and choice to create human and environment integration with greater hope and better QOL by means of a transformation of awareness of self, consciousness, and meaning.

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