

# Adaptation of the Illness Trajectory Framework to Describe the Work of Transitional Cancer Survivorship

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**T**o date, cancer survivorship has been conceptually limited. Concept analyses have revealed a need for clarification of conceptual and operational definitions of cancer survivorship (Doyle, 2008; Farmer & Smith, 2002).

The prevailing definition of survivorship comes from the National Coalition for Cancer Survivorship (1986), which labeled anyone who had received a cancer diagnosis as a survivor from that point forward. The period of survivorship immediately following completion of cancer treatment often is described in terms of significant absences—absence of treatment, absence of the treatment team, and, importantly, absence (or remission) of the cancer itself (Breaden, 1997; Dow, 2003; Institute of Medicine [IOM], 2006). Many survivors feel powerless during this period (Armstrong, 2001; Breaden, 1997; Carr, 2004; Pelusi, 1997) and some experience conflicting emotions resulting in psychological distress (Dow, 2003; Doyle, 2008; Ferrell & Hassey, 1997; IOM, 2006; Mellon, Northouse, & Weiss, 2006). Despite these stark psychological profiles, survivor and caregiver roles immediately following treatment are not described clearly; this contrasts with clear activity descriptions during cancer treatment. During treatment, survivors and their caregivers generally are depicted as engaged in a series of well-defined tasks necessary for successfully adhering to prescribed therapies and achieving treatment goals (Given & Sherwood, 2006; IOM, 2006). Successful transition from active cancer treatment to life following treatment has been shown to be a significant predictor of future outcomes, particularly survivors' and caregivers' psychological and emotional health (Cheng, Thompson, Ling, & Chan, 2005; Deimling, Sterns, Bowman, & Kahana, 2005; Ferrell & Hassey, 1997; Mellon et al., 2006). Understanding patients' and caregivers' work during active treatment or palliation has facilitated the development of important models of cancer care associated with improved outcomes among these survivors and their families (Gaugler et al., 2005; Given & Sherwood,

**Purpose/Objectives:** To examine and refine the Illness Trajectory Framework, and to address transitional cancer survivorship.

**Data Sources:** CINAHL<sup>®</sup>, PubMed, and relevant Institute of Medicine reports were searched for survivors' experiences during the year following treatment.

**Data Synthesis:** Using an abstraction tool, 68 articles were selected from the initial search (N > 700). Abstracted data were placed into a priori categories refined according to recommended procedures for theory derivation, followed by expert review.

**Conclusions:** Derivation resulted in a framework describing the work of transitional cancer survivorship, defined as survivor tasks, performed alone or with others, to carry out a plan of action for managing one or more aspects of life following primary cancer treatment. Theoretically, survivors engage in three reciprocally interactive lines of work: (a) illness-related, (b) biographical, and (c) everyday life work. Adaptation resulted in refinement of these domains and the addition of survivorship care planning under "illness-related work."

**Implications for Nursing:** Understanding this process of work may allow survivors and those who support them to better prepare for the post-treatment period. This adaptation provides a framework for future testing and development. Validity and utility of this framework within specific survivor populations also should be explored.

2006; Kozachik et al., 2001; Northouse, Kershaw, Mood, & Schafenacker, 2005). Models developed to describe the work of cancer survivors and their support people during the transitional survivorship period, which follows cancer treatment, can similarly guide research and practice interventions.

## Theory Derivation Procedures

Theory derivation is an iterative process that can be useful when an existing theory would benefit from refinement in light of new knowledge or evolution of a concept, such as cancer survivorship (Botes, 2002;

Walker & Avant, 2011). After selecting a phenomenon of interest, a parent theory must be selected that might successfully guide conceptual refinement. "The theorist borrows, modifies, and redefines relevant concepts and structures from the parent theory, to become meaningful within the context of the theorist's area of interest" (Pedro, 2010, p. 80). The parent theory selected to guide this theory derivation process was the Illness Trajectory Framework (Corbin & Strauss, 1988). In addition to the landmark IOM reports *From Cancer Patient to Cancer Survivor: Lost in Transition* (IOM, 2006) and *Cancer Care for the Whole Patient* (IOM, 2008), the CINAHL® and PubMed databases and major cancer journals such as *Oncology Nursing Forum* and *Seminars in Oncology* were searched for articles in the English language with abstracts containing keywords such as *cancer* or the Medical Subject Headings term *neoplasm* and the root *survivor* (as in *survivors* or *survivorship*). More than 700 articles initially were identified. Abstracts were reviewed for original research, systematic reviews of the literature, or expert opinions describing outcomes or activities occurring during the transitional survivorship period beginning around the time of completion of primary cancer treatment and extending through the first year of survival (Miller, Merry, & Miller, 2008). This is a period of adjustment considered highly heterogeneous among cancer survivors, as some continue with adjuvant treatments or recommended therapies, whereas others enter into a period of watchful waiting. Transitional survivorship has been characterized as a phase when, "the medical team is less involved, relief and celebration may be mixed with feelings of isolation, and depression is common" (Miller et al., 2008, p. 372). Articles that focused specifically on populations with advanced cancer, cancer recurrence, or the end of life were excluded, as these groups tend to experience illness trajectories that can differ substantially from patients treated for their first diagnosis of an early-stage cancer (Murray, Kendall, Boyd, & Sheikh, 2005). An abstraction tool was used to classify articles by research design, subject matter, population, cancer type, cancer trajectory phase, and type of survivorship work or activity described. A total of 68 articles were abstracted. Tasks identified with survivorship were placed into preliminary categories based on a broad interpretation of the Illness Trajectory Framework. Tasks that did not appear to fall directly into any of the a priori categories were placed into new categories. Reference lists from abstracted articles, relevant practice guidelines, and survivorship textbooks, along with focused searches within CINAHL and PubMed, then were used to identify additional resources to more fully describe categories within the derived framework.

The resulting theory derivation underwent three cycles of expert review. The first review was conducted with a group of staff oncology nurses at a National

Cancer Institute–designated comprehensive cancer center. The derived framework was presented to the nurses, who were invited to provide feedback regarding its appropriateness and potential utility for patients, families, and clinical staff. Revisions to the framework were made accordingly and presented before a group of doctoral-prepared nurse researchers and doctoral students who provided additional feedback on the theoretical dimensions of the framework and the theory derivation process. Finally, the framework was presented to a group of oncology nurses in senior research and administrative positions within the cancer center and associated nursing research centers.

## Parent Model: The Illness Trajectory Framework

In their classic study of chronic illness management, Corbin and Strauss (1985, 1988) conducted in-depth, unstructured interviews with 60 couples managing chronic illnesses or disabilities in the community setting. The aim of their grounded theory was to examine the different types of work involved in managing an illness at home over time, as well as how the tasks were done or not done, by whom, under what conditions, and with what consequences (Corbin & Strauss, 1985, 1988). Their focus on the work of patients and their caregivers was prompted by the recognition of the largely invisible nature of this work to clinicians and in the medical record (Star, 1995; Strauss, Fagerhaugh, Suczek, & Wiener, 1982). Corbin and Strauss (1988) initially defined the work of chronic illness management as, "a set of tasks performed by an individual or a couple, alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of the illness and the lives of ill people and their partners" (p. 9). The resulting framework, called the Illness Trajectory Framework, distinguishes between three interconnected and reciprocally interactive types of work entailed by chronic illness: illness-related work, biographical work, and everyday life work. Application of the framework to the experiences of caregivers and patients with conditions such as Alzheimer disease and HIV has yielded fresh insights and potential solutions to familiar challenges in chronic disease management (Bresalier et al., 2002; Star, 1995).

### Dimensions of the Model

**Illness-related work:** The focus of much of the current research on chronic illness management, illness-related work refers to the tasks necessary to manage or treat a chronic illness and its sequelae, such as symptoms, disability, or loss of function, including but not limited to: regimen work, crisis prevention and handling, symptom management, and diagnostics (Corbin & Strauss, 1988).

**Biographical work:** Defining and maintaining an identity over the course of a life is a person's biographical work. Illness can cause serious disruption to a person's biography. The Illness Trajectory Framework assumes that conditions impacting a person's biography include life stage; salient aspects of self loss that arise during illness; and a person's ability to adapt, come to terms with losses, and move on. Therefore, as Corbin and Strauss (1988) explained, "illness management must be examined in the context of that more encompassing life" (p. 10). Corbin and Strauss (1988) identified four basic biographical processes that occur in the context of chronic illness: (a) contextualizing (i.e., making the illness part of ongoing life); (b) coming to terms with the illness, its consequences, and one's own mortality; (c) restructuring one's self-concept; and (d) recasting one's biography into the future.

**Everyday life work:** Everyday life work covers the remaining work context in which biographical and illness work occur. It is defined as "the daily round of tasks that helps keep a household going" (Corbin & Strauss, 1988, p. 90). That work includes concrete, externally focused tasks such as bill-paying, shopping, driving, cooking, and cleaning, as well as internal tasks, such as managing stress, anxiety, and emotion. Finally, management in process involves the articulation work of organizing and coordinating "the varied types of work that are necessary to operationalize any plan of action, be it the management of illness or the building of a house" (Corbin & Strauss, 1988, p. 11). Although some of this work can be planned for, unexpected contingencies inevitably arise (Corbin & Strauss, 1985) and may impact chronic illness management work.

## Adaptation of the Model for Cancer Survivors

Cancer survivorship does not occur in a vacuum. Rather, survivors and their families experience their cancer journeys in the context of changing lives and communities. Although researchers often focus on the illness-related or self-care efforts of patients and caregivers, the broader context in which this work occurs often is lost (Bresalier et al., 2002). More importantly, the coordination or negotiation required to complete health-related tasks often is unacknowledged in spite of the resulting impact on health, quality of life, and survivorship outcomes. The overall concept of chronic illness work extends not only to the self-care or cancer treatment efforts of survivors and caregivers, but to all aspects of their lives. Symptom management, performance of formal and informal roles, household and relationship maintenance, and even identity construction are included in this work.

## Illness-Related Work

Even after primary cancer treatment (in the form of surgery, radiation, chemotherapy, and other pharmaceutical interventions, or some combination thereof), illness work remains substantial (see Table 1). However, this work also comes at a time when survivors receive significantly less formal and informal support (IOM, 2006; Miller et al., 2008). During this period, survivors also report confusion regarding who they can turn to for help (Ganz, 2009). That perceived lack of support can lead to high levels of anxiety and psychological distress, as well as exacerbation of existing health problems, which can contribute to negative sequelae of cancer treatment such as post-traumatic stress disorder (Bell, 2010; Kornblith & Ligibel, 2003).

**Regimen work:** Cancer survivors engage in numerous tasks related to maintenance of secondary and adjuvant therapies, treatment of functional losses and physical changes arising post-treatment completion, and recommended modifications to lifestyle and diet designed to maintain optimal health and prevent recurrence (Ostroff & Dhingra, 2007; Uhley & Jen, 2007; von Gruenigen et al., 2011). Cancer treatment also can lead to numerous functional losses, which may require active rehabilitation or additional therapeutic interventions (Earle, 2006, 2007; Silver, 2011). Functional consequences of treatment have been well documented and include challenges such as lymphedema, cognitive and vision changes, impaired immunity and bone health, and the need for reconstructive surgery (Bucholtz & Parisi, 2004; Poage, Singer, Armer, Poundall, & Shellabarger, 2008; Shivnan, 2004). Depending on the degree of functional loss, survivors may continue to receive therapy for weeks or years following completion of primary treatment.

**Symptom management:** Management of illness or treatment-related symptoms and late effects is an important component of regimen work for cancer survivors. Symptoms can manifest in multiple ways at various points along the survivorship trajectory, depending on the nature of the cancer, the treatments administered, and the unique characteristics of the individual. Symptoms to be managed following completion of primary cancer treatment can include, but are not limited to, fatigue (Bower, 2008; Carlson & Speca, 2007; Lemieux, Bordeleau, & Goodwin, 2007; Minton & Stone, 2008; Ng, Alt, & Gore, 2007); pain and peripheral neuropathies (Aksnes & Bruland, 2007; Beatty, Oxlad, Koczwara, & Wade, 2008; Chang & Sekine, 2007; Sullivan, Thibault, Savard, & Velly, 2007); taste changes, anorexia, malnutrition, nausea, and vomiting (Beatty et al., 2008; Ganz, 2009); challenges related to changes in sexual function or associated symptoms (Beatty et al., 2008; Bordeleau et al., 2010; Ganz, 2009; Ganz, Kwan,

**Table 1. Adaptation of the Parent Model: Illness and Biographical Work**

Domain	Tasks and Examples
<b>Illness Work</b>	
Regimen work	<ul style="list-style-type: none"> <li>Adhering to prescribed therapies and recommendations</li> <li>Obtaining necessary medications and medical equipment or supplies</li> <li>Learning the medication regimen and prescribed exercises</li> <li>Adjuvant therapies (e.g., tamoxifen)</li> <li>Reconstructive surgery</li> <li>Cancer rehabilitation</li> <li>Lifestyle modifications</li> <li>Scheduling and coordinating treatment visits</li> <li>Traveling to medical treatment or therapy facilities</li> <li>Waiting for healthcare practitioners</li> </ul>
Symptom management and managing late effects	<ul style="list-style-type: none"> <li>Managing symptoms or late effects associated with illness or treatment</li> <li>Learning about symptoms and symptom management</li> <li>Monitoring and reporting symptoms to healthcare practitioners</li> <li>Managing ongoing symptoms</li> <li>Preventing or managing late effects of cancer treatment</li> <li>Managing psychological sequelae (e.g., delayed distress, post-traumatic stress disorder)</li> </ul>
Diagnostics	<ul style="list-style-type: none"> <li>Arranging and undergoing surveillance or testing inherent to follow-up care</li> <li>Undergoing clinical surveillance and diagnostic testing</li> <li>Providing samples for testing (e.g., blood, urine, tissue)</li> <li>Performing self-examinations</li> </ul>
Crisis prevention and handling	<ul style="list-style-type: none"> <li>Acting to prevent or manage actual or potential illness-related crises</li> <li>Filtering and prioritizing information</li> <li>Preventing or managing secondary malignancies or recurrence</li> </ul>
Care-planning and maintaining continuum of care ( <i>new domain</i> )	<ul style="list-style-type: none"> <li>Survivorship care planning and maintaining the continuum of cancer care</li> <li>Developing a survivorship care plan</li> <li>Transitioning back to community and primary care</li> <li>Educating the primary care provider regarding treatments and the survivorship plan</li> <li>Communicating needs, treatment, and survivorship care plan to all healthcare practitioners</li> </ul>
<b>Biographical Work</b>	
Contextualizing	<ul style="list-style-type: none"> <li>Putting the cancer experience into context, including</li> <li>Seeing cancer and its consequences as part of everyday life</li> <li>Integrating survivorship care and follow-up into daily life</li> </ul>
Coming to terms	<ul style="list-style-type: none"> <li>Coming to accept the implications of cancer and cancer survivorship by</li> <li>Experiencing limitations or changes</li> <li>Reviewing implications of these changes</li> <li>Searching for meaning and reconciling</li> <li>Relinquishing one's former expectations and grieving losses</li> <li>Restructuring perspective</li> <li>Looking toward the future</li> </ul>
Reconstituting identity	<ul style="list-style-type: none"> <li>Adjusting to changes in one's identity, including:</li> <li>Physical</li> <li>Sexual</li> <li>Social</li> <li>Spiritual</li> <li>Psychological</li> </ul> <p>Integrating one's identity into a new conceptualization of wholeness around limitations or consequences of cancer</p>
Recasting biography	<ul style="list-style-type: none"> <li>Giving new direction to one's life plans, including</li> <li>Managing uncertainty</li> <li>Growing as a survivor</li> </ul>

Note. Based on information from Corbin & Strauss, 1985.

Stanton, Bower, & Belin, 2011; Jacobs et al., 2007; Lemieux et al., 2007); psychological distress, post-traumatic stress symptoms, and anxiety (Henselmans et al., 2010; Jim & Jacobsen, 2008; Kornblith & Ligibel, 2003; Nezu & Nezu, 2007; Roberts & Clarke, 2009); sleep disturbances (Bower, 2008; Carlson & Specca, 2007); cognitive disturbances and mild cognitive impairment (Bower, 2008; Correa & Ahles, 2008; Ferguson, Riggs, Ahles, & Saykin, 2007; Jacobs et al., 2007; Marin, Sánchez, Arranz, Auñón, & Barón, 2009); abnormal weight gain and night sweats (Befort & Klemp, 2011; Halbert et al., 2008; Jacobs et al., 2007); cardiac toxicities and symptoms of other chronic illnesses exacerbated or caused by treatment (Lemieux et al., 2007; Prosnitz, Chen, & Marks, 2005; Rozenberg, Antoine, Carly, Pastijn, & Liebens, 2007); and symptoms of musculoskeletal changes caused by the cancer or cancer treatments, such as fibrosis, muscle atrophy and deformity, lymphedema, and cancer treatment-induced bone loss (Aksnes & Bruland, 2007; Beatty et al., 2008; Camp-Sorrell, 2009; Rozenberg et al., 2007). Often, survivors will experience symptom clusters that can add a greater level of complexity to the work of symptom management (Gaston-Johansson, Fall-Dickson, Bakos, & Kennedy, 1999). One of the most common symptom clusters involves the triad of fatigue, sleep difficulties, and pain, all of which can render the work of managing other aspects of survivorship more difficult (Bower, 2008). New or emerging symptoms can be signs of the late effects of

cancer treatment, although they also may indicate a new health problem, such as recurrence or a secondary cancer (Befort & Klemp, 2011; Feuerstein, Bruns, Pollman, & Todd, 2010). Therefore, symptom management work includes learning the meaning of symptoms and appropriate management techniques, not excluding emotional management, along with appropriate symptom reporting. A significant proportion of cancer survivors will experience what is known as “delayed distress” and other post-traumatic stress symptoms. Post-traumatic stress disorder is characterized by three distinct symptom clusters: (a) intrusive thoughts and re-experiencing, (b) emotional numbness and avoidance of reminders, and (c) hyper-vigilance and physiologic arousal (Jim & Jacobsen, 2008). A growing number of studies suggest that many cancer survivors demonstrate multiple symptoms of post-traumatic stress, which may go unrecognized and untreated in the first year or two following completion of primary treatment (Henselmans et al., 2010; Jim & Jacobsen, 2008; Lengacher et al., 2009; Mehnert, Berg, Henrich, & Herschbach, 2009; Nezu & Nezu, 2007).

Late effects of cancer treatment are toxic consequences of cancer therapy that only emerge at some time after treatment is completed (IOM, 2006). Although information on the prevalence of late effects among cancer survivors remains limited, evidence suggests they are increasing because of the greater complexity and duration of cancer therapies (Bloom, Kang, Petersen, & Stewart, 2007; Ewertz & Jensen, 2011). Late effects of cancer treatment can include psychosocial distress, secondary cancers, and permanent damage to any of the organ systems affected by cancer treatments, leading to the development or exacerbation of other chronic diseases. Survivors must learn about potential late effects and may adopt strategies to prevent or manage their impacts on daily life; examples of behavioral changes may include smoking cessation, use of protective measures against sun exposure, and adherence to routine cancer screening guidelines (Ng & Travis, 2008). However, late effects can vary widely in their nature, severity, and onset (IOM, 2006), creating work that may differ substantially from survivor to survivor.

**Diagnostics and ongoing surveillance:** Another part of the survivorship period is diagnostics and ongoing surveillance. That work can involve scheduling and then making visits to healthcare providers; undergoing screening tests such as mammograms, radiography, and ultrasounds; providing tissue, blood, and urine samples for analysis; and routine performance of self-examinations (e.g., testicular, breast) (Earle, 2007; Snyder et al., 2009). Survivors also have discussed the psychological impacts of those follow-up diagnostics, particularly on anniversaries of treatment completion (Mehnert et al., 2009). In one study, 60% of breast cancer

survivors experienced heightened concern around the time of follow-up appointments (Beaver & Luker, 2005). Managing anticipatory anxiety or emotional sequelae at these times or whenever the survivor undergoes an examination that could reveal recurrence or incidence of a new cancer is important (Beatty et al., 2008).

**Crisis prevention and handling:** Crisis prevention and handling is, therefore, an important part of the work of cancer survivorship. Survivors must prepare themselves for the possibility of secondary malignancies or recurrence. Any symptom—a new pain, a discoloration of the skin, or a lump—can be interpreted as a sign that the cancer has returned (Henselmans et al., 2010). In light of the symptom burden experienced by many cancer survivors, such signs are not unusual. Considering that cancer survivors represent about 1 in 6 new-incident cancers reported to the National Cancer Institute’s Surveillance Epidemiology and End Results database (Ries et al., 2007), survivors must learn how to filter and prioritize the information they receive, not only from their own bodies, but also from media, friends, family, and providers. Such work is key to not becoming overwhelmed by the possibilities that each new piece of information may bring (Beatty et al., 2008). When a crisis such as recurrence does arise, the survivor also must work to address that event.

**Care-planning and maintaining continuum of care:** Finally, unlike other chronic disease processes, which can be managed continuously by a primary care provider (PCP) over the life course, cancer generally is treated by a team of specialists whose role shifts after the survivor has completed primary therapy. Survivors who have completed cancer treatment can find themselves in a sort of limbo between two sets of providers—the multidisciplinary oncology team that has managed their care during the preceding months and PCPs who will continue to support them in the community (Ganz, 2009; IOM, 2006). Survivors must negotiate the transition back to primary care, which can include tasks such as assessing a PCP’s knowledge and comfort level with providing survivorship care, educating the PCP about treatments received and the survivorship care plan, and communicating needs to the PCP as well as members of the oncology team who may provide ongoing surveillance and support. Thus, the task of survivorship care planning, even when initiated in the oncology setting, is a dynamic and ongoing process that may require considerable effort on the part of the survivor (Griffith, McGuire, & Russo, 2010). Survivors must also learn—often, by trial and error—who they can turn to for what types of support; what kinds of resources they have available to them; and how to manage the transition in terms of insurance, finances, and documentation, in addition to clinical concerns and supportive needs (Klimmek, Snow, & Wenzel, 2010).

## Biographical Work

Biographical work involves maintaining or reconstructing one's identity and self-concept. The title *survivor* carries with it various meanings that may or may not resonate with people who have undergone treatment for cancer (Beatty et al., 2008). Survivors have repeatedly described cancer as a permanently life-changing experience that results in an ongoing process of adjustment throughout the duration of survivorship (Doyle, 2008). The Illness Trajectory Framework originally described biographical work in terms of a process involving four primary stages: contextualizing, coming to terms, reconstituting identity, and recasting biography. The survivor may have differing success in reviewing their cancer experience, accepting its consequences, grieving any losses or alterations to the life they had once anticipated, and moving on with new or adjusted life plans.

**Contextualizing and coming to terms:** Contextualizing involves placing the cancer experience in the context of one's everyday life, which is a necessity of treatment and recovery that may take place in a variety of ways, depending on how the individual chooses (or is forced) to integrate experiences and activities of survivorship into the narrative of his or her day. An example of this might be when survivors arrange their schedules around follow-up appointments with their providers. Coming to terms takes the contextualizing process a step further. In coming to terms, cancer survivors experience the limitations or changes resulting from the cancer disease process and its treatment. Those experiences can include managing ongoing or emerging symptoms, sexual consequences of cancer treatment, or other alterations to body image or function that may have implications for the survivors' lifestyle, livelihood, relationships, and identity. A survivor facing functional limitations may need to accept regular assistance from caregivers, adjust occupational or caregiving duties, or use an assistive device to adapt (Beatty et al., 2008; Brearley et al., 2011; Cayless, Forbat, Illingworth, Hubbard, & Kearney, 2010). A survivor with alterations to sexual function may experience strain related to intimate relationships and marital roles. Some survivors who have faced their own mortality through the experience of cancer have reported altered social relationships with others (Beatty et al., 2008; Doyle, 2008). Friends and relations may become distant, or survivors may feel they can no longer relate to them (Lemieux et al., 2007), leading to feelings of isolation or lack of social engagement (Cayless et al., 2010; McKenzie & Crouch, 2004). Survivors must manage these changes and search for new meaning (Clarke, 2009; Vachon, 2008). Such loss may necessitate letting go of expectations and reconciliation through a process of grieving, followed by adoption of a new perspective on the future (Lemieux et al., 2007; McKenzie & Crouch, 2004).

**Reconstituting identity:** The duality of positive and negative aspects of the cancer experience has been well documented (Doyle, 2008). Adaptation of self-concept as a result of the cancer experience is known as reconstituting identity. As outlined earlier, survivors may have their self-conceptions challenged on multiple levels as a result of their cancer experience. Body image may be altered; sexual self-conceptions may be adjusted as a result of changes in physiology, sexual satisfaction, or desire; and social identity evolves in light of the perceived nature of relationships with others and their reactions (McKenzie & Crouch, 2004; Thornton & Perez, 2007). After treatment is completed, cancer survivors also have reported the need to achieve formal closure through ceremonies or other symbolic acts, and to develop and maintain an identity separate from that of a *cancer survivor* (Beatty et al., 2008). Spiritual or religious identities also may change throughout survivorship (Carlson & Speca, 2007; Vachon, 2008). Those alterations in self-concept can have serious psychological consequences (Beatty et al., 2008; Carlson & Speca, 2007).

**Recasting biography:** The degree to which a person can integrate these consequences of survivorship may determine whether he or she can successfully move on with life and grow as a survivor (Aksnes & Bruland, 2007; Cayless et al., 2010; Doyle, 2008; Jim & Jacobsen, 2008). Some survivors have described experiencing tension between cancer fatalism and a sense of activism (Morgan, Tyler, & Fogel, 2008), both of which have been well presented in the existing research literature on survivorship. Cancer fatalism is defined as "a belief that death is inevitable when cancer is present," whereas cancer activism is described as "strong action and motivation to overcome negative views of cancer and to achieve the goal of addressing cancer issues" (Morgan et al., 2008, p. 238). What tasks survivors engage in to manage this tension is not entirely clear, although uncertainty appears to play a role. Mishel et al. (2003) and Gil et al. (2006) also have described the role that management of uncertainty about one's future life course can have on quality of life. That work can involve creative new ways of thinking, as well as identification and management of triggers of negative thoughts.

## Everyday Life Work

Everyday life work represents the activities and exertions that might have been part of a survivor's life in the absence of cancer, and into which the cancer experience must be integrated (see Table 2). Those can include activities of daily living such as eating, bathing, and toileting, or instrumental activities of daily living such as cooking, shopping, and bill-paying. They also can be expanded to encompass the full scope and diversity of

each survivor's life context, such as occupational work, relationship work, health maintenance, child-rearing and informal caregiving responsibilities, socialization, recreation and volunteerism, and the work of managing stress and one's day-to-day emotions.

Integration of cancer survivorship into everyday work may involve refinements in any of these work domains. For example, the home environment may need to be modified to accommodate a loss of function. Similarly, recreational and social activities also might be adjusted in response to new limitations or to adhere to recommended lifestyle changes (Ashing-Giwa, Lim, & Gonzalez, 2010; Courneya, Karvinen, & Vallance, 2007; Stevinson, Campbell, Sellar, & Courneya, 2007). Some survivors expend extra effort engaging in social activities to overcome the sense of social isolation that sometimes occurs following completion of cancer treatment (Beatty et al., 2008; Roberts & Clarke, 2009). That can involve educating friends and family about the cancer experience and normalizing the experience for them such that they can successfully reconnect with the survivor (Beatty et al., 2008; Lengacher et al., 2009). Managing the unhelpful attitudes and expectations of people who equate completion of primary cancer treatment with an automatic return to life as it was before the cancer occurred also may be necessary (Beatty et al., 2008; Thornton & Perez, 2007). Survivors may choose to actively engage in various forms of cancer activism, including new types of volunteer work oriented around the survivorship community, growing closer to others who have shared similar experiences.

**Relationship work:** This includes any of the myriad of tasks associated with maintaining relationships (Weber & Solomon, 2008). Although this includes the relationships with friends and colleagues discussed earlier, it also encompasses the work of maintaining intimate partnerships, marriages, and family ties. Survivors may experience many changes in these relationships as a result of the cancer experience, including growing closer to partners or loved ones or, conversely, break-ups, divorce,

or changes in caregiving roles (Beatty et al., 2008), although several studies have failed to find evidence that survivors are at higher risk for divorce (Carlsen, Dalton, Frederiksen, Diderichsen, & Johansen, 2007; Schover, 2004). Learning how to communicate effectively can play a key role in the success or failure of these relationships (Kornblith & Ligibel, 2003). Some cancer survivors report working to actively protect families and friends from the emotional, psychological, and financial impacts of cancer. Sexual activities may be adjusted to accommodate ongoing symptoms or functional changes. A population-based study of cancer

**Table 2. Adaptation of the Parent Model: Everyday Life Work**

Domain	Tasks and Examples
Relationship work	Maintaining, renewing, or resolving social relationships, including <ul style="list-style-type: none"> <li>• Negotiating intimacy and sexual relationships</li> <li>• Managing others' unhelpful attitudes and expectations</li> <li>• Educating friends, family, and colleagues</li> <li>• Protecting loved ones from impacts of cancer</li> </ul>
Occupational work	Performance of paid or unpaid formal work duties, including <ul style="list-style-type: none"> <li>• Adjusting job duties as a result of limitations or symptoms</li> <li>• Negotiating return to work, employment transitions, or job loss</li> <li>• Dealing with issues of workplace discrimination</li> </ul>
Bill-paying	Paying bills and meeting financial obligations, including <ul style="list-style-type: none"> <li>• Assessing financial resources</li> <li>• Interpreting hospital bills and insurance information</li> <li>• Monitoring for and addressing billing errors</li> </ul>
Emotion work	Managing variable emotions in response to feeling rules, including <ul style="list-style-type: none"> <li>• Putting on a "game face" or brave front</li> <li>• Coping</li> </ul>
Psychological work	Maintaining or improving one's psychological well-being, including <ul style="list-style-type: none"> <li>• Managing daily and long-term stress</li> <li>• Managing prior mental health issues such as depression</li> </ul>
Health maintenance and health promotion	Other activities associated with the maintenance or promotion of overall health in the survivor, including <ul style="list-style-type: none"> <li>• Management of prior health issues or chronic conditions</li> <li>• Nutrition and exercise</li> <li>• Seeking and using health information and care</li> </ul>
Housekeeping and repairing	Maintaining the household, including <ul style="list-style-type: none"> <li>• Modifying home environment to accommodate any loss of function</li> <li>• Housekeeping, shopping, cooking, yard work, and home maintenance</li> </ul>
Child rearing and informal caregiving	Performance of parenting and informal caregiving tasks, including reclaiming or renegotiating caregiving roles
Socialization	Engaging or re-engaging with others socially, including <ul style="list-style-type: none"> <li>• Overcoming isolation</li> <li>• Participating in previous or new social activities</li> <li>• Overcoming feelings of cancer stigma</li> </ul>
Recreation	Engaging in activities for amusement or relaxation, including <ul style="list-style-type: none"> <li>• Adjusting recreation to adhere to recommended lifestyle changes</li> <li>• Volunteerism</li> </ul>

Note. Based on information from Corbin & Strauss, 1985.

survivors in the United States estimated that about 18% of newly diagnosed survivors reside with a minor child (Weaver, Rowland, Alfano, & McNeel, 2010), and many survivors also serve as informal caregivers to their spouses or other family members. As such, child-rearing and caregiving roles also may need to be renegotiated as the capacity to fulfill these roles evolves over the course of survivorship.

**Occupational work:** Occupational work plays a central role in the everyday life work of many survivors (Verbeek & Spelten, 2007). A growing body of literature documents the many challenges that survivors encounter when faced with transitions in employment following cancer diagnosis (Hoving, Broekhuizen, & Frings-Dresen, 2009; Tiedtke, de Rijk, Dierckx de Cast-erlé, Christiaens, & Donceel, 2010). Negotiating a return to work or an adjustment in work responsibilities can be anxiety-provoking because of concerns regarding job performance, cancer-related discrimination, and fear of losing employment or insurance as a result of these adjustments (Klimmek et al., 2010; Tiedtke et al., 2010; Wenzel & Steeves, 2008). Treatment-related mild cognitive impairment, fatigue, functional limitations, sleep disorders, and pain may impair a survivor's ability to work or concentrate, leading to lost productivity and increased absenteeism (Marin et al., 2009; Meadows et al., 2010). However, other research has found that survivors may work even harder as a result (Maunsell, Brisson, Dubois, Lauzier, & Fraser, 1999). Some survivors find they are unable to maintain their employment following treatment and choose to leave their jobs altogether. That can create future work: conducting a new job search, orienting to a new occupation, or abruptly adjusting to life in retirement.

**Bill-paying:** Paying bills also is an inevitable aspect of survivorship work. In addition to day-to-day bills paid prior to their illness, survivors also are faced with managing the costs of their therapies, follow-up, and any additional out-of-pocket expenses resulting from their cancer experience (Pisu et al., 2010). In the first year following completion of cancer treatment, average out-of-pocket medical costs for survivors have been estimated at about \$500 per month at one year postdiagnosis, with nonmedical costs such as parking or transportation estimated at \$137–\$174 per month (Pisu et al., 2010). Those costs vary considerably from survivor to survivor, with medical illness remaining the number one cause of personal bankruptcy in the United States (Himmelstein, Thorne, Warren, & Woolhandler, 2009). Researchers have found that bill-paying work entails assessing one's finances, interpreting hospital bills and information from private insurance companies or government insurance programs, negotiating with payers, monitoring for and addressing billing errors, and navigating the complicated world of government

healthcare financing or managed care (Klimmek et al., 2010; Wenzel & Steeves, 2008). Unfortunately, many survivors report that much of this work occurs after treatment has ended, when the survivor has less interaction with supportive services of the cancer treatment facility and also is striving to move forward from his or her cancer experience. Thus, the complexity of bill-paying work following treatment can serve as a "painful reminder" of the cancer experience and associated losses (Klimmek et al., 2010, p. 601).

**Emotion work:** Emotion work has been defined as the work of inducing or inhibiting emotions to render them appropriate for the situation (Hochschild, 1979). During the phase of active treatment, patients experience a wide range of emotions for which friends, family, and others may provide them a great deal of latitude, empathy, and support. However, survivors can encounter a very different set of feeling rules and expectations once treatment is complete. Although survivors continue to manage a host of challenges that can lead to a rollercoaster of emotions, including feelings of social isolation, anxiety, uncertainty and depression, they may feel the need to suppress or modulate these emotions to meet others' expectations (Beatty et al., 2008; Trask & Pearman, 2007). Those reactions can involve putting on a game face and projecting a good attitude to friends, family, and coworkers. Meeting these perceived expectations may require considerable emotion work at a time when social support has decreased (Lent, 2007; Vivar & McQueen, 2005).

**Psychological work:** Psychological work refers to maintaining or improving psychological well-being through activities such as managing daily stress. Studies using both self-report and clinical observation have shown that cancer survivors are at increased risk for psychiatric diagnoses such as major depression and anxiety disorders (Honda & Goodwin, 2004; Nezu & Nezu, 2007; Sheppard, 2007). As previously noted, cancer diagnosis and treatment may result in post-traumatic stress symptoms (Kangas, Henry, & Bryant, 2005). For some, psychological issues might have been present prior to cancer diagnosis. Symptoms such as pain, sleep disturbances, and fatigue can further exacerbate existing depression (Gaston-Johansson et al., 1999; Minton & Stone, 2008; Ng et al., 2007; Sullivan et al., 2007; Trask & Pearman, 2007). Lifestyle changes in diet, smoking, or drinking also may alter a survivor's available coping mechanisms (Ostroff & Dhingra, 2007). In light of the abundance of work to be performed in the weeks and months following treatment completion, survivors may need to quickly find new ways to manage daily stress and other mental health issues.

**Health maintenance and promotion work:** During transitional survivorship, health maintenance and promotion work includes performance of behaviors associated with maintenance or improvement of overall



health. With health promotion now included in the “three P’s” of survivorship care (Ganz, 2011), as well as an increased emphasis on inclusion of recommended screening guidelines for general health issues and late effects of cancer treatment in survivorship care plans, this may overlap considerably with the illness-related work of survivorship (Carver et al., 2007; Jankowski & Matthews, 2011; Meraviglia & Stuijberger, 2011).

**Management in process:** For survivors, management in process involves the organization and performance of the work described here to achieve their goals. That can include everything from the formal work of survivorship care-planning and goal-setting in the context of ongoing illness-related, biographical, and everyday life work to coordination of the many other types of work that constitute the life of any unique individual. Rather than performing this work alone, survivors conduct it in concert with others, including health professionals, informal caregivers and support people, colleagues, and family. Work types must be sequenced and prioritized such that tasks can be delegated to the correct individual and resources can be allocated to the appropriate task. Illness-related tasks, such as visits to the PCP, must be properly sequenced with the work of everyday life to avoid disruptions. Biographical work, such as coming to terms and grieving losses, may influence successful performance of everyday life work or illness-related tasks. In the original model, the three lines of work are inextricably linked and evolve over the remainder of the survivorship trajectory (Corbin & Strauss, 1985, 1988). Although some of this work can be planned, evolution is inevitable. Therefore, the articulation work of survivorship includes assessing and responding to the unforeseen.

## Implications for Nursing

Understanding the process of work during transitional cancer survivorship may allow survivors and those who support them to prepare for the tasks that can arise following treatment. The transitional survivorship work framework has been presented and reviewed by a series of nurse experts, including doctorally prepared nurse researchers, staff oncology RNs, advanced practice nurses, and nurse administrators. Reviewers stated that the framework resonated with their experiences as nurses and, in some cases, as cancer survivors themselves. The word *work* was considered particularly appropriate for the activities described by this conceptual framework. Expert reviewer suggestions for applications of the framework included its use in the development of educational tools for survivors and their families or support people, as a guide for survivorship care planning, and in the provision of anticipatory guidance or “coaching,” to facilitate survivors’ and caregivers’ preparation and

support during the transition from active treatment to “a new normal.” Reviewers also felt that the novel perspective provided by looking at transitional survivorship through the lens of work could illuminate new areas for research and interventions and also might be useful for exploring cancer-related health disparities among survivors and their support people.

## Conclusion

The revised framework presented in this article represents an attempt to synthesize existing knowledge regarding the period of transitional cancer survivorship to adapt a portion of the Illness Trajectory Framework to the unique experiences of cancer survivors in the months following primary treatment completion. The framework adds to the existing literature on cancer survivorship by making explicit the many types of work that survivors and the people who support them must coordinate and perform during a crucial phase in the survivorship trajectory. Next steps in this theory derivation process should include formative research to evaluate the validity and utility of this framework in various populations of cancer survivors, particularly those survivors who traditionally have been under-represented in research to date (Botes, 2002; Millon-Underwood, Phillips, & Powe, 2008; Oseni & Jatoi, 2007; Shavers & Brown, 2002). Given the reciprocally interactive nature of the three lines of survivorship work described, it also would be useful to explore timing and frequency of tasks within each domain and the ways in which illness-related work, biographical work, and everyday life work interact. Programs of research that focus on the ways in which contextual factors such as social support, local resources, culture, geographic location, or policy impact work performance and outcomes could potentially reveal opportunities for tailoring psychosocial care and interventions for survivors. Future research and ongoing evolution of the culture of survivorship may lead to new or revised definitions for the framework. The framework illuminates the “invisible” work of survivorship, thereby providing a basis for future testing and the further development of an evidence base to help survivors and the people who care for them achieve their larger personal goals once the goals related to treatment have been completed.

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