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## A Model Linking Uncertainty, Post-Traumatic Stress, and Health Behaviors in Childhood Cancer Survivors

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**A**lthough the overall rate of long-term survival has improved worldwide, cancer remains the leading cause of death among children aged 1–14 years in the United States (American Cancer Society, 2008). Young people with cancer may experience uncertainty (Koocher, 1985; Santacroce, 2003; Santacroce & Lee, 2006) and psychosocial distress (Kazak et al., 2004) about whether they will survive the primary cancer and whether they will develop medical late effects of cancer and treatment in survivorship (Greving & Santacroce, 2005; Pagano-Therrien & Santacroce, 2005). Given the increasing rates of long-term survival following a childhood cancer diagnosis, a model for understanding survivors' responses to childhood cancer and treatment should be developed. A greater understanding of survivors' health behaviors in particular can act as the first step to developing a means to change behaviors that may increase the risk for late effects and, therefore, affect survivorship.

Late effects are the chronic adverse consequences of a disease and its treatment. Young people who survive primary cancer because of the use of aggressive multimodal treatments are at heightened risk for late effects, which is an additional source of uncertainty and psychological distress. Seven of 10 survivors develop at least one medical late effect, and 50% of survivors with late effects present with disabilities that adversely alter quality of life (Dreyer, Blatt, & Bleyer, 2002). Late effects of childhood cancer can include the development of physical impairments and second malignancies, which significantly increase the risk of developing breast, central nervous system, bone, thyroid, lung, and skin cancers and acute nonlymphocytic leukemia after Hodgkin disease treatment with chest irradiation (Dickerman, 2007; Guerin et al., 2003; Inskip & Curtis, 2007; Laurie et al., 2002; Maule et al., 2007; Mertens et al., 2002; Sklar et al., 2000; van Leeuwen et al., 2000).

**Purpose/Objectives:** To consolidate the literature and provide a model to explain the links among uncertainty, post-traumatic stress syndrome, and health behaviors in adolescent and young adult childhood cancer survivors.

**Data Sources:** A systemic review of related literature and theory was used for the proposed model. The literature pertaining to the Uncertainty in Illness Theory, childhood cancer late effects, post-traumatic stress, and health behaviors was reviewed and critiqued from three data sets from 1979–2007: MEDLINE®, PsycInfo, and CINAHL®. Key words used for the search were *uncertainty* and *post-traumatic stress* as well as health behaviors, including *smoking*, *alcohol use*, *unsafe sex*, *sunscreen use*, and *physical inactivity*.

**Data Synthesis:** Childhood cancer survivors living with chronic uncertainty may develop a new view of life and, as a result, adopt more health-promotion behaviors and engage in less health-risk behaviors. However, survivors living with chronic uncertainty may generate symptoms similar to post-traumatic stress disorder and, therefore, adopt fewer health-promotion behaviors and engage in more health-risk behaviors.

**Conclusions:** The uncertainty that pervades the childhood cancer experience can lead to the development of symptoms that resemble those of post-traumatic stress. The symptoms can interfere with the adoption of healthy lifestyle behaviors and avoidance of health-risk behaviors.

**Implications for Nursing:** The theoretically derived model outlined in this article can be used to guide clinical interventions and additional research into the health behaviors of childhood cancer survivors.

Childhood cancer survivors have a 10–15 times greater risk for second malignancy than that of age-matched controls (Neglia et al., 2001) and about six-fold greater than the general population (Inskip & Curtis). Five-year childhood cancer survivors have a 10.8 times greater risk than that of the general U.S. population for overall mortality (Mertens et al., 2001). Physical impairments include pulmonary fibrosis, cardiac disease, infertility, metabolic syndrome, obesity or being

overweight, and osteoporosis after chest or cranial irradiation and chemotherapy (Dickerman; Pinto & Trunzo, 2005).

For adolescent and young adult childhood cancer survivors aged 15–39 years, the usual developmental challenges (e.g., difficulties with cognitive reasoning skills) can increase awareness of many medical late effects of cancer and treatment (Hobbie et al., 2000; National Cancer Institute, 2006). The awareness may put survivors at risk for chronic uncertainty and distress as well as difficulty with typical developmental transitions, such as gaining greater levels of social independence and integration (Hobbie et al.; Parry, 2003). Adolescents face challenges such as forming an identity, achieving academically, and building peer relationships as part of normal lifespan development; young adults face challenges related to entering the workforce, establishing intimate relationships, and forming a family (Erikson, 1968). Adolescent and young adult childhood cancer survivors engage in health-risk behaviors (e.g., smoking, drinking, physical inactivity, poor dieting, unprotected sex, sun exposure without the use of sunscreen) as part of their normal development. In addition, the uncertainty that pervades serious childhood illness can lead to the development of symptoms in survivors that resemble those seen in individuals with post-traumatic stress disorder (PTSD) (Mishel, 1990). PTSD and characteristic symptoms have been identified in adolescent childhood cancer survivors (Barakat, Kazak, Gallagher, Meeske, & Stuber, 2000; Erickson & Steiner, 2001; Kazak et al., 2001, 2004; Madan-Swain et al., 2000; Stuber et al., 1997) and young adult survivors (Erickson & Steiner, 2001; Hobbie et al.; Kazak et al., 2001; Meeske, Ruccione, Globe, & Stuber, 2001). In addition, the incidence of PTSD and level of symptoms in young adult childhood cancer survivors may exceed those reported for child and adolescent survivors (Hobbie et al.). Characteristic PTSD symptoms (e.g., intrusive recollections, avoidance of negative information and denial of continual risk, sleep issues) could interfere with childhood cancer survivors' acquisition of critical knowledge and skills as well as the development of an understanding of the health risks that arise from their medical history and treatment exposures.

By limiting engagement in health-risk behaviors, childhood cancer survivors can manage some of the uncertainty that pervades long-term survival, including uncertainty about the occurrence and severity of late effects (e.g., second malignancy). However, some researchers have found that adolescent and young adult childhood cancer survivors in the United States use tobacco and alcohol at rates similar to siblings without cancer (Green, Zevon, & Hall, 1997; Haupt et al., 1992; Hollen & Hobbie, 1993; Troyer & Holmes, 1988; Tyc, Hudson, Hinds, Elliott, & Kibby, 1997) and consistent with their age peers in the general population (Corkery

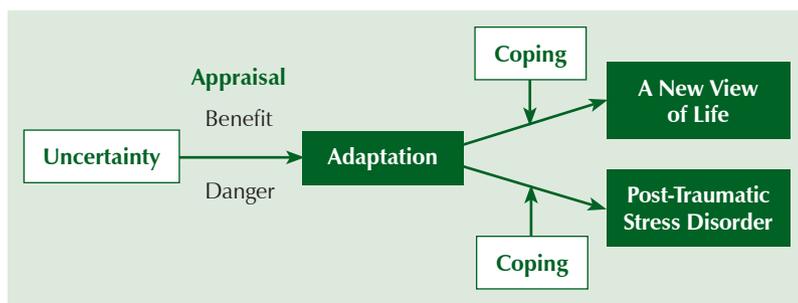
et al., 1979; Hollen & Hobbie, 1996; Leung et al., 2000). In addition, adolescent and young adult survivors lessen physical activity during and after treatment (Finnegan et al., 2007; Keats, Culos-Reed, Courneya, & McBride, 2006).

The Interaction Model of Client Health Behavior (IMCHB) (Cox, 2003) provides a conceptual framework to guide studies of health behaviors in cancer survivorship. Although the IMCHB helps researchers understand the interactions among client singularity (the unique interpersonal and contextual configuration of the individual), client-professional interaction, and health outcomes, its concepts are too broad to guide interventions that promote survivors' health behaviors. In addition, client singularity and perception of health vulnerability are not consistently associated with health-promotion behaviors, so other factors may motivate behavioral change (Hudson & Findlay, 2006). Uncertainty and post-traumatic stress have been negatively correlated with health-promotion behaviors in childhood cancer survivors (Lee, Santacroce, & Sadler, 2007). The two factors may provide a more consistent and specific association with health behaviors in childhood cancer survivors than the IMCHB's variables.

This article will consolidate the literature and provide a model to explain the links among uncertainty, post-traumatic stress, and health behaviors in adolescent and young adult childhood cancer survivors. According to the reconceptualized Uncertainty in Illness Theory (UIT) (Mishel, 1990) and a cancer-related research report (Santacroce & Lee, 2006), uncertainty can be a significant factor that generates PTSD symptoms and then influences health behaviors in childhood cancer survivors. The reviewed literature spanned the years from 1979–2007. Three databases, MEDLINE®, *PsycInfo*, and CINAHL®, were searched for articles published from 1979 to early 2007. Key words used in the search included *uncertainty*, *PTSD symptoms*, and *PTSD* as well as health-related behavior terms, such as *smoking*, *alcohol use*, *unsafe sex*, *sunscreen use*, and *physical activities*. The inclusion criteria were adolescent and young adult childhood cancer survivors.

## Uncertainty in Illness

Uncertainty is a significant feature of childhood cancer survivorship (Koocher & O'Malley, 1981; Parry, 2003), and the UIT (Mishel, 1981, 1988, 1990) has been used as a substantial framework in previous studies of the cancer population (see Figure 1). The UIT explains from an information-processing perspective for healthcare professionals how adults appraise illness-related stimuli to create meaning in illness situations. Uncertainty, the central concept of the UIT, has four elements: ambiguity about the illness state; lack of information about the illness, treatment, treatment effects, and effect management; complexity of the available information, the system of



**Figure 1. Portion of the Reconceptualized Uncertainty in Illness Theory**

Note. From "Reconceptualization of the Uncertainty in Illness Theory," by M. Mishel, 1990, *Image: The Journal of Nursing Scholarship*, 22(4), p. 258. Copyright 1990 by Blackwell Publishing. Adapted with permission.

care, and relationships with providers; and unpredictability of an individual's illness course, prognosis, and future quality of life and level of function (Mishel, 1981). When symptoms form a pattern and events are recognized as familiar, a stimuli frame can be created to lessen uncertainty. A stimuli frame is the form, composition, and structure of stimuli in illness-related events (Mishel, 1988). According to the UIT, structure providers (e.g., credible authorities, social supports, education) can positively affect the stimuli frame or directly reduce uncertainty. The cognitive capacities of an individual also can positively affect the stimuli frame and reduce uncertainty.

Uncertainty is inherently neutral; it can be appraised as either dangerous or beneficial. In acute illness and other extremely stressful situations in which the threat to life or the integrity of the self is perceived as being great, adults tend to appraise uncertainty as dangerous. When uncertainty is appraised as a danger and coping resources in the self and the environment are sufficient, individuals tend to take action to reduce uncertainty (Mishel, 1981); however, when uncertainty is appraised as a danger and coping resources are insufficient, individuals, including young people with cancer, tend to focus coping efforts on reducing awareness of whatever generates uncertainty and controlling the distressing emotions (Stewart & Mishel, 2000).

Mishel (1990) reconceptualized her original theory to more adequately describe individual responses to chronic illness. According to her reconceptualization, individuals can begin to see beneficial aspects of chronic uncertainty and develop probabilistic views of life with support from family, friends, and healthcare providers. The development of a new view of life is a positive psychosocial adjustment (Mishel, 1999) and can be perceived as growth through uncertainty (Bailey, Mishel, Belyea, Stewart, & Mohler, 2004). In addition, a new view of life may motivate individuals living with chronic illness to adopt health-promotion behaviors. However, when an evolution in appraisal and a new view of life lacks support or illness and usual life demands are excessive,

PTSD symptoms can become ingrained so that individuals increasingly engage in health-risk behaviors. For example, an individual may use alcohol or another sedating substances to limit awareness of whatever causes uncertainty and manage emotional distress.

## Uncertainty in Childhood Cancer Survivorship

Uncertainty generally is prevalent in survivorship of childhood cancer. In their classic study of 117 late adolescent and young adult childhood cancer survivors ( $\bar{X}$  = 18.1 years), Koocher and O'Malley (1981) found that childhood cancer survivors still were preoccupied with uncertainty long after the treatment period. In a study of 85 adolescent and young adult survivors, 35 (41%) reported chronic uncertainty (Novakovic et al., 1996).

Uncertainty in childhood cancer survivorship has received more attention than uncertainty in other chronic health conditions of childhood. In childhood cancer survivors, physiologic impairments (e.g., cortical atrophy) (Moore et al., 2000) and alterations in mental health (e.g., high levels of anxiety or depression) (Espy et al., 2001; Moore et al.) can compromise information processing and, therefore, heighten uncertainty. In a qualitative study of 23 late adolescent and young adult childhood cancer survivors ( $\bar{X}$  = 22 years), Parry (2003) found that uncertainty was an unrelenting and permanent part of life in childhood cancer survivorship, rooted in survivors' consciousness and primarily experienced as unpredictable worries related to potential late effects, including infertility, abnormalities in future offspring, or second cancers leading to early death. However, some study participants viewed uncertainty as a source of growth that gave them a changed outlook and deeper appreciation for life. The findings show that adolescent and young adult childhood cancer survivors can experience chronic uncertainty, and characteristic PTSD symptoms were among the responses to uncertainty.

## Post-Traumatic Stress

Traumatic events threaten the life of the self or a loved one. Such events include combat, being held hostage, natural disaster, and interpersonal violence (e.g., sexual assault). The American Psychiatric Association (APA) added PTSD to the *Diagnostic and Statistical Manual of Mental Disorders (DSM)-III* diagnostic criteria in 1980, and the diagnosis of a life-threatening illness (e.g., cancer) was specified as a traumatic event in 1984 (APA, 1994). Initial reactions to potentially traumatic events are intense fear, horror, and helplessness. Characteristic PTSD symptoms develop within three clusters:

re-experiencing the trauma, including symptoms of bad dreams, flashbacks, feeling of trauma, psychological and physical reactivity, and intrusive recollection; avoidance of reminders and numbing of emotions; and hyperarousal (e.g., hypervigilance to the illness and concentration, issues with sleep) (Pynoos, Rodriguez, Steinberg, Stuber, & Frederick, 1998). The development of PTSD symptoms can represent normative efforts to protect the self and others from threats (Santacrose, 2003). PTSD symptoms are psychopathologic (i.e., indicative of full PTSD when symptoms in all three clusters arise after exposure to a traumatic event, continue for more than one month, and are associated with high levels of distress or significant impairment in the performance of key life functions) (APA, 2000).

### Post-Traumatic Stress in Childhood Cancer Survivorship

PTSD prevalence in young adult childhood cancer survivors has ranged from 6% (Pelcovitz et al., 1998) to 16% (Rourke, Hobbie, Schwartz, & Kazak, 2007) to 22% (Meeske et al., 2001); the prevalence of PTSD in child and adolescent survivor samples ranged from 2% (Kazak et al., 1997) to 17% (Pelcovitz et al.). Overall, the prevalence of PTSD in adolescent and young adult cancer survivors is higher than in the general population (1%–14%) (APA, 2000; Bruce, 2006; Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995; Schwartz & Drotar, 2006) but not higher than in other populations of people at risk, such as those who lived in New York 1–2 months after the terrorist attacks on September 11, 2001 (Galea et al., 2002), and patients receiving intensive care (Baxter, 2004).

Although about 80% of childhood cancer survivors do not develop full PTSD, even one or two PTSD symptom clusters can interfere with survivors' management of health and daily living (Lee & Santacrose, 2007; Santacrose, 2003). For example, childhood cancer survivors may avoid cancer-related health care to manage uncertainty about future health, which can result in a lack of knowledge about potential late effects. In a study of 130 young adult childhood cancer survivors, Kazak et al. (2001) reported that PTSD symptoms were observed frequently, with 63% of participants reporting that they re-experienced symptoms, 31% reporting hyperarousal, and 15% reporting avoidance. In a structured interview study of 40 young adult survivors, Erickson and Steiner (2001) reported that the least clinically severe level of symptoms was found in 88% of participants. The findings suggest that adolescent and young adult childhood cancer survivors can develop PTSD symptoms after experiencing chronic uncertainty.

Although the diagnosis of a potentially life-threatening illness, such as cancer, was added to the *DSM-IV* as a stressor criterion for PTSD in 1994 (APA, 1994), cancer is unlike other traumatic stressors because some of its

specific features (e.g., singularity, duration, magnitude, degree of controllability of the experience) distinguish it from other stressors; therefore, labeling of cancer as a traumatic stressor remains controversial (Smith, Redd, Peyser, & Vogl, 1999). However, a substantial body of empirical research has found PTSD and PTSD symptoms (e.g., avoidance, intrusive thought, hyperarousal) in adult and childhood cancer survivors after cancer diagnosis and treatment (National Cancer Institute, 2007).

Nir (1985) first used PTSD diagnostic criteria to categorize the cognitive, emotional, and behavioral responses of children being treated for cancer. Building on Nir's work, Stuber, Nader, Yasuda, Pynoos, & Cohen (1991) hypothesized that trauma for children with cancer and their parents is not only limited to diagnosis but also can include multiple hospitalizations, repeated painful procedures, and cyclic courses of chemotherapy for patients. Two decades of research on PTSD symptoms has demonstrated that childhood cancer and treatment can have a strong and enduring effect on survivors' psychological adjustment. In addition, evidence shows that adolescent (Barakat et al., 2000; Erickson & Steiner, 2000, 2001; Madan-Swain et al., 2000) and young adult survivors (Erickson & Steiner, 2001; Hobbie et al., 2000; Kazak et al., 2001; Meeske et al., 2001) of childhood cancer can exhibit continued or new symptoms years after diagnosis and treatment completion.

### Health Behaviors

Health behaviors include health-risk behaviors and health-promotion behaviors. Engaging in health-risk behaviors may be expected in response to PTSD symptoms and normal development. For example, traumatic childhood experiences have been associated with an increased risk of adolescent and adult alcohol and drug use (De Bellis, 2002).

### Health-Risk Behaviors in Childhood Cancer Survivorship

Health-risk behaviors are actions that increase the risk of subsequent illness or injury; therefore, health-risk behaviors can contribute to leading causes of death (e.g., cancer), disability, and social problems among children and adults in the United States. About 38% (N = 920,000) of mortality across all ages in the United States can be attributed to health-risk behaviors, including smoking, physical inactivity, poor diet, or alcohol misuse (Centers for Disease Control and Prevention [CDC], 2007; Mokdad, Marks, Stroup, & Gerberding, 2004). Tobacco and alcohol use, unhealthy diet, and physical inactivity can heighten the chances of late effects (e.g., second malignancy, cardiovascular disease, osteopenia or premature osteoporosis) among individuals who have

been diagnosed with childhood cancer. The health-risk behaviors that shape the possibility of those late effects are modifiable; childhood cancer survivors may minimize their chances of second malignancy, cardiovascular disease, and osteoporosis by limiting related health-risk behaviors.

### Prevalence of Health-Risk Behaviors in Childhood Cancer Survivorship

The literature is inconsistent about whether childhood cancer survivors engage in fewer or greater numbers of health-risk behaviors than the general population or their peers. Some researchers have found that young adult childhood cancer survivors use tobacco and alcohol at lower rates than age-matched control groups (Larcombe, Mott, & Hunt, 2002), siblings (Tao et al., 1998), and the general population in the United States (Emmons et al., 2002, 2005; Mulhern et al., 1995; Tyc, Hadley, & Crockett, 2001), Australia (Bauld, Toumbourou, Anderson, Coffey, & Olsson, 2005), and the United Kingdom (Larcombe et al., 2002). Other researchers have found that young adult childhood cancer survivors use tobacco and alcohol as much as their sibling controls (Haupt et al., 1992; Troyer & Holmes, 1988) as well as the general population (Corkery et al., 1979; Green et al., 1997; Leung et al., 2000) in the United States.

### Health-Promotion Behaviors in Childhood Cancer Survivorship

Health-promotion behaviors can reduce the risk of specific types of cancer and common health conditions, including cardiovascular disease, obesity, and hypertension (Demark-Wahnefried et al., 2005; Hudson et al., 2002; Pinto & Trunzo, 2005). Childhood cancer survivors should engage in health-promotion behaviors and limit health-risk behaviors to reduce physical late effects (Ford & Ostroff, 2006). Health-promotion behaviors can be defined to include a positive approach to life, thus maximizing physical health as well as achieving the highest potential in all aspects of well-being (Walker, Sechrist, & Pender, 1987).

### Prevalence of Health-Promotion Behaviors in Childhood Cancer Survivorship

The literature about the prevalence of health-promotion behaviors in young adult childhood cancer survivors is limited and varied. A study of 209 survivors (age range = 11–33 years) reported that, although 90% of the participant survivors did not smoke at the time of study, only 59 (28%) met guidelines for physical activities, 33 (16%) followed low-fat diets, 44 (21%) practiced the five-a-day guidelines for fruits and vegetable consumption, and 65 (32%) met dietary reference intakes for calcium (Demark-Wahnefried et al., 2005). However, a study of 46 survivors (age range = 10–18 years) found that

preadolescent and adolescent survivors moderately practiced a variety of health-promotion behaviors (Tyc et al., 2001). In the same study, 76% (N = 35) of survivors did exercises three or more hours weekly and 62% (N = 29) of survivors ate balanced nutritious diets.

### Influence of Health-Risk Behaviors on Late Effects

Participation in health-risk behaviors can amplify late effects. For example, smoking may add to the pre-existing risk of late effects of pulmonary fibrosis, cardiac disease, and neoplasms (Emmons et al., 2002; Perkins et al., 2005; Schwartz, 1999; Tyc et al., 2003). Alcohol consumption can amplify the liver damage after hepatotoxic chemotherapy or liver radiation (Dickerman, 2007). As in the general population, childhood cancer survivors with high-fat diets who do not exercise regularly are at increased risk of treatment side effects (e.g., cardiovascular disease related to chest irradiation, chemotherapy exposure) (Pinto & Trunzo, 2005). Childhood cancer survivors can be at increased risk for early osteoporosis and osteopenia if their diets are low in calcium and they are sedentary (Haddy, Mosher, & Reaman, 2001). Exposure to the sun without sunscreen may increase skin cancer risk in childhood cancer survivors who have received radiation (Dickerman, 2007). Unprotected sex puts survivors at risk for HIV transmission or infectious disease that may lead to infertility (Bauld et al., 2005). The effects of engaging in health-risk behaviors jeopardizes health status for survivors as well as raises medical expenses.

### Factors Influencing Health-Risk Behaviors in Childhood Cancer Survivors

Sociodemographic and disease-related factors and psychological factors have been hypothesized to influence health-risk behavior in adolescent and young adult childhood cancer survivors.

**Sociodemographic and disease-related factors:** The findings about whether sociodemographic and disease-related factors can predispose adolescent and young adult childhood cancer survivors to engage in health-risk behaviors are contradictory. Some researchers have found higher levels of health-risk behaviors in female survivors (Corkery et al., 1979); some found higher levels in male survivors (Butterfield et al., 2006); and others (Mulhern et al., 1995; Tao et al., 1998) have found no gender differences. Although some studies have shown higher levels of health-risk behaviors in survivors whose cancer was diagnosed at an earlier age (Chen et al., 1996a), others have found higher levels of health-risk behaviors in survivors whose cancer was diagnosed at an older age (Emmons et al., 2002); still others found no correlation between age at diagnosis and health-risk behaviors (Tao et al.). In a study of about

9,000 childhood cancer survivors, Hispanic survivors reported less smoking and African American survivors reported fewer drinking issues (Castellino et al., 2005). The influence of race and ethnicity needs additional research. Previous studies also have failed to detect a difference in health-risk behaviors related to educational achievement level (Chen et al., 1996a, 1998; Emmons et al., 2002; Tao et al.), household income, or socioeconomic status (Emmons et al., 2002; Koocher & O'Malley, 1981; Mulhern et al.).

The relationships among sociodemographics, treatment factors, and health-risk behaviors in adolescent and young adult childhood cancer survivors warrant additional research. The identification of influencing factors that can be manipulated to minimize health-risk behavior in childhood cancer survivors may be helpful. For example, in a survey of 425 young adult survivors, researchers found that female survivors smoked more than male survivors when a close relative was a smoker (Corkery et al., 1979). Interventions to reduce smoking in female survivors may be more effective when delivered in tandem with a close relative or a friend who is a smoker than when delivered to female survivors alone. In addition, interventions that target psychological responses to childhood cancer may be more effective.

**Psychological factors:** Psychological distress, such as perceived vulnerability, also has been positively related to health-risk behaviors in childhood cancer survivors (Clarke & Eiser, 2007). The link is supported by a study of 796 smokers from the Childhood Cancer Survivors Study in which the severity of psychological symptoms was associated with higher rates of smoking, nicotine dependence, and lower levels of self-efficacy (Emmons et al., 2003, 2005).

Some researchers have taken the view that health-risk behaviors are a manifestation of poorer psychological adjustment (Chen et al., 1996b; Hollen, Hobbie, Finley, & Hiebert, 2001). Survivors with neurocognitive late effects induced by central nervous system-directed therapies can exhibit poor quality decision making about engagement in health-risk behaviors (Chen et al., 1996a, 1998; Hollen & Hobbie, 1993; Hollen, Hobbie, & Finley, 1997; Hollen et al., 2001; Lansky, List, & Ritter-Sterr, 1986) or have difficulty assigning meaning to illness-related events which may, therefore, increase mood disturbance and risk for engaging in health-risk behaviors. For example, in a survey study of 512 young adult survivors of acute lymphoblastic leukemia, Chen et al. (1996b) found that increased mood disturbance was a significant predictor of health-risk behaviors in men. Younger age at diagnosis and more CNS irradiation were related to health-risk behaviors that developed from

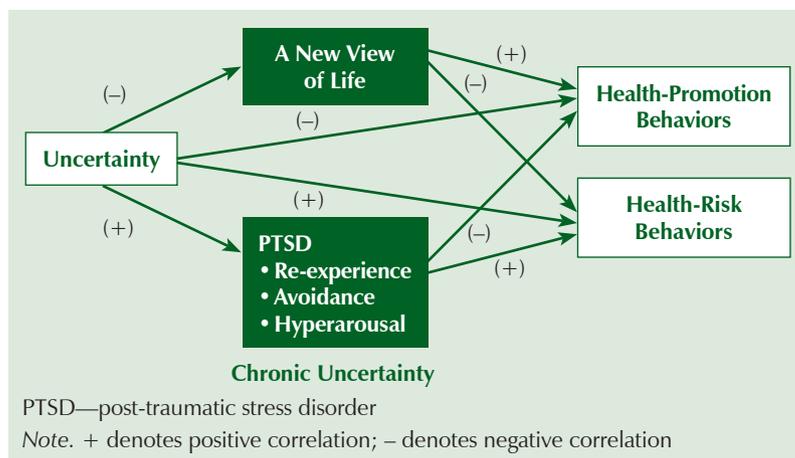
mood disturbance. Chen et al. (1996b) concluded that cognitive impairment after CNS irradiation at a young age may produce more school-related stress, leading to mood disturbance that ultimately can result in increased engagement in health-risk behaviors as a means to relieve psychological distress.

## A Proposed Model for Uncertainty, Post-Traumatic Stress, and Health Behaviors

A model for health behavior in adolescent and young adult childhood cancer survivors has been derived from this literature review (see Figure 2). Survivors living with chronic uncertainty may develop a new view of life and then adopt more health-promotion behaviors and engage in fewer health-risk behaviors. However, survivors living with chronic uncertainty may generate PTSD-like symptoms and, therefore, adopt fewer health-promotion behaviors and engage in more health-risk behaviors.

### Uncertainty and Health Behaviors

According to the reconceptualization of the UIT (Mishel, 1990), individuals may see beneficial aspects of chronic uncertainty and develop opportunistic views of life. The development of a new view of life may motivate individuals living with chronic illness to adopt health-promotion behaviors. However, PTSD symptoms can become ingrained so that individuals increasingly engage in health-risk behaviors when support for an evolution in appraisal and a new view of life is lacking or illness and usual life demands are excessive. Uncertainty related to late effects of childhood cancer has been found to increase survivors' health-risk behaviors. In



**Figure 2. Proposed Model for Predicting Relationships Among Uncertainty, Post-Traumatic Stress, and Health Behaviors in Childhood Cancer Survivors**

a qualitative study of 14 childhood cancer survivors aged 20–57 years ( $\bar{X} = 31.4$  years), researchers found that uncertainty about health affected survivors' health-risk behavior (Park, Emmons, Malloy, & Seifer, 2002). Among participants who were current smokers, the notion of "living for today" (Park et al.) was prominent, supporting the idea that survivors with uncertain futures want to enjoy life now; engagement in health-risk behavior can be part of that enjoyment. No survivor who smoked reported that a physician had discussed the risks of smoking with the survivor; therefore, uncertainty about how to minimize late effects related to smoking may have contributed to the survivors' health-risk behavior. In addition, survivors who did not smoke said that knowledge about late effects motivated their efforts to be healthy (Park et al.). The finding has been supported by two reports conducted by Tyc et al. (2006) and Hudson and Findlay (2006). In a self-report survey of 103 childhood cancer survivors aged 10–18 years, Tyc et al. (2006) reported that knowledge that can reduce the level of uncertainty was a predictor of survivors' perceptions of vulnerability, meaning the more knowledge survivors possessed about the consequences associated with tobacco use, the greater the perceived vulnerability to tobacco-related health risks. The more knowledge survivors possessed, the less uncertainty they felt and the more acutely they perceived risks to their health. The link between uncertainty and health-risk behaviors can, therefore, be predicted to be positive, and the link between uncertainty and health-promotion behaviors can be predicted to be negative.

### Uncertainty and Post-Traumatic Stress

The relationship among PTSD, its symptoms, and uncertainty has been described in two theories. Mishel (1990) hypothesized that individuals who appraise chronic uncertainty as dangerous and personal and environmental resources for coping as insufficient can develop symptoms, thoughts, and behaviors similar to those seen in people with PTSD. Foa, Zinbarg, & Rothbaum (1992) theorized that PTSD-related traumatic events are characterized by uncontrollability and unpredictability, which are features of uncertainty described by Mishel (1990).

Although a limited number of studies have been conducted regarding older adolescents and young adults with childhood-onset chronic health conditions, the findings to date concerning the relationship between uncertainty and psychological distress are consistent with those reported for adults (Mishel, 1997, 1999). In a study of 56 young adults aged 18–21 years ( $\bar{X} = 19$  years) with childhood onset asthma, Hommel et al. (2003) found that illness uncertainty was a significant predictor of anxiety. In addition, in a study of 40 college students with childhood-onset asthma aged 18–25 years

( $\bar{X} = 19.7$  years), Mullins, Chaney, Balderson, & Hommel (2000) reported a significant association between uncertainty and depression.

Studies on adolescent and young adult childhood cancer survivors support the positive relationship between uncertainty and psychological distress and the development of PTSD. Koocher and O'Malley (1981) were among the first investigators to address adolescent and young adult survivors' responses to the strong stressors, including uncertainty, inherent in childhood cancer. An in-depth analysis of 117 late adolescent and young adult childhood cancer survivors ( $\bar{X} = 18.1$  years) found that adolescent and young adult survivors tended to react to their illness-related stressors in three ways: being preoccupied with the idea that cancer will return and, ultimately, be fatal; believing that their past cancer treatment had immunized them against developing a second cancer in the future; or not worrying about cancer or the future (Koocher, 1985). The first group's reaction is consistent with characteristic PTSD symptoms for adolescents and young adults: biologic frailty and a sense of a foreshortened future. The second group's reaction appeared to use the thought of detachment to cope with the uncertain future, a reaction that correlates with avoidance characteristics of PTSD. The third group's response could be seen as a PTSD symptom in the form of avoidance of upsetting cancer-related thoughts as well as a usual tendency of adolescent and young adults to view themselves as being invincible and living for the day. Koocher's (1985) study suggests that PTSD symptoms were highly prevalent in the survivor population. However, Koocher did not report quantitative data. Later studies on the prevalence of PTSD supported that childhood cancer survivors developed at least one symptom of PTSD in more than 88% of cases (Erickson & Steiner, 2001; Kazak et al., 2001). In a study of 60 adolescents recently diagnosed with cancer, Neville (1998) found a positive relationship between uncertainty and psychological distress. In a study of 45 young adult childhood cancer survivors aged of 22–47 years ( $\bar{X} = 27.4$  years), Lee (2006) found that uncertainty and PTSD symptoms were positively correlated.

### Post-Traumatic Stress and Health Behaviors

The development of symptoms of PTSD can represent normative efforts to protect the self and others when confronting a threat (Santacrose, 2003). Childhood cancer and treatment have been defined as potentially traumatic events and therefore may trigger PTSD (APA, 1994). Adolescent and young adult survivors may engage in health-risk behaviors, such as substance use, to self-manage uncomfortable PTSD symptoms, particularly hyperarousal (e.g., rapid heart rate, irritability, difficulty sleeping). A paucity of accessible research is available about the relationship between PTSD symptoms and health-risk behaviors in adolescent and

young adult childhood cancer survivors. In a secondary analysis of randomized, controlled trial data from the self-report questionnaires of 149 women and 118 men aged 12–18 years who had not received cancer treatment for at least two years, Cox, McLaughlin, Steen, and Hudson (2006) reported that increased worrying about cancer and treatment was a predictor of substance use. In addition, individuals in the general population with hyperarousal symptoms have been shown to increase use of alcohol and other CNS depressants to control the symptoms (Nutt, 2000). For example, Vlahov, Galea, and Frankel (2002) reported that people in New York City and surrounding areas increased their substance use, including alcohol, after the terrorist attacks of September 11, 2001. PTSD symptoms, therefore, enhance health-risk behaviors and diminish health-promotion behaviors in adolescent and young adult childhood cancer survivors.

Comprehensive interventions, including clinical monitoring, providing individualized information, teaching coping skills, health education, and anticipatory guidance by expert providers (Hudson & Findlay, 2006) are needed to reduce uncertainty in survivorship. Long-term follow-up care, including education, screening, and support from healthcare providers with expertise in late effects and interests in survivorship issues, may reduce uncertainty in adolescent and young adult childhood cancer survivors (Santacroce, Kadan-Lottick, & Grey, 2003). The intervention research that targets uncertainty in childhood cancer survivors is growing but still is small compared to available research for adult cancer populations. An example of intervention research is a modifiable cognitive-motivational strategy found to be directly associated, although not to a statistically significant level, with tobacco-related health risks in childhood cancer survivors (Hudson & Findlay; Tyc et al., 2006). Methods for reducing uncertainty should be developed for the childhood cancer survivors. In the adult cancer population, interventions, such as providing information and coping skills (e.g., communication, cognitive reframing) that targeted uncertainty, have been developed for patients with prostate cancer (Bailey et al., 2004) and survivors of breast cancer (Mishel et al., 2005).

The positive relationship between uncertainty and health-risk behaviors as an adjustment outcome has been proposed theoretically (Mishel, 1990) and supported empirically in childhood cancer survivors (Park et al., 2002; Tyc et al., 2006). The positive relationship between PTSD symptoms and health-risk behaviors is supported by the reconceptualized UIT (Mishel, 1990) and has empirical support through the relationship of PTSD symptoms and health-risk behaviors with psychological distress (Chen et al., 1998; Cox et al., 2006; Lansky et al., 1986; Nutt, 2000; Santacroce, 2003). The positive relationship between uncertainty and

PTSD symptoms also has theoretical (Foa et al., 1992; Mishel, 1990; Santacroce, 2003) and empiric (Koocher, 1985; Lee, 2006; Neville, 1998) support. The positive relationship between a new view of life and health-promotion behaviors has been supported theoretically (Mishel, 1990), and the inverse relationships between uncertainty and health-promotion behaviors, between uncertainty and a new view of life, and between PTSD symptoms and health-promotion behaviors are supported by the UIT (Mishel, 1990) by Santacroce and Lee, 2006.

## Conclusion

The literature on uncertainty, PTSD, and health behavior in childhood cancer survivors has increased since 1999. More attention should be paid toward elaborating the view of uncertainty as a key element in the relationship between symptoms of PTSD and health behaviors in the future.

Some earlier studies about childhood cancer survivorship used qualitative methods that allowed central constructs to be identified, including uncertainty, PTSD, and health behaviors (Koocher, 1985; Koocher & O'Malley, 1981; Nir 1985; Novakovic et al., 1996). Researchers and clinicians must revisit and build upon existing knowledge to provide individuals with the tools to master cancer survivorship (Rowland, Aziz, Tesauro, & Feuer, 2001). This article has reviewed and synthesized the literature to develop a model for health behavior in adolescent and young adult childhood cancer survivors. The model has potential implications for basic nursing practice and for developing a cancer research program because it provides specific information that suggests uncertainty affects symptoms of PTSD and health behaviors in childhood cancer survivors. Additional research is needed to test the linkages in the model, to design and test health interventions to reduce health-risk behaviors in survivors, and to establish whether the findings of studies with samples drawn from the U.S. population can provide a basis for health interventions for non-Western adolescent and young adult childhood cancer survivors.

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## References

- American Cancer Society. (2008). *Cancer in children: What is childhood cancer?* Retrieved November 21, 2008, from [http://www.cancer.org/docroot/CRI/content/CRI\\_2\\_4\\_1X\\_Introduction\\_7.aspx?sitearea=](http://www.cancer.org/docroot/CRI/content/CRI_2_4_1X_Introduction_7.aspx?sitearea=)
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual—Text Revision (DSM-IV-TR™, 2000)*. Retrieved November 21, 2008, from <http://online.statref.com/titles/titleinfopage.aspx?titleid=37>
- Bailey, D.E., Jr., Mishel, M.H., Belyea, M., Stewart, J.L., & Mohler, J. (2004). Uncertainty intervention for watchful waiting in prostate cancer. *Cancer Nursing*, 27(5), 339–346.
- Barakat, L.P., Kazak, A.E., Gallagher, P.R., Meeske, K., & Stuber, M. (2000). Post-traumatic stress symptoms and stressful life events predict the long-term adjustment of survivors of childhood cancer and their mothers. *Journal of Clinical Psychology in Medical Settings*, 7(4), 189–196.
- Bauld, C., Toumbourou, J.W., Anderson, V., Coffey, C., & Olsson, C.A. (2005). Health-risk behaviors among adolescent survivors of childhood cancer. *Pediatric Blood and Cancer*, 45(5), 706–715.
- Baxter, A. (2004). Post-traumatic stress disorder and the intensive care unit patient: Implications for staff and advanced practice critical care nurses. *Dimensions of Critical Care Nursing*, 23(4), 145–150.
- Bruce, M. (2006). A systematic and conceptual review of post-traumatic stress in childhood cancer survivors and their parents. *Clinical Psychology Review*, 26(3), 233–256.
- Butterfield, R.M., Park, E.R., Mertens, A., Gritz, E.R., Li, F.P., & Emmons, K. (2006). Multiple risk behaviors among smokers in the Childhood Cancer Survivors Study cohort. *Psycho-Oncology*, 13(9), 619–629.
- Castellino, S.M., Casillas, J., Hudson, M.M., Mertens, A.C., Whitton, J., Brooks, S.L., et al. (2005). Minority adult survivors of childhood cancer: A comparison of long-term outcomes, health care utilization, and health-related behaviors from the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, 23(27), 6499–6507.
- Centers for Disease Control and Prevention. (2007). Assessing health risk behaviors among young people: Youth risk behavior surveillance system. Retrieved August 16, 2007, from <http://www.cdc.gov/ncdphp/publications/aag/yrbss.htm>
- Chen, E., Zeltzer, L.K., Bentler, P.M., Byrne, J., Nicholson, H.S., Meadows, A.T., et al. (1998). Pathways linking treatment intensity and psychosocial outcomes among adult survivors of childhood leukemia. *Journal of Health Psychology*, 3(1), 23–38.
- Chen, E., Zeltzer, L.K., Byrne, J., Nicholson, H.S., Meadows, A.T., Mills, J.L., et al. (1996a, June). *Pathways to risk behaviors in young adult survivors of childhood acute lymphoblastic leukemia*. Paper presented at the 4th International Conference on the Long-Term Complications of Treatment of Children and Adolescents for Cancer, Buffalo, NY.
- Chen, E., Zeltzer, L.K., Byrne, J., Nicholson, H.S., Meadows, A.T., Mills, J.L., et al. (1996b, May). *Psychological outcome in long-term survivors of childhood cancer*. Paper presented at the annual meeting of the Society of Behavioral Medicine, Washington, DC.
- Clarke, S., & Eiser, C. (2007). Health behaviours in childhood cancer survivors: A systematic review. *European Journal of Cancer*, 43(9), 1373–1384.
- Corkery, J.C., Li, F.P., McDonald, J.A., Hanley, J.A., Holmes, G.E., & Holmes, F.F. (1979). Kids who really shouldn't smoke. *New England Journal of Medicine*, 300(22), 1279.
- Cox, C.L. (2003). A model of health behavior to guide studies of childhood cancer survivors [Online exclusive]. *Oncology Nursing Forum*, 30(5), E92–E99. Retrieved November 24, 2008, from <http://www.ons.org/publications/journals/ONF/Volume30/Issue5/3005762.asp>
- Cox, C.L., McLaughlin, R.A., Steen, B.D., & Hudson, M.M. (2006). Predicting and modifying substance use in childhood cancer survivors: Application of a conceptual model. *Oncology Nursing Forum*, 33(1), 51–60.
- De Bellis, M.D. (2002). Developmental traumatology: A contributory mechanism for alcohol and substance use disorders. *Psychoneuroendocrinology*, 27(1–2), 155–170.
- Demark-Wahnefried, W., Werner, C., Clipp, E.C., Guill, A.B., Bonner, M., Jones, L.W., et al. (2005). Survivors of childhood cancer and their guardians. *Cancer*, 103(10), 2171–2180.
- Dickerman, J.D. (2007). The late effects of childhood cancer therapy. *Pediatrics*, 119(3), 554–568.
- Dreyer, Z., Blatt, J., & Bleyer, A. (2002). Late effects of childhood cancer and its treatment. In P. Pizzo & D. Poplack (Eds.), *Principles and practice of pediatric oncology* (pp. 1431–1461). Philadelphia: Lippincott Williams and Wilkins.
- Emmons, K., Li, F.P., Whitton, J., Mertens, A.C., Hutchinson, R., Diller, L., et al. (2002). Predictors of smoking initiation and cessation among childhood cancer survivors: A report from the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, 20(6), 1608–1616.
- Emmons, K.M., Butterfield, R.M., Puleo, E., Park, E.R., Mertens, A., Gritz, E.R., et al. (2003). Smoking among participants in the childhood cancer survivors cohort: The partnership for health study. *Journal of Clinical Oncology*, 21(2), 189–196.
- Emmons, K.M., Puleo, E., Park, E., Butterfield, R.M., Weeks, J.C., Mertens, A., et al. (2005). Peer-delivered smoking counseling for childhood cancer survivors increases rate of cessation: The partnership for health study. *Journal of Clinical Oncology*, 23(27), 6516–6523.
- Erickson, S.J., & Steiner, H. (2000). Trauma spectrum adaptation: Somatic symptoms in long-term pediatric cancer survivors. *Psychosomatics*, 41(4), 339–346.
- Erickson, S.J., & Steiner, H. (2001). Trauma and personality correlates in long term pediatric cancer survivors. *Child Psychiatry and Human Development*, 31(3), 195–213.
- Erikson, E.H. (1968). *Identity: Youth and crisis*. New York: Norton.
- Espy, K.A., Moore, I.M., Kaufmann, P.M., Kramer, J.H., Matthey, K., & Hutter, J.J. (2001). Chemotherapeutic CNS prophylaxis and neuropsychologic change in children with acute lymphoblastic leukemia: A prospective study. *Journal of Pediatric Psychology*, 26(1), 1–9.
- Finnegan, L., Wilkie, D.J., Wilbur, J., Campbell, R.T., Zong, S., & Katula, S. (2007). Correlates of physical activity in young adult survivors of childhood cancer [Online exclusive]. *Oncology Nursing Forum*, 34(5), E60–E69. Retrieved September 20, 2007, from [http://www.ons.org/publications/journals/ONF/Volume34/Issue5/pdf/csFinnegan%20\(e\).pdf](http://www.ons.org/publications/journals/ONF/Volume34/Issue5/pdf/csFinnegan%20(e).pdf)
- Foa, E.B., Zinbarg, R., & Rothbaum, B.O. (1992). Uncontrollability and unpredictability in post-traumatic stress disorder: An animal model. *Psychological Bulletin*, 112(2), 218–238.
- Ford, J.S., & Ostroff, J.S. (2006). Health behaviors of childhood cancer survivors: What we've learned. *Journal of Clinical Psychology in Medical Settings*, 13(2), 144–160.
- Galea, S., Resnick, H., Ahern, J., Gold, J., Bucuvalas, M., Kilpatrick, D., et al. (2002). Posttraumatic stress disorder in Manhattan, New York City, after the September 11th terrorist attacks. *Journal of Urban Health*, 79(3), 340–353.
- Green, D.M., Zevon, M.A., & Hall, B. (1997). Cigarette smoking among survivors of cancer diagnosed during childhood or adolescence [Abstract 1866]. *Proceedings of ASCO*, 16, 519a.
- Greving, D.M., & Santacroce, S.J. (2005). Cardiovascular late effects. *Journal of Pediatric Oncology Nursing*, 22(1), 38–47.
- Guerin, S., Dupuy, A., Anderson, H., Shamsaldin, A., Svahn-Tapper, G., Moller, T., et al. (2003). Radiation dose as a risk factor for malignant melanoma following childhood cancer. *European Journal of Cancer*, 39(16), 2379–2386.
- Haddy, T.B., Mosher, R.B., & Reaman, G.H. (2001). Osteoporosis in survivors of acute lymphoblastic leukemia. *Oncologist*, 6(3), 278–285.
- Haupt, R., Byrne, J., Connelly, R.R., Mostow, E.N., Austin, D.F., Holmes, G.R., et al. (1992). Smoking habits in survivors of childhood and adolescent cancer. *Medical and Pediatric Oncology*, 20(4), 301–306.

- Hobbie, W.L., Stuber, M., Meeske, K., Wissler, K., Rourke, M.T., Ruccione, K., et al. (2000). Symptoms of posttraumatic stress in young adult survivors of childhood cancer. *Journal of Clinical Oncology*, 18(24), 4060–4066.
- Hollen, P.J., & Hobbie, W.L. (1993). Risk taking and decision making of adolescent long-term survivors of cancer. *Oncology Nursing Forum*, 20(5), 769–776.
- Hollen, P.J., & Hobbie, W.L. (1996). Decision making and risk behaviors of cancer-surviving adolescents and their peers. *Journal of Pediatric Oncology Nursing*, 13(3), 121–134.
- Hollen, P.J., Hobbie, W.L., & Finley, S.M. (1997). Cognitive late effect factors related to decision making and risk behaviors of cancer-surviving adolescents. *Cancer Nursing*, 20(5), 305–314.
- Hollen, P.J., Hobbie, W.L., Finley, S.M., & Hiebert, S.M. (2001). The relationship of resiliency to decision making and risk behaviors of cancer-surviving adolescents. *Journal of Pediatric Oncology Nursing*, 18(5), 188–204.
- Hommel, K.A., Chaney, J.M., Wagner, J.L., White, M.M., Hoff, A.L., & Mullin, L.L. (2003). Anxiety and depression in older adolescents with long-standing asthma: The role of illness uncertainty. *Children's Health Care*, 32(1), 51–63.
- Hudson, M.M., & Findlay, S. (2006). Health-risk behaviors and health promotion in adolescent and young adult cancer survivors. *Cancer*, 107(7, Suppl.), 1695–1701.
- Hudson, M.M., Tyc, V.L., Srivastava, D.K., Gattuso, J., Quargnenti, A., Crom, D.B., et al. (2002). Multi-component behavioral intervention to promote health protective behaviors in childhood cancer survivors: The protect study. *Medical and Pediatric Oncology*, 39(1), 2–11.
- Inskip, P.D., & Curtis, R.E. (2007). New malignancies following childhood cancer in the United States, 1973–2002. *International Journal of Cancer*, 121(10), 2233–2240.
- Kazak, A.E., Alderfer, M., Rourke, M.T., Simms, S., Streisand, R., & Grossman, J.R. (2004). Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. *Journal of Pediatric Psychology*, 29(3), 211–219.
- Kazak, A.E., Barakat, L.P., Alderfer, M., Rourke, M.T., Meeske, K., Gallagher, P.R., et al. (2001). Posttraumatic stress in survivors of childhood cancer and mothers: Development and validation of the impact of traumatic stressors interview schedule (ITSIS). *Journal of Clinical Psychology in Medical Settings*, 8(4), 307–323.
- Kazak, A.E., Barakat, L.P., Meeske, K., Christakis, D., Meadows, A.T., Casey, R., et al. (1997). Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. *Journal of Consulting and Clinical Psychology*, 65(1), 120–129.
- Keats, M.R., Culos-Reed, S.N., Courneya, K.S., & McBride, M. (2006). An examination of physical activity behaviors in a sample of adolescent cancer survivors. *Journal of Pediatric Oncology Nursing*, 23(3), 135–142.
- Kessler, R.C., Sonnega, A., Bromet, E., Hughes, M., & Nelson, C.B. (1995). Posttraumatic stress disorder in the National Comorbidity Survey. *Archives of General Psychiatry*, 52(12), 1048–1060.
- Koocher, G.P. (1985). Psychosocial care of the child cured of cancer. *Pediatric Nursing*, 11(2), 91–93.
- Koocher, G.P., & O'Malley, J.E. (1981). *The Damocles syndrome: Psychosocial consequences of surviving childhood cancer*. New York: McGraw-Hill.
- Lansky, S.B., List, M.A., & Ritter-Sterr, C. (1986). Psychosocial consequences of cure. *Cancer*, 58(2, Suppl.), 529–533.
- Larcombe, I., Mott, M., & Hunt, L. (2002). Lifestyle behaviours of young adult survivors of childhood cancer. *British Journal of Cancer*, 87(11), 1204–1209.
- Laurie, S.A., Kris, M.G., Portlock, C.S., Rosenzweig, K.E., Miller, V.A., Krug, L.M., et al. (2002). The clinical course of nonsmall cell lung carcinoma in survivors of Hodgkin disease. *Cancer*, 95(1), 119–126.
- Lee, Y.L. (2006). The relationships between uncertainty and posttraumatic stress in survivors of childhood cancer. *Journal of Nursing Research*, 14(2), 133–142.
- Lee, Y.L., & Santacroce, S.J. (2007). Post-traumatic stress in long-term young adult survivors of childhood cancer: A questionnaire survey. *International Journal of Nursing Studies*, 44(8), 1406–1417.
- Lee, Y.L., Santacroce, S.J., & Sadler, L. (2007). Predictors of healthy behaviour in long-term survivors of childhood cancer. *Journal of Clinical Nursing*, 16(11c), 285–295.
- Leung, W., Hudson, M.M., Strickland, D.K., Phipps, S., Srivastava, D.K., Ribeiro, R.C., et al. (2000). Late effects of treatment in survivors of childhood acute myeloid leukemia. *Journal of Clinical Oncology*, 18(18), 3273–3279.
- Madan-Swain, A., Brown, R.T., Foster, M.A., Vega, R., Byars, K., Rodenberger, W., et al. (2000). Identity in adolescent survivors of childhood cancer. *Journal of Pediatric Psychology*, 25(2), 105–115.
- Maule, M., Scelo, G., Pastore, G., Brennan, P., Hemminki, K., Tracey, E., et al. (2007). Risk of second malignant neoplasms after childhood leukemia and lymphoma: An international study. *Journal of the National Cancer Institute*, 99(10), 790–800.
- Meeske, K.A., Ruccione, K., Globe, D.R., & Stuber, M.L. (2001). Post-traumatic stress, quality of life, and psychological distress in young adult survivors of childhood cancer. *Oncology Nursing Forum*, 28(3), 481–489.
- Mertens, A.C., Yasui, Y., Liu, Y., Stovall, M., Hutchinson, R., Ginsberg, J., et al. (2002). Pulmonary complications in survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study. *Cancer*, 95(11), 2431–2441.
- Mertens, A.C., Yasui, Y., Neglia, J.P., Potter, J.D., Nesbit, M.E., Jr., Ruccione, K., et al. (2001). Late mortality experience in five-year survivors of childhood and adolescent cancer: The Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, 19(13), 3163–3172.
- Mishel, M. (1981). The measurement of uncertainty in illness. *Nursing Research*, 30(5), 258–263.
- Mishel, M. (1988). Uncertainty in illness. *Image: The Journal of Nursing Scholarship*, 20(4), 225–232.
- Mishel, M. (1990). Reconceptualization of the uncertainty in illness theory. *Image: The Journal of Nursing Scholarship*, 22(4), 256–262.
- Mishel, M. (1997). *Uncertainty in illness scales manual*. Chapel Hill, NC: University of North Carolina.
- Mishel, M. (1999). Uncertainty in chronic illness. *Annual Review of Nursing Research*, 17, 269–294.
- Mishel, M.H., Germino, B.B., Gil, K.M., Belyea, M., Laney, I.C., Stewart, J., et al. (2005). Benefits from an uncertainty management intervention for African American and Caucasian older long-term breast cancer survivors. *Psycho-Oncology*, 14(11), 962–978.
- Mokdad, A.H., Marks, J.S., Stroup, D.F., & Gerberding, J.L. (2004). Actual causes of death in the United States, 2000. *JAMA*, 291(10), 1238–1245.
- Moore, I.M., Espy, K.A., Kaufmann, P., Kramer, J., Kaemingk, K., Miketova, P., et al. (2000). Cognitive consequences and central nervous system injury following treatment for childhood leukemia. *Seminars in Oncology Nursing*, 16(4), 279–290.
- Mulhern, R.K., Tyc, V.L., Phipps, S., Crom, D., Barclay, D., Greenwald, C., et al. (1995). Health-related behaviors of survivors of childhood cancer. *Medical and Pediatric Oncology*, 25(3), 159–165.
- Mullins, L.L., Chaney, J.M., Balderson, B., & Hommel, K.A. (2000). The relationship of illness uncertainty, illness intrusiveness, and asthma severity to depression in young adults with long-standing asthma. *International Journal of Rehabilitation and Health*, 5(3), 177–186.
- National Cancer Institute. (2006). *Closing the gap: Research and care imperatives for adolescents and young adults with cancer*. Bethesda, MD: Author.
- National Cancer Institute. (2007). *Post-traumatic stress disorder (PDQ®)*. Retrieved August 16, 2007, from <http://www.cancer.gov/cancer topics/pdq/supportivecare/post-traumatic-stress/healthprofessional>
- Neglia, J.P., Friedman, D.L., Yasui, Y., Mertens, A.C., Hammond, S., Stovall, M., et al. (2001). Second malignant neoplasms in five-year survivors of childhood cancer: Childhood cancer survivor study. *Journal of National Cancer Institute*, 93(8), 618–629.
- Neville, K. (1998). The relationships among uncertainty, social support, and psychological distress in adolescents recently diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, 15(1), 37–46.

- Nir, Y. (1985). Post-traumatic disorder in children with cancer. In S. Eth & R. Pynoos (Eds.), *Post-traumatic stress disorder in children* (pp. 121–132). Washington, DC: American Psychiatric Press.
- Novakovic, B., Fears, T.R., Wexler, L.H., McClure, L.L., Wilson, D.L., McCalla, J.L., et al. (1996). Experiences of cancer in children and adolescents. *Cancer Nursing*, 19(1), 54–59.
- Nutt, D. (2000). The psychobiology of posttraumatic stress. *Journal of Clinical Psychiatry*, 61(Suppl. 5), 24–32.
- Pagano-Therrien, J., & Santacroce, S.J. (2005). Bone mineral density decrements and children diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, 22(6), 328–338.
- Park, E.B., Emmons, K.M., Malloy, N.W., & Seifer, E. (2002). A qualitative exploration of health perceptions and behaviors among adult survivors of childhood cancers. *Journal of Cancer Education*, 17(4), 211–215.
- Parry, C. (2003). Embracing uncertainty: An exploration of the experiences of childhood cancer survivors. *Qualitative Health Research*, 13(2), 227–246.
- Pelcovitz, D., Libov, B.G., Mandel, F., Kaplan, S., Weinblatt, M., & Septimus, A. (1998). Posttraumatic stress disorder and family functioning in adolescent cancer. *Journal of Traumatic Stress*, 11(2), 205–221.
- Perkins, J.L., Liu, Y., Mitby, P.A., Neglia, J.P., Hammond, S., Stovall, M., et al. (2005). Nonmelanoma skin cancer in survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, 23(16), 3733–3741.
- Pinto, B.M., & Trunzo, J.J. (2005). Health behaviors during and after a cancer diagnosis. *Cancer*, 104(11, Suppl.), 2614–2623.
- Pynoos, R., Rodriguez, N., Steinberg, A., Stuber, M., & Frederick, C. (1998). *UCLA PTSD index for DSM-IV: Adolescent version*. Los Angeles: UCLA Trauma Psychiatry Service.
- Rourke, M.T., Hobbie, W.L., Schwartz, L., & Kazak, A.E. (2007). Post-traumatic stress disorder (PTSD) in young adult survivors of childhood cancer. *Pediatric Blood and Cancer*, 49(2), 177–182.
- Rowland, J.H., Aziz, N., Tesauro, G., & Feuer, E.J. (2001). The changing face of cancer survivorship. *Seminars in Oncology Nursing*, 17(4), 236–240.
- Santacroce, S.J. (2003). Parental uncertainty and post-traumatic stress in serious childhood illness. *Journal of Nursing Scholarship*, 35(1), 45–51.
- Santacroce, S.J., Kadan-Lottick, N., & Grey, M. (2003). Managing uncertainty in childhood cancer survivorship. Unpublished grant application (1R21 CA10674-01).
- Santacroce, S.J., & Lee, Y.L. (2006). Uncertainty, posttraumatic stress, and health behavior in young adult childhood cancer survivors. *Nursing Research*, 55(4), 259–66.
- Schwartz, C.L. (1999). Long-term survivors of childhood cancer: The late effects of therapy. *Oncologist*, 4(1), 45–54.
- Schwartz, C.L., & Drotar, D. (2006). Posttraumatic stress and related impairment in survivors of childhood cancer in early adulthood compared to healthy peers. *Journal of Pediatric Psychology*, 31(4), 356–366.
- Sklar, C., Whitton, J., Mertens, A., Stovall, M., Green, D., Marina, N., et al. (2000). Abnormalities of the thyroid in survivors of Hodgkin disease: Data from the Childhood Cancer Survivor Study. *Journal of Clinical Endocrinology and Metabolism*, 85(9), 3227–3232.
- Smith, M.Y., Redd, W.H., Peyser, C., & Vogl, D. (1999). Post-traumatic stress disorder in cancer: A review. *Psycho-Oncology*, 8(6), 521–537.
- Stewart, J.L., & Mishel, M.H. (2000). Uncertainty in childhood illness: A synthesis of the parent and child literature. *Scholarly Inquiry for Nursing Practice*, 14(4), 299–319.
- Stuber, M.L., Kazak, A.E., Meeske, K., Barakat, L., Guthrie, D., Garnier, H., et al. (1997). Predictors of posttraumatic stress symptoms in childhood cancer survivors. *Pediatrics*, 100(6), 958–964.
- Stuber, M.L., Nader, K., Yasuda, P., Pynoos, R.S., & Cohen, S. (1991). Stress response following pediatric bone marrow transplantation: Preliminary results of a prospective, longitudinal study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 30(6), 952–957.
- Tao, M.L., Guo, M.D., Weiss, R., Byrne, J., Mills, J.L., Robison, L.L., et al. (1998). Smoking in adult survivors of childhood acute lymphoblastic leukemia. *Journal of the National Cancer Institute*, 90(3), 219–225.
- Troyer, H., & Holmes, G.E. (1988). Cigarette smoking among childhood cancer survivors. *American Journal of Diseases of Children*, 142(2), 123–124.
- Tyc, V.L., Hadley, W., & Crockett, G. (2001). Prediction of health behaviors in pediatric cancer survivors. *Medical and Pediatric Oncology*, 37(1), 42–46.
- Tyc, V.L., Hudson, M.M., Hinds, P., Elliott, V., & Kibby, M.Y. (1997). Tobacco use among pediatric cancer patients: Recommendations for developing clinical smoking interventions. *Journal of Clinical Oncology*, 15(6), 2194–2204.
- Tyc, V.L., Lensing, S., Rai, S.N., Klosky, J.L., Stewart, D.B., & Gattuso, J. (2006). Predicting perceived vulnerability to tobacco-related health risks and future intentions to use tobacco among pediatric cancer survivors. *Patient Education and Counseling*, 62(2), 198–204.
- Tyc, V.L., Rai, S.N., Lensing, S., Klosky, J.L., Stewart, D.B., & Gattuso, J. (2003). Intervention to reduce to intentions to use tobacco among pediatric cancer survivors. *Journal of Clinical Oncology*, 21(7), 1366–1372.
- van Leeuwen, F.E., Klokman, W.J., Veer, M.B., Hagenbeek, A., Krol, A.D., Vetter, U.A., et al. (2000). Long-term risk of second malignancy in survivors of Hodgkin disease treated during adolescence or young adulthood. *Journal of Clinical Oncology*, 18(3), 487–497.
- Vlahov, D., Galea, S., & Frankel, D. (2002). New York City, 2001: Reaction and response. *Journal of Urban Health*, 79(1), 2–5.
- Walker, S.N., Sechrist, K.R., & Pender, N.J. (1987). The health-promoting lifestyle profile: Development and psychometric characteristics. *Nursing Research*, 36(2), 76–81.