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Survivorship

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This excerpt, chapter 2 from the book *Psychosocial Nursing Care Along the Cancer Continuum* (2nd ed.), edited by Rose Mary Carroll-Johnson, RN, MN, Linda M. Gorman, RN, MN, APRN, BC, OCN®, CHPN, and Nancy Jo Bush, RN, MN, MA, AOCN®, is part of a series of clinically relevant reprints that appear periodically in the *Clinical Journal of Oncology Nursing*.

Cancer therapists talk in terms of a 'five-year survival rate,' by which they mean the number of patients with a given tumor who will live five years beyond the time of diagnosis. It is an arbitrary way of measuring human existence but useful for scoring the likelihood of escape from cancer. In mid-March 1980, I tiptoed past the invisible line and into the future."

—Fitzhugh Mullan, 1983

As an evolving focus in clinical practice, education, and research, cancer survivorship has emerged as a prominent yet enigmatic milestone within the cancer trajectory. Not afforded the intensity of study nor the rigor of public attention as cancer treatment and, more recently, end-of-life care, living beyond a diagnosis of cancer often is deemed a privilege not deserving of query despite its numerous quandaries.

More than two decades have passed since the phenomenon of cancer survivorship began to gain prominence in the lay public and within professional venues. Progress has been made in the arenas of advocacy and lobbying for research funding to advance the fledgling evidence base addressing life after cancer (Clark & Stovall, 1996; Ganz, 2001). It is timely to review the state of the science of cancer survivorship with particular emphasis on its psychosocial challenges. Controversies and possibilities for the future will be proposed as oncology nurses play a major role in this expanding paradigm of cancer care (Ferrell, Virani, Smith, & Juarez, 2003).

Definitional Dilemmas

The historical construct of survivorship was associated with living through extraordinary life situations such as fires, floods, earthquakes, volcanic eruptions, wars, and concentration camps (Dow, 1990). In the mid-1900s, when cancer uniformly was deemed an incurable disease, family members were considered survivors following the death of a loved one (Leigh, 1994). Since the more recent inception of the cancer survivorship movement, semantics have been debated. Prompting this deliberation was an evolving consensus that the historical medical model used to identify cancer survivors was unsuitable. Izsak and Medalie (1971) were first credited with bringing this contention to notoriety.

> Survival rates, while justifiably important in themselves, cover only a portion of the total problem. These rates do not relate to how the patient survives, at what cost to his physical functioning, how he adapted to his condition from a psychological point of view, and how he is fulfilling his roles in his family, at work, among friends, and in the wider society. (pp. 179–180)

More than a decade later, Mullan (1985), a physician and cancer survivor, wrote a poignant editorial to colleagues in the *New England Journal of Medicine* addressing the inadequacies of the definitional paradigm at that time. He suggested that there was no "moment of cure" or "invisible line" that a patient traversed to become a survivor.

> During these years I frequently wondered when I could safely declare victory. When could I say simply that I was cured? Actuarial and population-based figures give us survival estimates for various cancers, but those figures do not speak to the individual patient whose experience is unique and not determined or described by aggregate data. Many patients are 'cured' long before they pass the five-year mark and others go well beyond the five-year point with overt or covert disease that removes them from the ranks of the 'cured' no matter how well they feel. Survival is a much more useful concept because it is a generic idea that applies to everyone diagnosed as having cancer, regardless of the course of illness. (pp. 270–271)

Mullan (1985) formulated a new theory about cancer survival. He proposed that patients transition through phases of acute,

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extended, and permanent survival, each characterized by distinct coping agendas. Figure 2-1 compares Mullan's conceptualization with the medical model, correlating permanent survival with the classic distinction of "being cured." The National Coalition for Cancer Survivorship (NCCS) adopted this construct and delineated components of survivorship as

- The act of living on, no matter what happens
- Beginning the moment the patient is told he or she has cancer and continuing for the rest of the patient's life
- Extending far beyond the restrictions of time and treatment
- A dynamic concept with no artificial boundaries
- A process of "going through," suggesting movement through phases
- A continued or ongoing process rather than a stage of survival
- A healing process
- Not dependent on biology or medical outcomes, but reflecting quality of life
- The experience of living with, through, or beyond cancer (Leigh, 2001).

A cancer survivor then is any person who has been diagnosed with cancer, from the time of discovery and for the balance of life (NCCS, 2004). For the purposes of this chapter, however, extended and permanent survival are the foci of analysis.

Scope of Survivorship

The burgeoning attention to cancer survivorship can be linked with two significant corollaries. First, advances in cancer treatment have facilitated long-term survival in a greater number of patients with a variety of tumor types. These success stories have challenged the long-standing notion that a cancer diagnosis equates with inescapable death (Loescher, Clark, Atwood, Leigh, & Lamb, 1990). This growing number of people living with a history of cancer has prompted recognition of a new subset of patients we know little about. Consider the following (Boyle, 2002; Dow, 2003; Jemal et al., 2005; Leigh, 1992; Rowland, Aziz, Tesauro, & Feuer, 2001; Stat Bite, 2004).

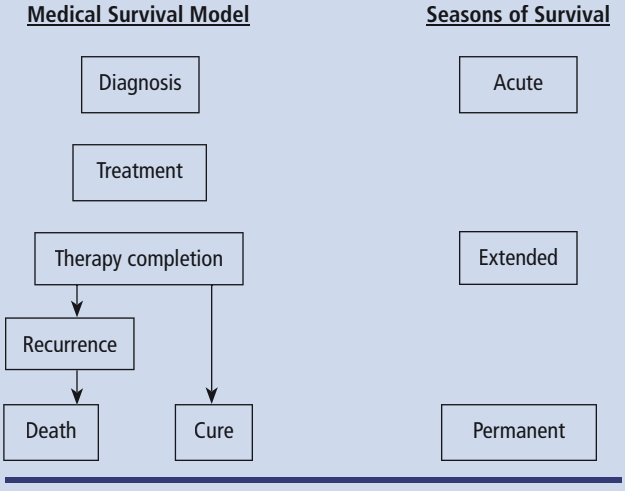

Figure 2-1. Comparison of the Medical Survival Model With Mullan's "Seasons of Survival"

- Over the past three decades, the number of cancer survivors has increased from three million in 1971 to 9.8 million in 2001.
- Sixty percent of adults and 77% of children diagnosed with cancer will survive more than five years.
- Fourteen percent of survivors were diagnosed more than two decades ago.
- Sixty percent of cancer survivors are age 65 or older.
- Approximately 71% of female cancer survivors have histories of breast, gynecologic, or colorectal primaries.
- Nearly two-thirds (63%) of male cancer survivors have had malignancies of the prostate, other genitourinary sites (e.g., testicular, renal), or the lower bowel (e.g., colon, rectum).
- Estimation of the numbers of secondary cancer survivors (i.e., family members) is unattainable.

Second, increasing concern over long-term effects of aggressive therapies instituted in the 1970s and early 1980s has warranted regard for the development of organ compromise and treatment-related second cancers (Matesich & Shapiro, 2003; Theodoulou & Seidman, 2003).

Little doubt exists that the number of Americans with and at risk for cancer will grow exponentially because of the increasing number of older adults, who are most vulnerable to cancer (Boyle, 2003a). This projection, along with continued progress in treating cancer, will engender a larger cohort of survivors who are living longer with a history of cancer (Yabroff, Lawrence, Clauser, Davis, & Brown, 2004). These survivors also will face an increased risk for the development of second and third malignancies (Kattlove & Winn, 2003). The prominence of coexisting chronic illness with advanced age may complicate early symptom recognition. Additionally, the ethnicity profile of survivors will change as American society grows into a more heterogeneous cultural mix. Attention to ethnicity profile is imperative as culturally prescribed norms may affect health-seeking behavior, symptom verbalization, self-care practices, and the provision of family support (Ashing-Giwa, Padilla, Tejero, & Kim, 2004; Dirksen & Erickson, 2002; Farmer & Smith, 2002; Gil-Fernandez et al., 2003). A paucity of studies have addressed cultural diversity within the construct of cancer survivorship (Aziz & Rowland, 2002; Gotay, Holup, & Pagano, 2002). Yet significant research is needed to plan post-therapy and long-term interventions, especially in the field of ethnogeriatrics (Baider et al., 2004; Schultz, Stava, Beck, & Vassilopoulou-Sellin, 2004).

The most comprehensive body of evidence concerning the physical and emotional ramifications of living with a history of cancer has focused on survivors who historically were the first to benefit from aggressive chemotherapy that evolved in the 1970s. These patient cohorts include childhood survivors of acute leukemia and young adult survivors of Hodgkin lymphoma and testicular cancer (Clift & Thomas, 2004; Fizazi, Chen, & Logothetis, 2002; Fleer, Hoekstra, Sleijfer, & Hoekstra-Weebers, 2004; Ganz, 2003; Hale et al., 1999; Jenkinson et al., 2004; Levin, Brown, Pawletko, Gold, & Whitt, 2000; Metayer et al., 2000; Mykletun et al., 2005; Nyandoto, Muhonen, & Joensuu, 1998; Shusterman & Meadows, 2000; Stevens, Mahler, & Parkes, 1998; Zebrack et al., 2002). More recently, survivorship following breast cancer has received considerable attention largely because of this malignancy's growing incidence and its prominence within public venues (Beaver & Luker, 2005; Ganz et al.,

2002, 2004; Lindsey, Waltman, Gross, Ott, & Twiss, 2004; Mandelblatt, Armetta, Yabroff, Liang, & Lawrence, 2004; Schover, 2004). General implications of surviving cancer can be imposed upon subsets of cancer survivors. However, more in-depth investigations are necessary to fully understand the scope and intensity of issues germane to tumor type, treatment, patient age, and a host of other variables (Kattlove & Winn, 2003).

Psychosocial Correlates of Surviving Cancer

In the late 1970s, Veronesi and Martino (1978) published their revelation of an unrecognized problem in the continuing management of cancer. They called attention to cancer's long-term social consequences and stressed the pervasiveness of patient anxiety and feelings of isolation during the latter phase of the cancer continuum. The prevalence and intensity of these issues frequently were underestimated by oncology professionals. These Italian cancer specialists made recommendations to reconfigure the long-term care of patients and address gaps in service. Of particular note was the following statement.

> One of the most important tasks of medicine and society is to do all that is possible to make the patient's life after treatment the most normal possible and similar to that led before the dramatic event. However, to obtain satisfactory results in this direction, a complete change of all the approaches to the problem of cancer would be necessary. (p. 349)

That same year, Woods and Earp (1978) published their findings of breast cancer survivors. They documented the relationship between persistent physical disability (e.g., lymphedema, restricted hand motion, reduced strength in the affected arm) and incidence of depression in women who were considered cured following mastectomy. The study also described an association between women's need to communicate their concerns and the families' desire to avoid such dialogue. Termed "conversational isolationism," this phenomenon exemplified how the women triggered emotional distress in their families by disclosing their fears about cancer recurrence and the possibility of dying prematurely. The families responded by deterring or avoiding these conversations, which ultimately left the women feeling isolated and without significant support during critical times of need. In a similar context, today's cancer survivors may be reticent to voice concerns that arise during long-term survival for fear of appearing less than grateful for their newfound positive bill of health (Turner et al., 2005).

At each phase of the cancer journey, coping challenges can be considered analogous to "parachuting into a jungle with no survival skills" (Ferrell & Dow, 1996, p. 76). With little or misleading information to guide adaptation, patients and families often face this life-threatening experience feeling ill-equipped to master this new challenge. The literature on emotional ramifications of coping during long-term survival following cancer can be clustered into seven themes. These include reactions of loss and grief, recurrence anxiety, feelings of isolation and abandonment, coping with transitional crisis, dilemmas associated with reentry and work, reevaluation of life priorities, and family coping. A number of mediating or enhancing factors influence these responses, such as patient age, family unit stability, degree of social support and spiritual orientation, evidence of concurrent family stressors, premorbid history of mental illness, nature and degree of role responsibilities, communication style, information requirements, and access to resources to aid coping (Ferrell, Smith, Juarez, & Melancon, 2003; Halstead & Fernsler, 1994; Matthews, 2003; Mellon, 2002; Mellon & Northouse, 2001; Sammarco, 2001; Sapp et al., 2003; Vachon, 2001; Varni, Katz, Colegrove, & Dolgin, 1994). Because quality of survival is in the eye of the beholder, it is imperative that survivors' needs are carefully and individually assessed (Leigh, 1992). This includes determination of interventions to enhance the quality of long-term survivorship and the identification of potential or real pathologies that may compromise continued coping (Hewitt & Rowland, 2002; Kornblith & Ligibel, 2003; Ross et al., 2003; Saleeba, Weitzner, & Meyers, 1996; Spijker, Trijsburg, & Duivenvoorden, 1997). "Flashing back," a survivor-specific emotional response similar to a post-traumatic stress disorder, also must be considered (Amir & Ramati, 2002; Carter, 1993; Kwekkeboom & Seng, 2002; Yehuda, 2002). Figure 2-2 lists coping agendas associated with long-term survivorship in relation to other phases of the cancer continuum.

Although nonpsychological implications of cancer survivorship are not the focus of this chapter, it must be emphasized that coping is appended to the incidence and intensity of physiologic long-term sequelae. The enduring demands of physiologic compromise can affect survivors' emotional status (Dorval, Maunsell, Deschenes, Brisson, & Masse, 1998; Redaelli, Stephens, Brandt, Botteman, & Pashos, 2004; Schimmer et al., 2001; Yabroff et al., 2004). Physiologic compromise includes both the effects of cancer therapy and the development of secondary cancers resulting from curative modalities (Bhatia & Sklar, 2002; Deniz, O'Mahoney, Ross, & Purushotham, 2003; Matesich & Shapiro, 2003; Syrjala et al., 2004; Theodoulou & Seidman, 2003). For example, the growing body of evidence concerning the prominence of fatigue following cancer therapy may influence the stamina required to cope during protracted survivorship (Bower et al., 2000; Cella, Davis, Breitbart, & Curt, 2001; Gelinas & Fillion, 2004; Gross, Ott, Lindsey, Twiss, & Waltman, 2002; Knobel et al., 2001; Mast, 1998a; Ruffer et al., 2003). Cognitive impairment, which may interfere with memory and interpersonal communication, has become a focus of study in the evaluation of adult long-term effects (Ahles & Saykin, 2001; Harder et al., 2002; Schagen, Hamburger, Muller, Boogerd, & van Dam, 2001; Tannock, Ahles, Ganz, & van Dam, 2004; Wefel, Lenzi, Theriault, Buzdar, et al., 2004). Knowledge resulting from neuro-oncology and other pediatric trials where cranial radiation was delivered has been applied to adult populations (Anderson et al., 2001; Brown et al., 2003; Challinor, Miaskowski, Moore, Slaughter, & Franck, 2000; Jansen, Miaskowski, Dodd, & Dowling, 2005; Lilja, Portin, Hamalainen, & Salminen, 2001; Meyers, Geara, Wong, & Morrison, 2000; Salminen et al., 2003). Most recently, cognitive impairment has been correlated with the receipt of adjuvant chemotherapy in women with breast cancer and also has been associated with long-term effects following bone marrow transplantation and immunotherapy (Ahles et al., 2002; Harder et al.; Kirkwood et al., 2002; O'Shaughnessy, 2003; Rugo & Ahles, 2003; Wefel, Lenzi, Theriault, Davis, &

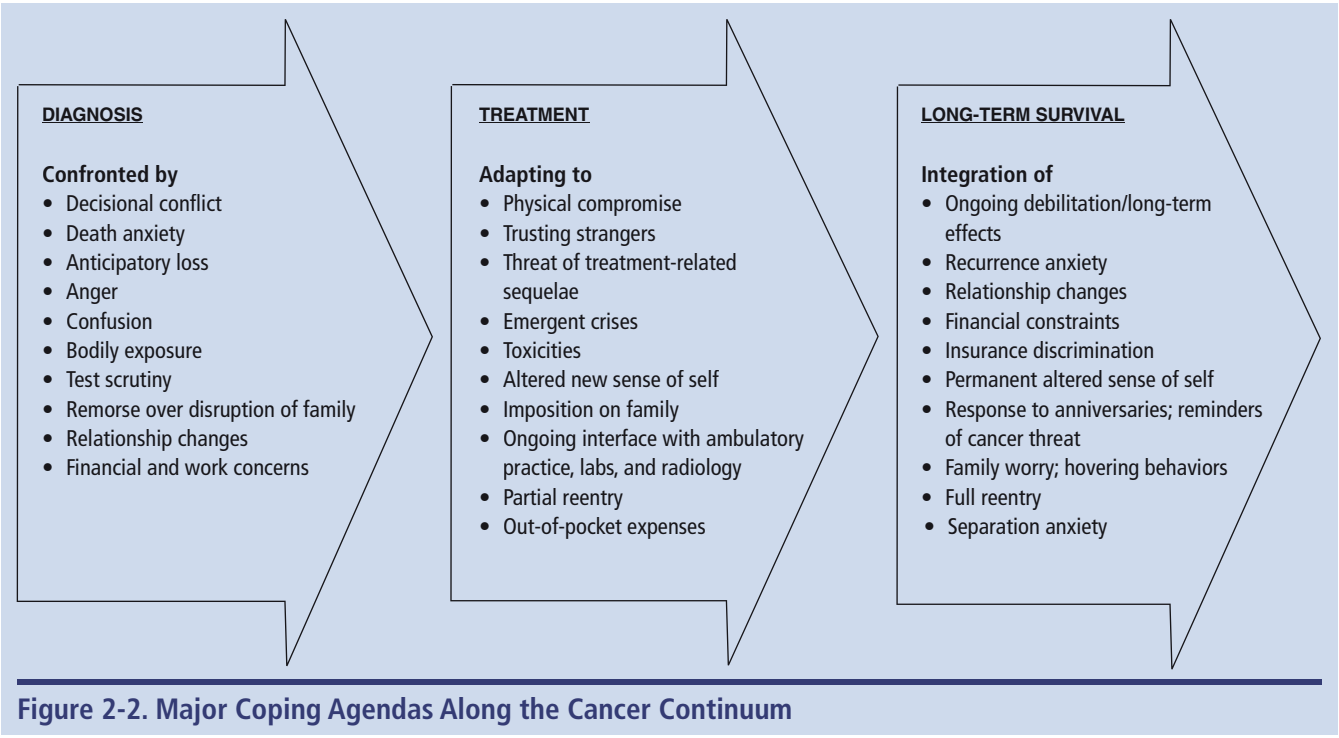

Figure 2-2. Major Coping Agendas Along the Cancer Continuum

Meyers, 2004). Subsequent information derived from ongoing clinical trials will further delineate how altered cognition affects long-term quality of life.

The course of patients' survival continuum influences coping. Consider the following trajectories as possibilities (Welch-McCaffrey, Hoffman, Leigh, Loescher, & Meyskens, 1989).

- Live cancer-free for many years
- Live many years cancer-free but die rapidly of a late recurrence
- Live cancer-free following the first cancer but then develop a second primary cancer
- Live with intermittent periods of active disease
- Live with persistent disease
- Live on after expected death

The psychosocial demands related to each of these trajectories impose unique burdens of anxiety, emotional lability, and fear in both survivors and their families. Uncertainty is a nebulous stress that frequently prompts these responses and predominates over time (Mishel, 1997; Nelson, 1996). Waiting, a major theme evident throughout cancer, prompts uncertainty and its resultant psychosocial sequelae (Gaudine, Sturge-Jacobs, & Kennedy, 2003; Wallace, 2003).

Loss and Grief

> Givens are no longer certainties; life is no longer infinite; health is no longer assumed. Death is not for someone else but for everyone. (A patient quoted in Lewis, 1993)

Loss is germane to the entire populace of cancer survivors. Although loss frequently is related to a concrete entity, such as a material possession, loved one, or body part or function, the conception of loss is much broader than this. It may relate to a diminished sense of oneself as healthy, fit, young, attractive, strong, adaptable, sexual, a compatible partner and provider, resourceful, dependable, or employable (Rudberg, Nilsson, & Wikblad, 2000; Wilmoth, 2001). Grief also may be voiced over the loss of how life used to be before the intrusion of cancer (Ferrell & Dow, 1996). Responses of grief and loss earlier in the cancer trajectory may transcend extended or permanent survival, especially if they were not addressed or resolved around their time of presentation. The acute treatment phase of cancer survivorship requires that targeted attention be focused on mastering the therapies employed to treat one's cancer and to adapt to the aftereffects of these therapies. Hence, some issues of loss and grief may have been discounted during this time frame. The reality of loss may only surface when treatment is completed and the permanence of cancer-imposed modifications become realized. Some patients describe this phenomenon as surreal, almost dreamlike, as the acuity and intensity of earlier phases of cancer treatment preclude one's true grasp of what transpired.

Because children and young adults were the focus of early research about survivorship, reproductive compromise has generated considerable interest over time. Loss of fertility in the prime of life has been deemed a significant consequence of successful treatment for cancer (Averette, Mirhashemi, & Moffat, 1999; Huyghe et al., 2004). Despite decades of study, conflicting reports prevail about the potential of conception following aggressive cancer therapy, particularly with alkylating antineoplastics and pelvic fields of radiation (Aisner, Wiernik, & Pearl, 1993; Moore & Foster, 2000; Puscheck, Philip, & Jeyendran, 2004). Additionally, the long-term emotional ramifications of infertility have not been fully explored (Braun, Hasson-Ohayon, Perry, Kaufman, & Uziely, 2005; Weigers, Chesler, Zebrack, & Goldman, 1998; Zebrack, Casillas, Nohr, Adams, & Zeltzer, 2004). Safety concerns of pregnancy following successful treatment of a hormone-related tumor continue to be debated (Blakely et al., 2004; Surbone & Petrek, 1997).

Ethical dilemmas also may arise as the mother's longevity and health of the fetus are deliberated (Kenney et al., 1996; Petrek, 1994).

Recurrence Anxiety

> I still don't renew subscriptions for three years, just annually. (A patient quoted in Wyatt, Kurtz, & Liken, 1993)

Recurrence anxiety is worry focused on the possibility that the cancer will return. It is a pervasive and, at times, overwhelming dread experienced by families as well as patients (Dow, 1992; Welch-McCaffrey et al., 1989). It is the coping response that all survivors can expect to experience. Recurrence anxiety can be described as, "Walking through life with a dark cloud hanging over your head, never knowing if or when the cancer will recur," or "Sitting on a powder keg waiting for it to go off" (Schmale et al., 1983, p. 166). Early work by Shanfield (1980) described the cancer experience.

> The experience of having had cancer is a permanent one, characterized by an easy access to the initial affect associated with the illness and the recovery period, a continuing concern about one's mortality, and an enduring sense of vulnerability. (p. 133)

The usual pattern of recurrence anxiety is erratic with the exception of the immediate period following treatment completion. The first year following therapy cessation generally is associated with the most intense concerns about recurrence (Cella & Tross, 1986; Fobair & Mages, 1981; Hayden et al., 2004; Kornblith & Ligibel, 2003). Recurrence anxiety resurfaces when unusual symptoms are noted and at times of health surveillance and follow-up (Boyle, 1999; Vickberg, 2001; Wenzel et al., 2002). It can produce two distinct behaviors. Hypochondriasis may evolve, as the survivor suspects that any somatic change or new symptom portends the cancer's return. Recurrence anxiety also can elicit avoidance behaviors whereby physician contact is circumvented for fear that physical follow-up could diagnose the malignancy's reappearance. Episodic worry incited by symptom suspicion, return doctor visits, or exposure to fellow survivors with progressive cancer can evoke chronic anxiety in cancer survivors (Powel & McFadden, 1995). Recurrence anxiety also may prevail in families, prompting "hovering behaviors" and persistent scrutiny of the survivor's physical status. This may solicit conflict within the couple or family unit as the survivor attempts to minimize or dismiss cancer's presence in his or her life while the family maintains focus on its possible return. However, over time, recurrence anxiety usually diminishes, with periodic episodes resurfacing around physician visits and the presence of unusual somatic complaints (Gil et al., 2004; Langeveld, Grootenhuis, Voute, de Haan, & van den Bos, 2004).

Isolation and Abandonment

> I also cried because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned and terrified. This was the rocky beginning of cancer survivorship for me. (A patient quoted in McKinley, 2000)

The aloneness associated with survivorship can be a horrific part of the cancer journey (Bushkin, 1993). The sense of detachment may emanate from feeling different, uniquely vulnerable, or stigmatized. It also may originate from survivors' fears that their social support network will withdraw or ultimately detach completely (Pedro, 2001). Ambulatory, healthy-appearing survivors may be refused the intensity of indulgence given initially around diagnosis and active therapy. Yet ongoing emotional concerns may persist long term.

As therapy ends, survivors may experience separation anxiety (Lethborg, Kissane, Burns, & Snyder, 2000; Ward, Viergutz, Tormey, DeMuth, & Paulen, 1992). This distancing from the treatment team can be quite traumatic. Although patients generally are happy about completing therapy, the lack of contact with and exposure to the treatment team frequently prompts concern. With close contact gone, worry may emanate about whom to go to with questions or concerns, especially if the fear of recurrence predominates. Recurrence anxiety is especially intense in the absence of active therapy to manage the malignancy.

Relationship changes may ensue in both social and intimate contexts. Family caregivers may not anticipate being stigmatized in their own social circles (Boyle et al., 2000). Friends and coworkers may treat family members differently based on their proximity to the person facing life-threatening cancer. One wife reported, "When I returned to work after my husband's treatment was over, my coworkers acted like I was the one who had cancer. They avoided me like the plague" (H. Katz, personal communication, 1994). Identification with the family member may prompt an existential crisis heralded by the predominance of death anxiety, highly correlated with a diagnosis of cancer (Amir & Kalemkerian, 2003; Rawnsley, 1994).

> Our fear of death makes it essential to maintain a distance between ourselves and anyone who is threatened by death. Denying our connection to the precariousness of others' lives is a way of pretending that we are immortal. Yet, cancer connects us to one another because having cancer is an embodiment of the existential paradox that we all experience: We feel that we are immortal, yet we know that we will all die. (Trillin, 1981, p. 699)

Alterations in intimacy and sexuality also enhance feelings of isolation (Dorval, Maunsell, Taylor-Brown, & Kilpatrick, 1999; Dow, 1995; Ganz, 2001; Ganz et al., 2002; Zebrack, Casillas, et al., 2004). Unable to decipher the root cause of change as being fatigue, worry, or newfound unattractiveness, both survivors and family members despair that the security associated with prior close relationships may be permanently jeopardized. Hence, at a time when both the survivor and primary caregiver need support and emotional connectivity, detachment rather than closeness may become the norm.

Transitional Crisis

> He just doesn't seem as though he can forget about it and just lead a normal life. It's curtailing our life. It's something I wish that he would get over but I don't think that he is going to. (Family member quoted in Little, Paul, Jordens, & Sayers, 2002)

A transition implies moving from one relatively stable state, with an experience of disorganization and upheaval during the process, toward another stable state (Clarke-Steffen, 1993). Transitions generally are considered stressful because they impose adaptational challenges, evoke anxiety, and require a period of readjustment (MacLean, Foley, Ruccione, & Sklar, 1996). It has been widely acknowledged that chronically ill children require help with major life transitions (Hobbie & Ogle, 2001; Konsler & Jones, 1993). Developmentally tailored clinics, educational workshops, and outreach community-based support provide interventions to master new transitions within the context of pediatric oncology. However, comparable needs of adults transitioning through various phases of illness are infrequently acknowledged.

Major adjustments within the cancer experience include changes in one's sense of self from well person to sick patient (upon cancer diagnosis), ill patient to well person (upon successful completion of therapy), and episodic well person to ill patient (when follow-up testing is performed, reinforcing the sick role during intermittent hospitalizations, or when recurrence becomes a suspicion or is diagnosed). Additionally, age-specific implications of survivorship must be considered as supportive care interventions are planned (President's Cancer Panel, 2004; Utley, 1999; Weekes & Kagan, 1994). Table 2-1 outlines some examples of developmental challenges during various periods of transition in survivorship.

Another major transition for all survivors and their loved ones has received attention primarily in pediatric oncology settings. The family unit's attempts to "get back to normal" following treatment are, in fact, impossible. The intrusion of cancer causes permanent change in how survivors and families respond and cope. A new norm must be constructed for the family unit to move forward (see Figure 2-3). Families facing cancer must reconstruct reality and change its future orientation, manage information, assign meaning to illness, reorganize roles, manage therapeutic regimens, and evaluate and shift priorities (Clarke-Steffen, 1993). Although originally designed to depict family coping requirements during childhood cancer, this model has equivalent meaning within the adult cancer experience.

Reentry and Work

I lost my breast, not my brain. (Anonymous)

Regardless of age, some degree of cancer-related stigma should be expected and frequently makes reentry problematic. Going back to school is considered a stressful time for children with a history of cancer that is well served by professional support and advocacy, whereas adults are expected to return to work and family life without comparable aid.

Reestablishing oneself back into precancer lifestyle norms may occur gradually during the course of active cancer therapy or abruptly following completion of treatment depending upon individual requirements for hospitalization and recovery. Coworkers and colleagues usually expect compromise in physical functioning during active therapy but may be unaware of comparable needs long term. Survivors themselves may have misconceptions about their ability to resume pretreatment work patterns following treatment. Even young adult, childhood, and adolescent cancer survivors have noted work- and school-related functional impairment upon reentry. Needing to work fewer hours, taking on lighter job responsibilities, or requiring more frequent breaks are a few examples of adaptations required (Bloom et al., 1993; Helder et al., 2004; Joly et al., 1996).

Concern over employment discrimination is significant (Boyle, 1996). Discrimination in the workplace may include "shunning," a concerted effort to avoid contact with the survivor (Berry, 1993). Feeling "job lock" (the inability to pursue other employment options as a result of cancer-related bias) and problems with obtaining health insurance or experiencing a loss of benefits are real concerns for cancer survivors (Christ, Lane, & Marcove, 1995; Langeveld et al., 2004). Survivors may be bypassed for promotions or job transfers because they may be considered incapable or have questionable longevity. Additionally, job termination remains a fear in today's workplace (Schultz, Beck, Stava, & Sellin, 2002). Regardless of positive trends in dispelling myths about survivors' work performance, many supervisory personnel continue to believe that upon return to work, survivors may no longer be able to perform their job adequately or may not take their job seriously (Stat Bite, 1993). More than one-half of patients with cancer ultimately will survive long term, yet it appears that many employers remain entrenched in the old paradigm that equates cancer with a death sentence. The Americans with Disabilities Act (ADA) can protect survivors from discriminatory practices by employers and can lobby for accommodation of disability in the workplace (Bradley & Bednarek, 2002; Hoffman, 1997). Yet, the ADA's power to eliminate discrimination rarely has been tested (Arnold, 1999). As perceptions change about the uniform lethal nature of cancer, so may work-related stigma. Recent reports of the absence of discrimination at work are indeed promising (Maunsell et al., 2004).

Reevaluating Life Priorities

Face it. You've got to be like me to really appreciate how silly it is to read a letter from Dear Abby's column about a

Table 2-1. Developmental Challenges During Transitional Crises in Survivorship

AGE GROUP	PARENTAL SEPARATION	SURVIVOR GUILT	REENTRY	ROLE CHANGE	DISCRIMINATION/ISOLATION
Pediatrics	X		X		X
Adolescence	X	X	X	X	X
Young Adult	X	X	X	X	X
Middle Age		X	X	X	X
Older Adult		X		X	X

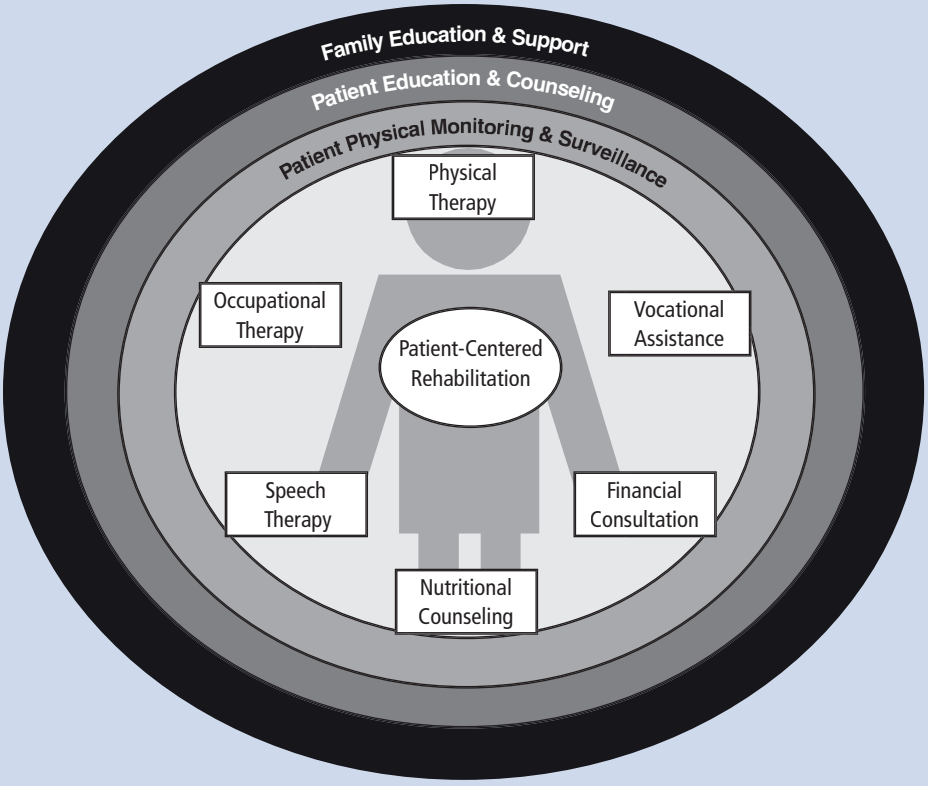

Figure 2-3. Elements of Rehabilitative Interventions to Enhance Long-Term Cancer Survival

> woman upset because her neighbor hasn't returned her salad bowls. It's like, "Oooooh lady, how can you stand it?" (Bombeck, 1989, p. xxi)

Empirical evidence exists about the positive nature of living through and beyond cancer. The threat of death followed by recovery often prompts cancer survivors to reexamine life's meaning. Deemed a secondary benefit of having cancer, life review frequently reconfigures personal measures of quality of life (Gotay, Isaacs, & Pagano, 2004). Life review often results in minimization of minor anxieties that, following diagnosis, appear inconsequential when compared to the threat of cancer (Maher, 1982; Tomich & Helgeson, 2002). A philosophic reflection on the meaning of life may result in the reexamination of the role of spirituality in everyday life, past coping styles, and precipitants of emotional crisis (Vickberg et al., 2001). Younger survivors may find this introspection most beneficial (Schroevers, Ranchor, & Sanderman, 2004).

Family Coping

> We do a lot of waiting, a lot of resting, a lot of waiting and a lot of resting. When you love someone, you just kind of hang in there and let whatever the course is take hold. (Family member quoted in Boyle et al., 2000)

Cancer is a family disease (Boyle, 2003b; Moulton, 2000; Rowland et al., 2001). Considered "secondary survivors," families have unique issues and provocations as they cope with life after cancer (Boyle et al., 2000; Mellon, 2002). Families must integrate and synthesize information often of a secondhand nature, monitor and supervise ongoing care requirements, and worry in isolation about what the future holds. Guilt may prevail. (Could I have recognized the symptoms earlier? Should I have forced him to go to the doctor even though he resisted? How could I have been so consumed with the kids that I did not see his weight loss?) These enduring feelings can plague families long term. Families experience frustration and feel isolated, confused, and tired in response to the competing demands of providing usual family care in conjunction with accommodating survivor needs. More in-depth investigation of family issues during survivorship is required because the future portends the addition, rather than the detraction, of caregiving expectations that are imposed on families.

Intervention Considerations

To address the perception of being "caught in a black hole of system unresponsiveness," more comprehensive care is required for adult survivors in both the extended and permanent phases of survival (Belec, 1992; Gray, 1992). Such care should model programs that are offered for cardiac and stroke rehabilitation because these illnesses are considered chronic conditions rather than fatal ones. Follow-up care should be more than the routine testing that currently is provided to detect recurrence, second primaries, or other complications (Beaver & Luker, 2005; Bhatia & Sklar, 2002; Deniz et al., 2003; Matesich & Shapiro, 2003).

Just as cancer treatment is tailored to patients' needs within acute survival, follow-up care also should be customized and individualized. In many cases, interventions during permanent survival will be comparable to what is provided during extended

survival. Hence, interventions appropriate to both of these phases require contemplation.

Follow-up care should be rendered as an extension of services provided by the cancer care team. This team, unlike community-based generalists, knows the survivor over time and the natural history of the malignancy (Adewuyi-Dalton, Ziebland, Grunfeld, & Hall, 1998; Oeffinger et al., 2004). This continued relationship with the core team fosters trust and enhances communication as a result of the longevity of this affiliation. Some new healthcare providers with complementary skills and knowledge will need to be added to the team during extended and permanent survival (e.g., physical therapist). Of benefit is the review of pediatric follow-up programs that have been operational for decades and thus may serve as a template for adult-focused program development. The specific domains within extended and permanent survival that require intervention include (Kattlove & Winn, 2003)

- Surveillance to detect recurrent cancer
- Assessment of genetic susceptibility to cancer (both survivors and family members)
- Detection of a second primary malignancy
- Monitoring of treatment complications
- Dealing with physiologic alterations related to cancer or its treatment
- Support for psychosocial problems.

Again, separation of physiologic and psychosocial issues is formidable. Thus, comprehensive follow-up programs that offer myriad interventions during protracted survival are required (Boyle, 2003b). Any attempt to provide novel follow-up services for adult survivors must be accompanied by companion assistance for families. Additionally, data that demonstrate value-added benefit, cost effectiveness, and improved quality-of-life outcomes will substantiate program viability.

Physiologic Surveillance

Planning for monitoring physiologic problems during survivorship should be tumor-, treatment-, and age-specific. Tumor-related issues pertain to the natural history of the malignancy with specific concern about metabolic compromise, usual patterns of metastases, and recurrence trajectories (Emens & Davidson, 2003; Mahon, Williams, & Spies, 2000; Nuver, Smit, Postma, Sleijfer, & Gietema, 2002; Svobodnik et al., 2004). Consideration of tumor type and cancer stage is important because it influences both the type and frequency of surveillance. Treatment type dictates surveillance of specific organs or physiologic processes (Theodoulou & Seidman, 2003). Age-related factors may heighten awareness of comorbidity in symptom presentation. Both empirical and evidence-based findings have driven recommendations for follow-up care (Christianson & Anderson, 2003; Evans, 2002; Kattlove & Winn, 2003; Kondagunta, Sheinfeld, & Motzer, 2003; Meyerhardt & Mayer, 2003; Patel, Zagars, & Pisters, 2003; Pfister, Benson, & Somerfield, 2004; Smith, 2003; Vaughn, Gignac, & Meadows, 2002; Vaidya & Curtin, 2003; Wooldridge & Link, 2003; Yao & DiPaola, 2003). As a result of the growing volume of breast cancer survivors, most research has focused on their long-term symptom distress and requirements for continued follow-up care (Bottomley et al., 2005; Burstein & Winer, 2000; Carpenter et al., 2004; Chlebowski, Kim, & Col, 2003; Collins, Bekker, & Dodwell, 2004; Emens & Davidson; Eversley et al., 2005; Mast, 1998b; Partridge, Winer, & Burstein, 2003; Schover, 2004; Utley, 1999). Testing of these recommendations is necessary to formulate evidence-based guidelines that provide cancer care providers with an organized strategy for surveillance (Ganz, 2001; Loprinzi, 1995). Such guidelines would dictate the timing of physiologic examination, the type and scope of diagnostic testing and screening evaluations, and the nature of needed psychosocial support.

Psychosocial Support

Emotional, family, and work-related concerns must be addressed with comparable rigor as physiologic compromise. A broader range and frequency of interventions will be required during the "first year out" as the stresses of reentry and recurrence anxiety predominate during this time frame (Boyle, 1999). The provision of psychosocial support generally depends more upon survivor preference and acceptance than on physiologically based surveillance interventions. Possible support options within the psychosocial realm include the following.

1. Educational forums to minimize uncertainty, dispel misconceptions, and enhance coping skills during long-term survival should be offered with equal intensity as those provided prior to the initiation of new cancer therapy (Mullan, 1984). These offerings may include individual sessions, workshops, and small group teaching for both survivors and families. Additionally, written and Internet-based materials from reputable sources that address expectations during survivorship are needed to augment formal teaching sessions (Boyle, 1999; Sharp, 1999; Tesauro, Rowland, & Lustig, 2002).
2. Counseling to enhance mastery of common emotional sequelae is germane to long-term survivorship. Individual sessions, groups, marital counseling, and peer support for both survivors and families are required. Anticipation of survivor-specific coping themes (e.g., recurrence anxiety, reentry problems, workplace discrimination, infertility, relationship changes) is important. By emphasizing personal strengths and the benefits of positive reappraisal, quality of life can be improved (Dorval et al., 1999; Dow, 1995; Fiore, 1979; Kessler, 2002; O'Connor & Wicker, 1995; Rauch, Miny, Conroy, Neyton, & Guillemin, 2004; Welch-McCaffrey et al., 1989).

Issues related to planning physiologic follow-up and psychosocial care present uncertainty, such as when to educate the patient and family about post-therapy expectations. In cases where education regarding survivor issues was provided prior to the end of treatment, the majority of patients frequently did not remember the content of these discussions (Boyle et al., 2000). Around the end of active therapy, patients and families may be consumed with getting through treatment; hence, reception of new information about life after treatment may be limited. Patients thus require significant reinforcement of teaching and should not be expected to easily retain information about follow-up care.

Finally, long-term screening of adults with a history of childhood cancer remains in question. The questions of how much, how long, and by whom require answers along with factors that promote adherence with surveillance guidelines (Kadan-Lottick et al., 2002; Yeazel et al., 2003; Zebrack, Eshelman, et al., 2004).

Rehabilitation Programs

Within the auspices of health promotion and wellness resides an important but neglected opportunity to foster living well with a history of cancer—rehabilitation. In considering the acceptance of rehabilitation as a component of follow-up care for patients with cardiac disease, the absence of such in cancer care suggests pervasive negativism and bias about the utility and efficacy of rehabilitation.

Rehabilitation is the bridge that leads a person from a condition of diversity to a condition of normality (Veronesi & Martino, 1978). It is a practical attempt to maximize independence and dignity in individuals who have had cancer (Watson, 1992). A rehabilitation program for cancer survivors should be individually planned with attention to minimizing deficits and reinforcing strengths (Mellette, 1993). Its correlation with improved long-term outcomes requires intensive study (Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005). Some rehabilitation interventions include (see Figure 2-3)

- Physical, occupational, and speech therapy
- Psychosocial, vocational, financial, and nutritional counseling.

Additional rehabilitation team members augment the expertise of the cancer team with the use of their specialty knowledge (Wells, 1990). For example, physical therapists can address deconditioning and reduced endurance while increasing strength and compensating for functional decline. Nutritional counselors can foster a sense of control to navigate survivors toward long-term wellness (Chlebowski, 2003; Demark-Wahnefried & Rock, 2003). Occupational therapists can recommend energy-conserving techniques in the home to decrease debilitating fatigue. Attention to issues involved with returning to work is an important component of societal reintegration of cancer survivors (Spelten, Sprangers, & Verbeek, 2002). Programs that focus on recovery give survivors and caregivers a strong message of hope. These programs acknowledge that living on following a cancer diagnosis is a realistic option. Education, emotional support, and exercise with intensive follow-up can foster patients' quality of life while contributing to physiologic and psychosocial wellness (Courneya & Friedenreich, 1999; Courneya et al., 2003; Cox & Wilson, 2003; Gambosi & Ulreich, 1990; Jacobs & Hobbie, 2002; Pinto, Eakin, & Maruyama, 2000; Pinto & Maruyama, 1999; Pinto & Trunzo, 2004). This becomes increasingly important as cancer survivorship becomes recognized as a distinct clinical entity within cancer care (Kattlove & Winn, 2003).

Research

Evidence is required to drive innovation within the survivorship paradigm. Acknowledging the critical role of family survivors in the research agenda is imperative (Moulton, 2000). The trend of heightened acuity and greater intensity of cancer therapies will require continued investigation of the long-term burden of cancer and its treatment (Schimmer et al., 2001; Yabroff et al., 2004). Positive outcomes of survivor research can enhance lobbying for programmatic insurance coverage when reduced debilitation and quicker return to work can be quantified. Figure 2-4 lists some examples of research questions that require attention. Investigation of these issues is best served by interdisciplinary inquiry and research designs, and consensus with primary and secondary survivors on the meaning of findings. Concern about special, at-risk survivor populations also mandates investigation of oncology nurses and physicians who themselves survive cancer or survive the cancer experience as family members (Welch-McCaffrey, 1984). How this personal experience impacts professional retention and interaction with patients and families requires extensive study.

Conclusion

Survivorship is the challenge faced daily by millions who are engaged in defiance of cancer and in the affirmation of life (Mullan, 1996). In a variety of instances, however, advances in cancer therapies have added years to life but not necessarily life to years. The dilemmas and challenges of survivorship are multiple and require significant practice innovations based on the science of research findings. In today's cancer care paradigm, survivorship is a life lived in a context of evolving knowledge (Little et al., 2002).

Survivorship is a nurse-intensive phenomenon (Ferrell, Virani, et al., 2003). Oncology nurses are a critical influence on patients'

- Quality of life related to
  - Impact of various therapies long term
  - Baseline performance status and prognostic indicators
  - Surviving second cancers
  - Ethnicity
  - Socioeconomic status
  - Marital status
  - Presence of concurrent comorbid illness
- Long-term effects on families
- Education and support preferences based on age, "time out" post-therapy completion, and type of treatment
- Scope and nature of employment and workplace barriers to successful reentry
- Impact of nurse-led education, support, and surveillance during patient transition into the phase of extended survival
- Impact of intensive psychosocial follow-up with patients having pre-cancer histories of emotional illness
- Recurrence anxiety
  - Prompts and reinforcers for health-seeking behaviors and health surveillance
  - Characteristics over time
  - Patient variables associated with hypochondriasis and physician avoidance

Figure 2-4. Themes for Cancer Survivor Research Focusing on Psychosocial Challenges

Note. Based on information from Dow, 2003; Gibson, 2004; Gotay & Muraoka, 1998; Helder et al., 2004; Lindsey et al., 2004; Moore et al., 2002; Svobodnik et al., 2004.

ability to transition through the cancer continuum. Wilmoth (2001) described one element of this as helping survivors to move to a new level of equilibrium following a cancer-related crisis. Both patients and families who evolve through the cancer trajectory could benefit from the long-term support, education, and advocacy that the same oncology nurses they trusted in earlier phases of their cancer experience could provide during long-term survivorship. This, however, requires oncology nurses to expand their body of knowledge to encompass the recognition and management of unique issues pertinent to living with a history of cancer. In the future, its significance will grow as education, support, advice, symptom scrutiny, and a holistic orientation to care for survivors and their families will be expected. Poletti (1985) poignantly described that the role of the oncology nurse is to help the patient to be a fully functioning person first and a patient with cancer second. This is the essence of nursing expertise and scholarship following life after cancer.

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