# **ONLINE EXCLUSIVE**

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# **Preventing Second Cancers in Cancer Survivors**

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**Purpose/Objectives:** To provide a systematic review of the secondary prevention practices of cancer survivors guided by the Interaction Model of Client Health Behavior.

Data Sources: Articles published in peer-reviewed journals from 1996–2007.

**Data Synthesis:** Despite their increased risk for second cancers, few cancer survivors maintain regular follow-up with a clinician knowledgeable of late effects. Cancer screening rates for cancer survivors are below optimal levels recommended for the general population. Multiple antecedents explain survivors' health practices. Few tested interventions are available to promote secondary prevention practices among cancer survivors.

**Conclusions:** Cancer survivors are less likely to adopt secondary prevention practices than individuals without a cancer history.

Implications for Nursing: Nurses can encourage cancer survivors to adopt secondary prevention practices by providing positive reinforcement, support, and education. As more comprehensive, evidence-based guidelines for longitudinal care become available, nurses will be able to provide care to survivors with greater confidence and certainty.

ne of the most incredible success stories of modern medicine is that a cancer diagnosis is no longer a death sentence. For many, cancer is a survivable illness. Whereas essentially no one survived cancer 40 years ago, 59%–65% of adults and 70%–92% of children will survive beyond five years after a cancer diagnosis today (Davies, 2007; Ries et al., 2006). An estimated 3.3% of Americans are cancer survivors (Ries et al.).

Despite these encouraging statistics, progress in survival has come at a cost. Being cancer-free does not mean being free from the effects of the illness and its treatment. In fact, many survivors encounter long-term changes in their health status that are absent immediately after cancer treatment but manifest later when they are considered "cured" from cancer (Oeffinger & Hudson, 2004; Tichelli & Socie, 2005). Recent research suggests that approximately 62% of cancer survivors have had at least one chronic health problem, 28% a severe condition, and 24% have three or more chronic health problems (Oeffinger et al., 2006). Survivors with the poorest health typically are those who have had central nervous system or bone tumors and those with cognitive impairment as a result of their cancer (Pogany et al., 2006; Reulen et al., 2007).

One of the most devastating late effects cancer survivors face is the development of a new cancer arising as a result of

# Key Points . . .

- Cancer survivors are at increased risk of second cancers.
- Secondary prevention practices, including lifelong surveillance and cancer screening, may reduce the burden of second cancers.
- The prevalence of secondary prevention practices is low among all cancer survivors.
- Physical, social, cognitive, motivational, affective, and environmental antecedents to longitudinal cancer-related health care are modifiable targets of interventions.

the mutagenic effects of treatment, genetic predisposition, or aging. Second cancers are concerning because they predispose survivors to morbidity and early mortality through their effect on general health, quality of life, and long-term survival (Hudson, 2005).

At least 750,000 Americans (almost 8%) have been diagnosed with more than one form of cancer, and it is expected that at least one in nine people will develop two cancers in his or her lifetime (Mariotto, Rowland, Ries, Scoppa, & Feuer, 2007). Survivors of childhood cancer are 3 to 11 times more likely to develop cancer compared to the general population (Cardous-Ubbink et al., 2007; Inskip & Curtis, 2007). Estimates suggest that, following cancer in adulthood, survivors have a two-fold risk of developing cancer (Mahon, 2005; Somerville, 2003). Common second cancers include leukemia and solid tumors, particularly cancers of the breast and thyroid. An emerging risk for childhood cancer survivors is the development of cancers of adulthood, including cancers of the genitourinary system, head and neck area, and gastrointestinal tract (Bassal et al., 2006). Most concerning is that second cancers may appear at any time during cancer

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survivorship and develop at a much younger age than in the general population (Bhatia, Blatt, & Meadows, 2006; Tichelli & Socie, 2005).

The implication of this increased risk for second cancers is the need for comprehensive cancer care that extends from the cancer diagnosis until death (Pollack et al., 2005). Once longterm survival has been achieved, vigilant care must continue in the form of secondary prevention interventions (Hudson, 2005). In the general population, secondary prevention interventions, including life-long surveillance, cancer screening, and health education, are recommended for the early detection of cancers and timely introduction of treatments to prevent or control cancers before signs and symptoms are apparent (Champion & Rawl, 2005). For cancer survivors, this proactive approach to cancer control translates into maintenance of cancer-free survival and prevention of cancer-related morbidity (Pollack et al.). Despite the potential for secondary prevention interventions to reduce the burden of second cancers, no reviews of the secondary prevention practices of cancer survivors have been conducted.

The purpose of this article is to examine the effect that having a cancer history has on an individual's adoption of secondary prevention practices. This systematic literature review describes the prevalence of and factors associated with secondary prevention practices among cancer survivors and effects of interventions promoting their use. Conceptual and methodologic limitations of the current research, directions for future research, and implications for nursing practice also are addressed.

## Literature Search

PubMed, PsychINFO<sup>®</sup>, and CINAHL<sup>®</sup> computerized databases were searched for studies reporting prevalence rates and interventions targeting secondary prevention practices among cancer survivors. Key words included *cancer survivor*, *screening*, *prevention*, *follow-up*, *long-term care*, *surveillance*, and *health behaviors*. Reference lists of articles found in this search also were scanned for possible studies to include in the review.

Criteria for inclusion of articles in the review included (a) written in English, (b) published in a peer-reviewed journal during the past decade, and (c) involved survivors of childhood or adult cancer. The context of the articles was limited to five years after treatment to ensure that the focus was on long-term survival as opposed to the detection of local disease recurrence (Tichelli & Socie, 2005). Studies were excluded if they did not address healthcare use or cancer screening patterns.

## Conceptual Framework Guiding the Review

The Interaction Model of Client Health Behavior (IMCHB) (Cox, 2003) provided the conceptual structure for the review. The IMCHB is used as a tool for nurses to understand the multidimensionality of the antecedents to cancer survivors' secondary prevention practices. A simple linear model cannot fully explain the secondary prevention practices of cancer survivors; instead, an interaction model of health behavior that accounts for individual and contextual variables is needed. Applied to cancer survivors, the IMCHB is a framework for the assessment, development, and implementation of health promotion programs directed at supporting secondary prevention of second cancers, including adherence to recommended follow-up care and cancer screening regimens. Two important assumptions are made in the IMCHB that maximize its use for this review article: (a) individual characteristics interact with sociopsychological and environmental factors as causal factors of health behavior, and (b) human emotions affect the behavioral responses of individuals.

The major elements of the model are health outcomes, client singularity, and client professional interaction (Cox, 2003). Health outcomes in the model include health behaviors and the health states that result from those behaviors. Secondary prevention practices were the health outcomes of interest for this review. As an antecedent to health behaviors, client singularity (the uniqueness of an individual) is a description of the individual according to background variables, intrinsic motivation, cognitive appraisal, and affective responses. The model describes four aspects of the client-professional interactions important for the development of health promotion programs—health education, affective support, decisional control, and professional competency.

## Health Outcome: Prevalence of Secondary Prevention Practices Among Cancer Survivors

Within the IMCHB model, the element of health outcomes includes healthcare use (Cox, 2003). The health outcome of interest for this article is secondary prevention practices among cancers, specifically lifelong surveillance and cancer screening practices. See Table 1 for prevalence rates of lifelong surveillance and cancer screening practice among cancer survivors reported in the literature.

### Lifelong Surveillance

Lifelong surveillance of cancer survivors is a critical priority for cancer control plans (National Cancer Policy Board, 2003). In recent years, models of follow-up care that draw more actively on the skills of primary healthcare providers, advanced practice nurses, or multidisciplinary teams are being advocated to ensure cancer survivors receive education and preventive services as well as ongoing primary healthcare services (Oeffinger & McCabe, 2006). Regular follow-up care for cancer survivors is recommended to facilitate the early identification and management of late effects, including second cancers, and to reduce the frequency of severe complications and morbidity, easing the impact on the healthcare system. Another benefit of lifelong surveillance is that it creates a "teachable moment" that provides an opportunity to correct any knowledge deficits cancer survivors may have about their cancer risk and what they can do about that risk (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005).

Despite the potential benefits of long-term follow-up, as many as 60% of survivors report no regular medical follow-up visits (Arvidson, Soderhall, Eksborg, Bjork, & Kreuger, 2006; Earle & Neville, 2004; Mols, Coebergh, & van de Poll-Franse, 2007; Nord, Mykletun, Thorsen, Bjoro, & Fossa, 2005; Oeffinger et al., 2004; Shaw et al., 2006). Of the survivors receiving long-term follow-up care, 70%–92% reported having had

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	Study	Design/Assessment of Outcomes	Participants	Prevalence Rates
ONCOLOGY NURSING FORUM – VOL 35, NO 2, 20	Andersen & Urban, 1998	Survey/interview survey	248 breast cancer survivors ages 52–82 from a rural population	Mammography: 70% within the past year
	Aparicio-Ting & Ramirez, 2003	Survey/survey	112 Hispanic cancer survivors (54 with primary breast cancer and 58 with primary cervical cancer) and 2,062 Hispanic women with no history of cancer	Mammography: 80%–92%; Pap testing: 77%–86%
	Arvidson et al., 2006	Survey/questionnaire (closed- and open- ended questions)	245 Swedish survivors of childhood leukemia, lymphoma, and Wilms' tumor with a mean age of 25 $$	Medical follow-up: 40%
	Bellizzi et al., 2005	Cross-sectional survey/National Health Interview Survey (1998–2001)	7,384 cancer survivors age 18 and older and 121,347 adults age 18 or older with no history of cancer (controls)	Mammography: 88% within the past two years; Pap testing: 80% within the past three years; PSA testing: 75% within the past year. Female cancer survivors were more likely to have had a mammogram and Pap test compared to controls. Male cancer survivors were more likely than controls to have had PSA testing within the past year.
	Bloom et al., 2006	Pre- and post-test randomized trial/pretest questionnaire	133 survivors of Hodgkin disease ages 19–54 who received chest radiation before age 35	Mammography: 80% any time, 60% within the past 14 months, 36% in maintenance stage; CBE: 100% any time, 88% within the past 14 months, 80% in maintenance stage; BSE: 25% within the past year
	Butterfield et al., 2004	Survey/questionnaire	541 childhood cancer survivors from the CCSS cohort who were identified as smokers and enrolled in a smoking cessation program	Have a primary healthcare provider: 76%
	Castellino et al., 2005	Survey/questionnaire	8,767 childhood cancer survivors from the CCSS cohort (443 African American survivors, 503 Hispanic survivors, and 7,821 non-Hispanic Caucasian survivors)	General medical contact: 80% (African American), 82% (Hispanic), 88% (non-Hispanic Caucasian); general physical examination: 61% (African American), 62% (Hispanic), 65% (non-Hispanic Caucasian); cancer- related medical visit: 36% (African American), 47% (Hispanic), 42% (non-Hispanic Caucasian); medical visit at a cancer center: 17% (African American), 27% (Hispanic), 18% (non-Hispanic Caucasian); CBE: 66% (African American), 57% (Hispanic), 64% (non-Hispanic Caucasian); BSE: 35% (African American), 32% (Hispanic), 28% (non-Hispanic Caucasian); BSE: 35% (African American), 32% (Hispanic), 28% (non-Hispanic Caucasian); Row (non-Hispanic Caucasian); TSE: 28% (African American), 18% (Hispanic), 17% (non-Hispanic Caucasian)
×	Crom et al., 2005	Descriptive, exploratory/focus groups	20 female survivors of Hodgkin disease ages 16–26 who received chest radiation	BSE: 50%
	Diller et al., 2002	Prospective cohort/questionnaire	90 survivors of Hodgkin disease ages 24–51 who received chest radiation	Mammography: 47% within the prior two years; BSE: 9%
	Duffy et al., 2006	Matched cohort/National Health Interview Survey (1996–1998)	340 women age 40 and older with no breast cancer history (controls) matched on race and ethnicity and age (varied $\pm$ 5 years)	Mammography: 78%; CBE: 88%; Pap testing: 60%. Survivors were more likely to receive breast cancer screening than controls.
	Earle et al., 2003	Matched cohort/Medicare data (1997–1998)	5,965 Medicare-eligible survivors of nonmetastatic breast cancer and 6,062 Medicare patients with no history of cancer (controls) with a mean age of 78 matched on age and race and ethnicity	Mammography: 74%; Pap testing: 31%; colon examination: 17%; survivors received more cancer screening than controls.
				(Continued on next page)

## Table 1. Summary of Studies Reporting the Prevalence Rates of Secondary Prevention Practices Among Cancer Survivors

BSE—breast self-examination; CBE—clinical breast examination; CCSS—Child Cancer Survivor Study; FOBT—fecal occult blood test; GP—general practitioner; PSA—prostate-specific antigen; TSE—testicular self-examination

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	Study	Design/Assessment of Outcomes	Participants	Prevalence Rates
	Earle & Neville, 2004	Matched cohort/Medicare data (1997–1998)	14,884 Medicare-eligible survivors of nonmetastatic colorectal cancer and 16,659 Medicare patients with no history of cancer (controls) with a mean age of 80 matched on age, gender, race and ethnicity, and geographic location	Consultation with oncologist: 50%; consultation with oncologist and GP: 92%. Cancer survivors were slightly more likely to have mammograms than controls. Controls were more likely to have Pap testing than cancer survivors.
	Eiser et al., 1996	Clinic audit/questionnaire	93 childhood cancer survivors with mean age of 16	Long-term follow-up clinic attendance: 66% annually, 29% every three to nine months
1	Hudson et al., 2002	Longitudinal, randomized control trial/base- line health practices questionnaire	266 childhood cancer survivors ages 12–16 who attended St. Jude Children's Research Hospital after completion of therapy clinic	Self-examinations (BSE and TSE): 27%
ONCOL	Johnson et al., 2004	Clinic audit/clinic database, treatment sum- maries, previous employment study, and case review	385 childhood cancer survivors ages 11–18	Long-term follow-up clinic attendance: 87%
OGYN	Mahon et al., 2000	Survey/survey	668 outpatient oncology nurses	Mammograms, CBE, and Pap testing are more consistently performed than colon examinations.
NURSING F	Mayer et al., 2007	Cross-sectional survey/National Cancer Institute's 2003 Health Information Trends Survey	619 cancer survivors and 2,141 adults with no personal or family history of cancer	Mammography: 92%; Pap testing: 99%; PSA testing: 76%; colon ex- amination or FOBT: 85%. Cancer screening is significantly higher among survivors than the comparison group for colorectal cancer but not breast or prostate cancer.
DRUM – VO	Mols et al., 2007	Population-based, cross-sectional/survey (similar questions to annual population- based health monitoring surveys)	1,112 Dutch cancer survivors of endometrial cancer, prostate cancer, and non-Hodgkin lymphoma	Consultation with GP: 82%–92%; consultation with specialist: 71%–92%. Cancer survivors used more health services than controls. Comparable percentages of the cancer survivor and general population visited GPs. Survivors were more likely to visit a specialist.
L 35, NO	Nord et al., 2005	Case control/Nord-Trondelag Health Survey (1995–1997)	1,674 cancer survivors and 16,659 population-based controls matched on age and gender	Consultation with GP: 70%; consultation with specialist: 43%. Cancer survivors used more health services than controls, particularly survivors of leukemia or lymphoma.
2, 200	Oeffinger et al., 2004	Retrospective cohort/questionnaire	9,434 childhood cancer survivors from the CCSS cohort with a mean age of $\ensuremath{27}$	General medical contact: 87%; general physical examination: 71%; cancer- related medical visit: 42%; medical visit at a cancer center: 19%
∞	Shaw et al., 2006	Case-control/questionnaire	2,152 survivors of childhood and adolescent cancer from the Canadian Late Effects Study Cohort and 2,432 population-based controls ages $6-37$	Consultation with GP: 71%; consultation with specialist: 68%; consultation with oncologist: 29%; survivors were more likely than controls to visit a specialist or oncologist.
	Taylor et al., 2004	Cross-sectional survey/postal survey	GPs of 10,797 childhood cancer survivors from the British Childhood Cancer Survivor Study cohort	Consultation with oncologist: 35%
	Trask et al., 2005	Case control/National Health Interview Survey and Cancer Control Module (2000)	2,151 cancer survivors and 30,195 adults with no history of cancer (controls)	Cancer screenings: 21%–77%. Compared to controls, cancer survivors had higher rates of mammography, CBE, Pap testing, PSA testing, and colorectal cancer screenings.
	Yeazel et al., 2004	Retrospective cohort/questionnaire	9,434 survivors of childhood cancer from the CCSS cohort and 2,667 siblings without cancer (controls)	Mammography: 21%; CBE: 62%; BSE: 27%; Pap testing: 78%; TSE: 17%. Survivors obtained more cancer screenings than sibling controls.

Table 1. Summary of Studies	<b>Reporting the Prevalence</b>	Rates of Secondary Preve	ention Practices Among Cance	r Survivors <i>(Continued)</i>
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a consultation with a general practitioner (GP) and fewer than half report visiting an oncologist (Butterfield et al., 2004; Castellino & Hudson, 2002; Castellino et al., 2005; Mols et al.; Nord et al.; Oeffinger et al., 2004; Shaw et al.; Taylor et al., 2004). Survivors reported having one cancer-related evaluation per year, although these visits may be as frequent as every three to six months even five years after treatment (Earle, Davies, Greenfield, Ross, & Eiser, 2005; Eiser et al., 1996; Shaw et al.). Population-based survey studies indicate that survivors are more likely to seek specialist care than noncancer controls, but the prevalence of primary healthcare use provided by GPs among survivors is comparable to that of the general population (Mols et al.; Nord et al.; Shaw et al.).

Although survivors' self-reported healthcare patterns concur with those reported by healthcare providers (Taylor et al., 2004), preliminary results from Johnson, Horne, Felbower, Butler, & Gaster (2004) suggested that self-report data underestimates the true prevalence of long-term follow-up. Through an audit of administrative databases and chart reviews, Johnson et al. found that 87% of childhood cancer survivors attend long-term follow-up clinics.

### Cancer Screening

Cancer screening is appropriate for cancers that present a threat to morbidity and mortality if undetected; have a predictable history and biology; are treatable during their early stages; and are predicted accurately with accessible, cost-effective screening tests (Champion & Rawl, 2005). For the general population, evidence-based screening tests are recommended for the early detection of breast, cervical, and colorectal cancers (Canadian Cancer Society and National Cancer Institute of Canada, 2006; Sunga, Eberl, Oeffinger, Hudson, & Mahoney, 2005). Prostate and testicular cancer screenings also are possible but convincing evidence of their effectiveness in reducing mortality is limited (Canadian Cancer Society and National Cancer Institute of Canada).

**Breast cancer:** Mammograms and clinical breast examinations (CBE) are recommended for breast cancer screening, particular for women with a history of breast, ovarian, or endometrial cancer and those treated with chest radiation for Hodgkin disease (Children's Oncology Group [COG], 2006; Mahon, 2005). As indicated for the general population, breast self-examination (BSE) is not recommended for cancer survivors because no evidence exists that BSE improves survival or increases benign biopsy rates (Rosolowich & Breast Diesease Committe of the Society of Obstetricians and Gynecologists of Canada, 2006). Women are encouraged, however, to perform BSE to know what is normal for them and promptly respond to any changes or concerns.

Oncology nurses report that mammograms and CBE are two of the most consistently performed cancer screening activities for cancer survivors (Mahon, Williams, & Spies, 2000). Not surprising, several studies have found low BSE prevalence rates among cancer survivors, ranging from 9%– 25% among survivors of adult cancers (Bloom, Steward, & Hancock, 2006; Diller et al., 2002) and 28% among survivors of childhood Hodgkin disease (Yeazel et al., 2004). In general, higher rates of adherence have been reported for CBE and mammography. Researchers have found that the proportion of women who have had a recent CBE is similar for survivors of childhood cancers (63%) (Yeazel et al.) and adult cancers (68%) (Trask et al., 2005). Fewer long-term survivors of childhood cancer (21%) report having had a mammogram (Yeazel et al.) than survivors of adult cancer (75%–92%) (Bellizzi, Rowland, Jeffery, & McNeel, 2005; Mayer, Terrin, Menon, & Kreps, 2007; Trask et al.). These studies also found that survivors were significantly more likely to have practiced breast cancer screening than sibling controls or population-based noncancer controls, even when breast cancer survivors were excluded from the analysis.

Cervical cancer screening: The Pap test has been available for the past 50 years as a screening test for cervical cancer (COG, 2006; Mahon, 2005). Pap testing is used to identify precancerous lesions and early presymptomatic cervical cancer. According to oncology nurses, the Pap test is another consistently performed cancer screening for cancer survivors (Mahon et al., 2000). The Childhood Cancer Survivor Study ([CCSS], 2004) is the only study to date that reports the prevalence of Pap testing among female survivors of childhood cancer. Of the 4,414 females in the CCSS cohort, 78% reported having had a Pap test within the previous three years (Yeazel et al., 2004). Similarly, data from the National Health Interview Surveys conducted in the United States indicated that the prevalence of Pap testing across all cancer sites among survivors of adulthood cancers ranges from 80%-99% (Bellizzi et al., 2005; Trask et al., 2005). As is the case with other cancer screenings, cancer survivors were more likely than women with no cancer history to have had a Pap test (Aparicio-Ting & Ramirez, 2003; Bellizzi et al.; Earle & Neville, 2004; Earle, Burstein, Winer, & Weeks, 2003; Trask et al.).

**Colorectal cancer screening:** Periodic screening for colorectal cancer is recommended beginning at age 50 through fecal occult blood testing (FOBT) and colorectal examinations (i.e., colonoscopy and flexible sigmoidoscopy) (COG, 2006; Mahon, 2005). Although childhood cancer survivors treated with abdominal radiation are at highest risk for developing colorectal cancer (Bhatia et al., 2003), no studies report the prevalence of colorectal cancer screenings among survivors of childhood cancer.

Compared to other cancer screenings, oncology nurses report that colorectal cancer screenings are the least frequently performed on survivors of adult cancers, with more screenings performed using FOBT (32%-48%) than colorectal examinations (20%–28%) (Mahon et al., 2000). In contrast, self-reported screening rates indicate that survivors receive more colorectal examinations (43%) than FOBT (21%) (Trask et al., 2005). When American Medicare insurance data is analyzed, the prevalence of colorectal cancer screening falls to 17% among cancer survivors (Earle et al., 2003). Colorectal cancer screening is more common among cancer survivors than with individuals without a history of cancer (Earle et al., 2003; Trask et al.). In a study using data from the 2000 National Health Interview Survey in the United States, Trask et al. found that when colon cancer survivors are excluded, survivors were 36% more likely to have had an FOBT and more than 85% more likely to have had colorectal examinations than controls.

**Prostate cancer screening:** Prostate-specific antigen (PSA) testing often is used for the early detection of prostate cancer for men over the age of 50 (Mahon, 2005). Population-based surveys indicate that 57%–85% of men have had PSA testing (Mayer et al., 2007; Trask et al., 2005), with 75% having PSA testing in the past year (Bellizzi et al., 2005). When prostate cancer survivors are excluded, cancer survivors are

more likely to have had PSA testing than noncancer controls (Bellizzi et al.; Trask et al.).

**Testicular cancer screening:** As is the case with BSE, testicular self-examination (TSE) is not recommended for testicular cancer screening but offers men the opportunity to get to know their bodies well enough to detect changes. The prevalence of TSE among male survivors of adult cancers remains unknown. Baseline data from a multicomponent health promotion intervention for survivors of childhood cancer indicated that 27% perform monthly self-examinations (Hudson et al., 2002). When only TSE is considered, the prevalence rate of self-examinations decreases to nearly 17% (Yeazel et al., 2004). Although the prevalence rate is low, research from the CCSS cohort indicated that survivors were more likely than their siblings to perform a monthly TSE (Yeazel et al.).

#### Summary

Compared to the general population, the prevalence of secondary prevention practices among cancer survivors is generally lower than recommended. Cancer survivors' pattern of healthcare use is not surprising given the fragmentation of follow-up services available, particularly in the United Kingdom and United States (Oeffinger et al., 2004; Taylor et al., 2004). Even when cancer centers are able to provide comprehensive long-term follow-up programs, they often do not have adequate staffing and resources for the delivery of follow-up care to the growing cancer survivor population (Oeffinger & McCabe, 2006).

Many conceptual areas need further investigation in the study of health outcomes. Although the prevalence rates of lifelong surveillance and screening are of value, more detail about how and why individuals seek out follow-up care, such as cancer survivors' independent access of health information sources to inform their decisions and self-referred or professional-referred use of formal or informal healthcare services (e.g., frequency of visits, type and nature of services sought), is needed. In addition to healthcare use, other behaviorally related conceptual outcomes have been identified by Cox (2003), including health status indicators, problem-severity indicators, adherence to recommended care regimens, and satisfaction with care.

# Client Singularity: Factors Associated With Secondary Prevention Practices of Cancer Survivors

Within the IMCHB model, an understanding of client singularity is necessary to identify the physical, social, cognitive, motivational, affective, and environmental antecedents of the longitudinal cancer-related health care of cancer survivors (Cox, 2003). Client singularity is a reflection of background and dynamic variables.

#### **Background Variables**

Four background variables may directly explain survivors' secondary prevention practices or serve as determinants of dynamic variables of client singularity: demographics, social influences, previous healthcare experiences, and environmental resources (Cox, 2003).

**Demographic variables:** Compared with noncancer controls, cancer survivors who demonstrate secondary prevention behaviors are more likely to be female, married, and have higher levels of education, income, and employment (Aparicio-Ting & Ramirez, 2003; Bloom et al., 2006; Earle & Neville, 2004; Johnson et al., 2004; Oeffinger et al., 2004; Yeazel et al., 2004). This pattern holds true for survivors of childhood and adult cancers.

Research consistently finds that age is a predictor of secondary prevention practices among cancer survivors. The proportion of survivors reporting cancer-related visits decreased with age (Arvidson et al., 2006; Oeffinger et al., 2004; Shaw et al., 2006). In fact, researchers have found that by age 30, only 40% of survivors consult a specialist and 10% visit an oncologist; by age 40, only 12% receive any follow-up care (Shaw et al.; Taylor et al., 2004). However, the only study to compare healthcare use among cancer survivors age 70 and older with those younger than age 70 found no age differences (Mols et al., 2007). The opposite age effect is found for cancer screening in that survivors age 30 and older were more likely than younger survivors to report having participated in cancer screening (Bloom et al., 2006; Diller et al., 2002; Yeazel et al., 2004).

Ethnicity also plays an important role in predicting secondary prevention practices. When all preventative services, including cancer screening, are considered, research shows that African American survivors receive fewer services compared to survivors of other ethnicities (Earle et al., 2003). However, ethnic minority status is not always a predictor of lack of health care. In a study of 8,767 childhood cancer survivors from the CCSS cohort, Castellino et al. (2005) found that in comparison to non-Hispanic Caucasian survivors, African American survivors were more likely to report compliance with gender-specific screening strategies and Hispanic survivors were more likely to report a cancer center visit.

**Social influences:** Only one study has investigated the influence of family on a survivors' decision to engage in preventive health behaviors. In a study evaluating the breast health promotion activities of female survivors after the diagnosis of childhood Hodgkin disease, Crom, Hinds, Gattuso, Tyc, and Hudson (2005) found that pressure from family, observing a relative's struggle with cancer, and love for their own child motivated women's participation in breast cancer screening.

Previous healthcare experiences: Survivors' primary diagnoses are one of the most significant predictors of secondary prevention practices. Studies on nonattendance patterns in Canada and the United Kingdom have found that survivors of leukemia and lymphoma are most likely to attend long-term follow-up clinics, and survivors of central nervous system tumors, retinoblastoma, germ cell tumors, and carcinoma are least likely to attend clinics (Shaw et al., 2006; Taylor et al., 2004). Evaluations of cancer screening practices have shown that the prevalence of Pap testing ranges from 18% for colorectal cancer survivors, 77% for cervical cancer survivors, and 60%-86% for breast cancer survivors (Aparicio-Ting & Ramirez, 2003; Duffy, Clark, & Allsworth, 2006; Earle & Neville, 2004; Earle et al., 2003). Similarly, the prevalence of mammograms ranges from 54% among colorectal cancer survivors, 80% among cervical cancer survivors, and 70%-92% among breast cancer survivors (Andersen & Urban, 1998; Aparicio-Ting & Ramirez; Bellizzi et al., 2005; Duffy et al., 2006; Earle & Neville; Earle et al., 2003). Differences in the prevalence rates of mammograms among breast cancer survivors may be attributable to differences in how the primary cancer was detected. Andersen and Urban found that women

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whose primary breast cancer was detected by mammography were more likely than other women to receive surveillance mammography.

Research also shows that survivors with a history of highrisk cancer treatment demonstrated below optimal cancerrelated follow-up and cancer screening. Only 35%–39% of high-risk survivors had regular follow-up with an oncologist (Arvidson et al., 2006; Shaw et al., 2006). Similarly, studies found prevalence rates of under 25%, 30%–35%, and 80% for BSE, mammography, and CBE, respectively, among women who were treated with chest radiation (Bloom et al., 2006; Bober, Park, Schmookerler, Medeiros Nancarrow, & Diller, 2007; Diller et al., 2002; Mayer et al., 2007; Yeazel et al., 2004). These screening rates are, however, higher than those for survivors without such a treatment history.

Another predictor of healthcare use is the time since diagnosis. As is the case with age, increasing time since diagnosis has been associated with more visits to a GP and fewer to an oncologist (Shaw et al., 2006; Taylor et al., 2004). For example, Shaw et al. found that 75% of survivors ages 15–19 after diagnosis consulted a GP and only 15% consulted an oncologist.

Environmental resources: Navigating the healthcare system to receive optimal longitudinal health care can be challenging for survivors. Research indicates that lack of health insurance is an important factor associated with lack of cancer-related follow-up and cancer screening (Bloom et al., 2006; Bober et al., 2007; Mayer et al., 2007; Oeffinger et al., 2004; Yeazel et al., 2004). Access to secondary prevention services also is influenced by the type of facility and clinician providing the services. Studies on breast and colorectal cancer survivors have found that survivors report receiving more cancer screenings when they receive care from a teaching hospital compared with a nonteaching hospital (Earle et al., 2003; Earle & Neville, 2004). These studies also showed that survivors who saw only an oncologist were more likely to undergo surveillance mammography, those who saw only a GP were more likely to have a colonoscopy or Pap test, and those who saw an oncologist and GP received all three cancer screenings. Another significant contributor to screening behavior is physician recommendations. Research has shown that cancer screening rates are lower when physicians tell survivors that screening is unnecessary (Bober et al., 2007; Mayer et al., 2007).

### Dynamic Variables

Survivors' decisions to be proactive regarding their health may be influenced by such dynamic variables as affective responses, motivation, and cognitive appraisal (Cox, 2003). These variables are interrelated such that attitudes, knowledge, and beliefs contribute to motivation and emotions, and emotions can influence motivation and beliefs.

Affective responses: The IMCHB proposes that affective responses may contribute to behavioral decision making (Cox, 2003). Many survivors are not getting regular cancer screening because of fears of finding an abnormality or fears of missing something (Bober et al., 2007; Crom et al., 2005). Another barrier is survivors' lack of concern about future health because they want to avoid thinking about illness and cancer risk (Bober et al., 2004; Yeazel et al., 2004).

**Motivation:** If survivors are influenced by the belief in selfcontrol over health actions, the IMCHB predicts that survivors will be more motivated to seek long-term follow-up care and practice healthy behaviors (Cox, 2003). Research shows that some survivors believe they can prevent second cancers (Bober et al., 2007; Mayer et al., 2007), but Costanzo, Lutgendorf, Bradley, Rose, and Anderson (2005) demonstrated that this belief translates into successful health actions. In a study investigating the cancer attributions and health behaviors of long-term endometrial and cervical cancer survivors, Costanzo et al. found that women who believed medical check-ups and cancer screening were important preventative measures were more likely to obtain regular mammograms and Pap tests than women who did not share this belief.

**Cognitive appraisal:** Based on the IMCHB model, knowledge, attitudes, and beliefs about health, cancer, treatment, and health behaviors may influence the secondary prevention practices of cancer survivors (Cox, 2003). Research consistently shows that nearly half of survivors are unaware of their increased risk for second cancers, and of those who are aware, a significant proportion understand themselves to be at equal or lower risk than individuals of the same age (Blacklay, Eiser, & Ellis, 1998; Bloom et al., 2006; Diller et al., 2002; Hudson et al., 2002). However, contrary to expectation, preliminary results suggest that cancer survivors who perceive themselves to be at high risk for developing cancer are not more likely to get regular cancer screenings (Bloom et al.; Diller et al.; Mayer et al., 2007).

Knowledge of screening guidelines is another factor that had been identified as influential in the adoption of secondary prevention practices. In a study evaluating the knowledge and screening practices of Hispanic breast and cervical cancer survivors, Aparicio-Ting and Ramirez (2003) found that although overall knowledge of screening guidelines was low, women who knew more about breast cancer screening were more likely to participate in mammography. Knowledge of Pap testing was not, however, associated with Pap test use.

### Summary

The degree to which individual variables exert an influence on secondary prevention practices of cancer survivors has been difficult, thus far, to determine. Clearly, more research is warranted to better understand how social influences affect survivors' decisions to participate in life-long surveillance and cancer-screening programs. Evidence illustrates the need for additional study about survivors' secondary prevention practices that integrates individual level variables and controls for contextual variables. Understanding causal pathways from antecedent variables, particularly the understudied affective response as correlated with health behaviors, must be addressed.

## Client-Professional Interactions: Interventions Promoting Secondary Prevention Practices Among Cancer Survivors

Another element of the IMCHB is the client-professional interactions or interventions that support or discourage health behaviors (Cox, 2003). To date, five intervention studies have focused on improving the secondary prevention practices of cancer survivors. These interventions aim to (a) attend to survivors' emotional needs, (b) alter affective responses and inform cognitive appraisal though the provision of useful health information, and (c) support survivors' capacity to make decisions about their own health.

Two randomized trials delivering risk-counseling interventions to cancer survivors were identified. The randomized control trial by Hudson et al. (2002) sought to evaluate a multibehavioral intervention offered to childhood cancer survivors attending a long-term follow-up clinic. Survivors were randomized to receive either standard care or standard care and the intervention. The intervention featured health behavior training of a health goal chosen by the survivor, health goal commitment, and telephone follow-up to reinforce the training. Of the 131 survivors in the intervention group, 14% committed to performing monthly BSE and TSE. These survivors were the only ones in the intervention group to show improvement in their selected health goal. This study provides evidence supporting the feasibility of targeting cancer screening practices for modification.

The second randomized trial investigated the effects of a telephone counseling intervention on the initiation of breast cancer screening activities among women who received chest radiation before age 35 for Hodgkin disease (Bloom et al., 2006). Stratified randomization was used to assign women to either the intervention group or control group (delayed intervention) based on whether they were in mammogram maintenance (i.e., have had mammograms in the past and intend to continue having them). The intervention addressed women's concerns about their breast cancer risk and screening, and promoted mammography for women age 25 and older and CBE for women younger than age 25. The intervention produced significant increases in mammography maintenance and CBE maintenance postintervention. Women most affected by intervention were those younger than age 40.

In light of the significant knowledge deficits demonstrated among cancer survivors, interest in evaluating the effects of educational interventions on their secondary prevention practices is growing. Two studies (Blacklay et al., 1998; Eiser, Hill, & Blacklay, 2000) have tested the hypothesis that increasing childhood cancer survivors' awareness of late effects would influence follow-up clinic attendance and cancer screening. The first study was based on a sample of 55 survivors attending a late-effects follow-up clinic in the United Kingdom, and the other was a replication study with a sample of 263 survivors. The intervention for both studies was an information package with general information for all survivors and specific information related to likely late effects of treatment. Blacklay et al. found that the intervention produced a significant increase in survivors' awareness of the importance of follow-up, but only 40% performed self-examinations. In the study by Eiser et al. (2000), ratings of the importance of follow-up did not change. However, participants in the intervention were more ready to make behavioral changes and more confident in their ability to make such changes. These results are encouraging because cancer survivors are at least interested in changing their health behaviors.

Finally, the advent of self-advocacy training programs promises to help survivors achieve a sense of control over their lives by giving them the skills necessary to make decisions and to negotiate the healthcare system (Walsh-Burke & Marcusen, 1999; Zebrack, Oeffinger, Hou, & Kaplan, 2006). Preliminary data from the Young Adult Survivors Conference indicated that survivors who participate in an advocacy skills training program intend to locate and consolidate their medical records, find out more about their own health risk, and get appropriate follow-up care (Zebrack et al.). The next step in this research would be to determine if survivors follow through with their intentions.

#### Summary

The literature on interventions to promote secondary prevention practices in cancer survivors is small but growing. Intervention studies that use a theory-driven explanatory framework are needed. These studies could test models, including IMCHB, to determine which components best predict behavior changes and actual secondary prevention practices of survivors. The full benefits of evaluating interventions to prevent second cancers through randomized controlled trials have not yet been realized. When planning to conduct these trials, researchers must consider that cancer survivors often refuse to participate because they lack interest in health promotion (Tercyak, Donze, Prahlad, Mosher, & Shad, 2006). Recruitment efforts that seek to correct knowledge deficits about second cancer risk and the role of behavior in health promotion may facilitate trial participation.

## Limitations of Current Research Research Design

Much of the research on secondary prevention patterns relies on a quantitative research design with the intent of generating hypotheses or hypothesis testing. Although the findings from quantitative research are valuable, a more comprehensive understanding of the secondary prevention practices among cancer survivors could be gained by approaching the topic with a qualitative research design. Qualitative research would be best suited to answering how and why questions about the meanings cancer survivors assign to their health and healthrelated behaviors (Woodgate, 2000). This research would acknowledge cancers survivors as experts of their own cancer survivorship experience.

Another problem with respect to the research design is the relative absence of longitudinal research. The research conducted to date is primarily retrospective and cross-sectional. Prospective longitudinal cohort studies are needed to understand if the background and dynamic variables proposed in the IMCHB truly are related to survivors' secondary prevention practices. Prospective studies would be valuable in determining causal relationships and addressing issues of temporality (Hudson, 2005). In addition, prospective evaluations of the interventions promoting secondary prevention practices for cancer survivors must be pursued with the same standards that are used for randomized drug trials to provide survivors with effective, proven strategies for reducing second cancer risks (Hudson).

#### Study Samples

One of the biggest challenges in reviewing the state of secondary prevention research is that differences in sample demographics make comparisons across studies problematic. Given that population demographics for surveyed regions may be representative of the entire cancer survivor population, caution must be used when interpreting results because they may not accurately reflect average secondary prevention practices across cancer survivors. Much of what is known about secondary prevention practices among cancer survivors is based on survivors of childhood cancer or breast cancer among adults.

Another problem in the reviewed studies is the presence of sampling biases. Studies included many participants who were younger than the cancer screening guidelines set for the general population. Thus, the lower prevalence rates of some cancer screening practices among young adult cancer survivors were expected. Another bias is the inclusion of survivors who attend follow-up clinics and survivors who are a part of the CCSS cohort. These survivors are likely a knowledgeable and motivated group. Accordingly, the prevalence of secondary prevention practices may have been lower if survivors who practice avoidance or wish to forget their cancer experience were included in the reviewed studies.

## **Data Collection Methods**

How researchers described and counted secondary prevention practices differed from study to study. Consulting an oncologist was assumed to be indicative of receiving cancerrelated follow-up, but the content of medical visits was not assessed. Without knowing the purpose of each healthcare visit, researchers cannot be sure which visits were for cancerrelated follow-up care and which were for other reasons. Also problematic is that how researchers measured whether survivors met cancer screening recommendations depended on which recommendations were used as the standard. Some studies compared survivors' cancer screening practices to consensus, disease-oriented guidelines, and others compared them to recommendations from professional societies.

Another problem with the reviewed studies is the reliance on different data sources. For some studies, the determination of healthcare use was based on self-report and not externally verified reports. Self-report may not, however, be reliable because many survivors do not understand the rationale for follow-up visits or screening tests (Oeffinger et al., 2004). Other studies relied on Medicare claims to study secondary prevention practices. One limitation of using administrative databases for research purposes is that it is not always evident as to whether a procedure was performed for routine or diagnostic indications (Cooper et al., 2006). Procedures such as mammography or colon examination may be performed for routine surveillance or to diagnosis symptoms. Thus, the prevalence of cancer screening practices among cancer survivors may be misleading if procedures performed for diagnostic purposes and not routine indications were included.

## **Directions for Future Research**

More comprehensive evidence-based guidelines for the long-term care of cancer survivors are needed. Guidelines should evolve from research that aims to determine the roles of oncologists, GPs, and survivors in survivorship care; define the optimal timing and most effective methods for intervening in health behaviors; and evaluate the feasibility and cost-effectiveness of different strategies for surveillance and prevention of second cancers (Oeffinger & McCabe, 2006). The IMCHB should serve to set the future direction for nursing research in these areas because it accounts for the complex interaction between individual health behavior and the context in which the behavior occurs.

Because perceptions of vulnerability do not always correlate with health-promoting practices, mediating factors other than health perceptions should be investigated. Consideration must be given to understanding the interrelationships among secondary prevention practices and other health behaviors. Future research also should address the perceptions of family and friends about the risks that survivors face and their role in encouraging survivors to adopt secondary prevention practices.

## Implications for Nursing

Oncology nurses in every healthcare setting can be proactive in initiating cancer screening and prevention strategies in their routine nursing care of long-term cancer survivors (Kolb-Smith, 2002). The key to a successful health promotion program designed to improve the long-term survival of cancer survivors is the development of a program that acknowledges the context within which survivors' behavior exists and programs directed toward the predictors of health behavior.

The IMCHB may be used by nurses as a useful assessment framework. Elements of client singularity, specifically those modifiable elements (motivation, cognitive appraisal, and affective responses) are most amenable to nursing intervention. Nurses can encourage survivors to adopt secondary prevention practices by providing positive reinforcement, support, and education. Survivors need to learn about their second cancer risk and about treatment, genetic, and behavioral factors that affect this risk. Nurses should encourage survivors to maintain regular follow-up appointments for clinical assessments and teach them to look for and report the signs and symptoms of second cancers. It is imperative that nurses counsel survivors in the risks of performing self-examinations. Because good technique is essential, a referral to a healthcare professional trained in the technique may be required (Rosolowich & Breast Disease Committee of the Society of Obstetricians and Gynecologists of Canada, 2006). Nurses also can impart information shared with survivors to family members, who might encourage survivors to have regular medical checkups and participate in cancer screening programs. Nurses need to remember the psychosocial aspects of risk notification and stresses associated with cancer screening. Nurses should address any concerns or worries survivors might have about their future health and ask survivors about fears they may have about seeking help.

## Conclusion

In conclusion, this review has not unequivocally determined whether cancer survivors represent a high-risk group that would benefit from secondary prevention interventions. What this review does show is that the cancer screening practices of cancer survivors are below optimal levels recommended for the general population, despite their increased risk for second cancers. Regular health monitoring and cancer screening practices appropriate for age and gender are recommended to reduce the burden of second cancers through early diagnosis and treatment.

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