

# Creating the Basis for a Breast Health Program for Female Survivors of Hodgkin Disease Using a Participatory Research Approach

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**Purpose/Objectives:** To learn from female survivors of Hodgkin disease about their perceptions of their current health status and future health risks, self-care practices to prevent or diminish health risks, and what kind of breast health program could benefit them, including the most effective methods and optimal times for learning about breast health.

**Design:** Participatory research using focus groups.

**Setting:** Urban pediatric cancer center.

**Sample:** 1 African American and 19 Caucasian female survivors of Hodgkin disease aged 16–26 years, diagnosed at least two years before the start of the study, and treated with mantle radiation therapy. Participants were recruited during visits to an outpatient clinic.

**Methods:** Six open-ended questions were asked during three separate focus group sessions. Transcribed data were evaluated by content analysis techniques and analyzed to identify common themes.

**Main Research Variables:** Current health status and perceived health risks, current health practices, and effective methods and timing for breast health teaching.

**Findings:** Survivors reported feeling damaged by their cancer and its treatment and perceived that they were at risk for breast cancer. Self-care and risky behaviors also were reported. Internal influences (e.g., fear) and external influences (e.g., family) motivated survivors to participate in health promotion activities. Effective methods identified for learning about breast health included having access to other survivors, being respected as an adult, and having one-on-one staff teaching and peer support. The preferred timing of teaching varied, but survivors generally supported a gradual provision of information.

**Conclusions:** A positive listening environment is important for developing a breast health program for survivors. An essential first step is to create an opportunity for survivors to tell about their experiences with cancer, including its impact on their lives. Information regarding breast health must be provided in multiple formats during and after treatment if good practices are to be undertaken.

**Implications for Nursing:** The provision of adequate information during and after therapy as well as peer counseling in a positive listening environment are important in helping survivors participate in health promotion activities.

Five-year survival rates of pediatric patients with Hodgkin disease now are approaching 90% (Hudson & Donaldson, 1997; Ries et al., 2001). Therefore, increasing attention is being focused on long-term sequelae, including second cancers. Women who have survived Hodgkin disease and received thoracic irradiation during puberty have a risk of developing breast cancer that is estimated to be 35–75 times greater than age- and race-matched controls (Bhatia et al.,

## Key Points . . .

- Female survivors of Hodgkin disease who received thoracic irradiation as a part of their therapy have a risk of developing breast cancer that is estimated to be 35–75 times greater than age- and race-matched controls.
- Despite education regarding the risk, 86% of survivors do not participate in any behaviors to promote breast health.
- Oncology nurses can facilitate survivors' self-care behaviors by listening to patients and giving risk-related information, teaching breast self-examination in multiple formats at various times during and after the completion of therapy, and creating or promoting opportunities for peer-based counseling.

2003; Sankila et al., 1996; Wolden, Lamborn, Cleary, Tate, & Donaldson, 1998). Numerous studies have documented that breast cancer is the most frequent solid tumor in women previously treated for pediatric Hodgkin disease (Bhatia et al., 1996; Hudson et al., 1998; Sankila et al.; Wolden et al., 1998, 2000). Research findings indicate a need for risk education and heightened breast cancer surveillance in this group of cancer survivors.

Oncology nurses are in a unique position to educate female survivors of Hodgkin disease about the risk of secondary

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breast cancer. Nurses have the opportunity to encourage health promotion behaviors, such as breast self-examination, discussion of risk factors with primary care physicians, and regular breast diagnostic imaging. Before education begins, nurses must understand what motivates female survivors to participate in a self-care program that promotes the early detection of breast cancer.

Few findings are available about the health knowledge and breast cancer risk awareness of female survivors of Hodgkin disease. Preliminary results of a study evaluating breast screening behaviors of female survivors at a median of 16 years after diagnosis of Hodgkin disease showed that 43% perceived their breast cancer risk to be the same as their peers and 86% did not perform breast self-examination regularly (Diller et al., 2002). Mammography screening was performed more commonly in women 35 years of age or older (88%) and less commonly in women younger than 35 years of age (50%). More than half (57%) had received information about their risk of breast cancer from the media; only 45% had discussed the risk with their oncologist.

Similar knowledge deficits were observed in survivors of childhood cancer who participated in a health promotion study (Hudson et al., 2002). Baseline surveys revealed that many participants underestimated their risk of treatment complications: Fifty-three percent had no recollection of being told about their increased risk of a second cancer. However, the development of a second cancer was the complication of greatest concern to them. The results underscore the need to improve patient education regarding breast cancer risk among female survivors of Hodgkin disease and promote adherence to a breast cancer screening program. Therefore, the objectives of the present study were to describe breast health practices used by female survivors of Hodgkin disease to detect secondary early-stage breast cancer, identify what motivated survivors to engage in breast health practices, and explore survivors' perceptions of the best methods and timing to assist them in learning about breast health practices.

## Literature Review and Theoretical Framework

### Breast Cancer After Treatment of Hodgkin Disease

Female survivors of Hodgkin disease have a significantly higher risk of developing breast cancer than women in the general population. This increased risk begins as few as five years after the completion of therapy and lasts for decades. Cumulative incidences of breast cancer among female survivors of Hodgkin disease in various studies range from 4%–35% at 20 years postdiagnosis (Kenney et al., 2004; Wahner-Roedler et al., 2003), representing an 8- to 75-fold increased risk compared to age-matched population controls. Most breast cancer lesions in female survivors of Hodgkin disease are ductal carcinomas in situ or infiltrating carcinomas (Bhatia et al., 1996; Cutuli et al., 1997; Diller et al., 2002; Kaste et al., 1998; Neglia et al., 2001). Breast tumors occur at the margin or in the field of irradiated tissue (Yahalom, 2003).

Factors documented to influence the risk of breast cancer in survivors of Hodgkin disease include chest wall radiation, chemotherapy with alkylating agents, hormonal stimulation, and underlying chromosomal abnormalities. The potential carcinogenic role of each of these factors alone or in combination has been debated (Deniz, O'Mahony, Ross, & Purushotham,

2003; Kenney et al., 2004; Tinger et al., 1997; van Leeuwen et al., 2003). Yahalom (2003) argued that the increased risk of breast cancer in female survivors of Hodgkin disease undoubtedly is associated with use of radiation therapy. Radiation therapy has been a standard treatment for Hodgkin disease since the 1960s. Historically, relatively high doses of radiation (i.e., > 40 Gy) have been used. In a recent study, Travis et al. (2003) demonstrated that in patients receiving only radiation therapy the relative risk of developing breast cancer correlated with the total dosage of mantle radiation received. Patients who received 4 Gy or more of radiation had a 3.2 times higher relative risk of developing breast cancer than those who received lower doses. Patients who received more than 40 Gy were eight times more likely to develop breast cancer. Bhatia et al. (2003) also found that risk factors influencing breast cancer after chest irradiation include higher cumulative doses (i.e., > 30 Gy) and longer time from radiation.

The evidence is less clear regarding the carcinogenic effect of chemotherapy alone or given in addition to radiation therapy. Many chemotherapy agents (particularly alkylating agents) are carcinogenic. However, Travis et al. (2003) reported an unexpected reduced risk for breast cancer in survivors of Hodgkin disease treated with alkylating agents alone (relative risk = 0.6) and only a 1.4-fold increased relative risk in survivors treated with alkylating agents plus radiotherapy. Kenney et al. (2004) reported similar findings, speculating that the carcinogenic potential of alkylating drugs may be offset by limiting ovarian function and inducing early menopause, thereby inhibiting the stimulation of hormone-sensitive breast tissue and reducing the potential for breast cancer.

Other host factors, such as predisposing genetic mutations and family history, have not been well-studied in large cohorts of survivors of childhood cancer but also may contribute to an increased risk of secondary breast cancer. The limited reports of predominantly adult cohorts with secondary breast cancer have not identified an association with cancer-predisposing genetic mutations like *TP53*, *BRCA1*, *BRCA2*, or *ATM* (Gaffney et al., 2001; Nichols et al., 2003; Offit et al., 2002).

In recent years, therapy for Hodgkin disease has been modified to reduce the risk of secondary breast cancer without compromising survival (Hudson, 2002; Hudson & Constine, 2004). Radiation therapy now is used as consolidation therapy after chemotherapy and not as primary treatment. Only involved lymph nodes are targeted for therapy. In addition to a reduction in the volume of breast tissue exposed to radiation, reductions also have been made in radiation doses (typically, from 40 Gy to 20–30 Gy). In a report from the Late Effects Study Group, Bhatia et al. (2003) noted that none of the survivors of Hodgkin disease who received less than 26 Gy of radiation to the mantle region developed breast cancer. However, Bhatia et al. (2003) also noted that patients are at an increased risk after radiation doses as low as 15 Gy.

Because the increased risk of secondary breast cancer persists for decades, survivors of pediatric Hodgkin disease must undergo heightened surveillance. Increased surveillance is particularly important because the median age of survivors in which secondary breast cancer is diagnosed is younger than 40 years, an age before which routine surveillance usually is initiated (Aisenberg et al., 1997; Goss & Sierra, 1998; Powers, Cox, & Reintgen, 2000; Smith, Cokkinides, & Eyre, 2004). In addition to the timing of surveillance, the optimal method of breast cancer screening in survivors is controversial (Kriege et

al., 2004). Mammography, the gold standard screening modality for breast cancer, currently has limited ability to evaluate dense premenopausal breasts and constitutes an additional radiation exposure (Esserman, 2002; Williams, Kaplan, Petersen, & Lieberman, 1986). Although detecting malignant breast changes may be difficult in young women, investigations of the use of mammography in high-risk groups of women younger than 35 years have shown that abnormal findings are correlated with identifying breast cancer (Goss & Sierra). Recognizing the limitations of mammographic screening in young women and the significant risk of developing breast cancer, the Children's Oncology Group (2004) has recommended a program of surveillance including monthly self-examination and annual clinical examination with mammography. Despite its failure to reduce breast cancer mortality in the context of a randomized, controlled trial of low-risk women, breast self-examination still is recommended for those at high-risk because of its association with a shorter time from the appearance of clinical symptoms to the diagnosis of breast cancer as well as diagnosing the disease at earlier clinical stages, when tumors are smaller and the incidence of metastasis to axillary nodes is lower (Thomas et al., 2002). An annual clinical examination by an experienced healthcare provider should begin at puberty, and its frequency should be increased to twice yearly at age 25. Annual mammography screening should be initiated after a patient is 25 years old and approximately eight years have elapsed since the completion of radiation therapy. The recommendations of the Children's Oncology Group include increasing awareness that childhood cancer treatment predisposes survivors to breast cancer and encouraging behaviors that modify breast cancer risk, such as discussing concerns with and being examined yearly by an experienced clinician.

## Participatory Research

The tenets of participatory research were chosen as the conceptual basis for this research because the researchers wanted to learn directly from female survivors about how their breast health needs could be served best by the healthcare system. Participatory research emphasizes the need to establish a dialogue between researchers and individuals affected by a certain life situation to learn firsthand about individuals' practical needs as they exist within a cultural context. Findings typically lead to programmatic, educational, or even political action (Reason, 1988). The individuals who participate in this kind of research often are viewed by clinicians as becoming more involved in their own development as a result of participation (Fals-Borda, 1988). The action that results from such research stems from the concerns of those who are most affected, in this case female survivors of Hodgkin disease at risk for developing subsequent breast disease. Participatory research tends to move through a three-stage cycle: problem identification, solution seeking, and solution implementation (Swantz & Vainio-Mattila, 1988). Problem identification in this patient population occurred in Hudson et al.'s (2003) health practices study in which female survivors reported their low rate of breast health practices. The current study was part of the solution-seeking stage.

## Methods

### Study Design and Implementation

A descriptive, exploratory design with a focus group format (Krueger & Casey, 2000; Morgan, Krueger, Scannell,

& King, 1997) was used to identify the current health status and motivations for practicing breast health behaviors among survivors of Hodgkin disease. The researchers also attempted to define effective methods and optimal times for teaching about breast health. Eligible patients were female survivors of Hodgkin disease who

- Were 16–26 years old
- Had attained at least a Tanner III stage of pubertal breast development on physical examination (i.e., enlargement of the breast without separation of breast and areola; immature areola, but increasingly darkly pigmented; nipple at or above the mid-plane of breast tissue when patient is seated upright [Ross, 1985])
- Had completed therapy for Hodgkin disease at least one year previously
- Had achieved a complete response to a single course of multimodality therapy
- Had no evidence of active disease
- Had received supradiaphragmatic irradiation that included irradiation of the breast.

Survivors who were at an outpatient clinic for a routine examination and met the study criteria were asked to participate in one of three focus group discussions held during a three-month period. The study was limited to three focus groups because of time and budget constraints. Two patients refused to participate and another was ineligible because of recurrent Hodgkin disease. Before initiation, the study was approved by the hospital's institutional review board. Written informed consent was obtained from participants 18 years of age or older; assent was obtained from younger patients with parental consent. Treatment and demographic information was abstracted from each participant's clinical record.

Audiotape recordings of the discussions were made. Discussions were guided by six questions that examined survivors' current health status and motivation for practicing breast health behaviors (see Figure 1). A research team familiar with the care of female survivors of Hodgkin disease developed the questions and the sequence in which the questions were asked. The questions were evaluated in a pilot study of six female survivors of Hodgkin disease who were patients in the outpatient clinic but did not participate in the focus group discussions. No revision was necessary after the pilot study.

### Data Analysis

Recordings of the sessions were transcribed verbatim, and the transcripts (more than 250 single-spaced pages per session) were loaded into The Ethnograph software (Scolari, Thousand Oaks, CA), which numbered the data for sorting and coding. One team member validated the accuracy of the transcripts before data analysis began. Data were analyzed using approaches that involved pragmatic and semantic content analysis (Krippendorff, 1980; Krueger & Casey, 2000; Morgan et al., 1997). Each question was used as the unit of analysis for coding.

The principal investigator and one facilitator coded the data and developed a coding dictionary. Codes were developed to describe participants' current health status and future health risks, current health practices and reasons for doing them, and opinions about effective methods and optimal times for teaching about breast health. After the dictionary was developed, three additional researchers experienced in analyzing data from focus

We are going to spend some time talking today about what you do to take care of your health and why you do those things.

- Tell us about your current health status and what health risks you face in the future.

Let's talk about things you are currently doing to help protect your health. Think about these things for a moment.

- What are these practices, and what caused you to start doing these things?

We're interested in designing a program to help Hodgkin disease survivors understand their risk of secondary breast cancer and practice behaviors that would promote the early detection of a tumor.

- When, during or after therapy, would be the best time to cover this?
- What would be the most effective format?

Think about a time during therapy when you learned a lot about some aspect of your cancer. Tell us about that time.

- What helped you learn?

Our job is to find out how best to teach Hodgkin disease survivors the benefits of self-care activities that promote early detection of breast cancer.

- Have we missed anything?

### Figure 1. Introduction and Focus Group Questions

group discussions independently coded the data (inter-rater reliability of coding = 0.82–0.87). The total frequency of each code and the frequencies of each code per group were noted. Concept analysis resulted in the development of an exploratory model using a modification of the Wilson technique (Wilson & Streatfield, 1977). The model suggested relationships between survivors' perceptions of their current health status, their motivation for practicing breast health behaviors, and potential interventions to enhance participation.

Several measures ensured that the results accurately reflected participants' feelings and thoughts. Questions were designed by a team that included a social worker, two pediatric oncologists, a psychologist, and two advanced practice oncology nurses. These individuals each have cared for pediatric survivors of cancer for 15 or more years and understand the issues concerning female survivors of Hodgkin disease. The questions were evaluated in a pilot study. The group facilitators were oncology clinical nurse specialists who had received formal training in focus group methodology. Notes describing subtle nuances of communication were maintained. Codes, definitions, and themes were labeled using the participants' words so that the researchers' interpretation would reflect participants' perceptions accurately. Participants verified their summary comments at the conclusion of each discussion. Researchers coding the data were trained to ensure consistent interpretation of codes and definitions. Codes were reviewed with a sample of participants to determine their accuracy and completeness.

## Results

### Participants' Characteristics

The participants were 20 female survivors of Hodgkin disease who were treated in the Ambulatory Care Clinic of St. Jude Children's Research Hospital in Memphis, TN. The median age of the participants was 22.3 years (range = 16.6–25.4 years), the median age at diagnosis was 16.8 years (range = 11.2–19.6 years), and the median length of time since diagnosis

of Hodgkin disease was 4.2 years (range = 2.5–11.8 years). All participants had completed therapy for Hodgkin disease at least one year previously. Nineteen participants were Caucasian, and one was African American. Fifteen patients had favorable (i.e., stage I or II localized) disease, and five had unfavorable (i.e., stage III or IV) disease.

The treatment for Hodgkin disease in this group of survivors was a single course of risk-adapted, combined modality therapy in which low-dose, involved-field radiation therapy was administered in conjunction with four to six cycles of non-cross-resistant chemotherapy consisting of alkylating agents, anthracyclines, dacarbazine, and bleomycin. The involved fields of patients who achieved a complete response after two cycles of chemotherapy received 1,500 cGy; involved fields of patients who achieved a partial response received 2,550 cGy. All participants received chest irradiation that included irradiation of breast tissue. For patients without axillary node involvement, mantle radiation was modified to exclude the axilla in an effort to reduce irradiation of breast tissue. No participant had experienced recurrent disease.

### Content Analysis

Each focus group consisted of five to eight participants. Sessions lasted 50–70 minutes. Before the questions were discussed, participants in the first two focus groups, without prompting, shared intimate narratives of their diagnoses and treatment. Some offered long descriptions of events that preceded a delayed diagnosis. Others described feelings of disbelief and chaos that occurred after diagnosis. Many reported still being able to sense their parents' anxiety and fear. In these comments, participants only peripherally related their experiences with Hodgkin disease to their current experiences or health. The dominant themes of these reflections were consistent with many codes relating to feelings of anxiety and perceptions of being different and of being less (in all areas of life) than before diagnosis. For example, one participant remembered

I was so scared. Everyone told me that I would be fine; everything was just going to be the same as before [diagnosis]. They kept telling me that . . . like they were trying to convince themselves. Everyone told me that I was lucky. Having Hodgkin disease is not lucky . . . but surviving is.

These stories clarified the extraordinary need of survivors to be heard.

Participants addressed the study questions only after their reflections had been explored. Content analysis of the data generated 32 codes: Twelve codes described health status and future health risks, eleven described current health protective behaviors and fear of extremes of medical care, and nine described effective methods and optimal timing for breast health teaching. The most common codes for each category are noted in Tables 1, 2, and 3.

#### Description of health status and future health risks:

The prominent theme in the survivors' descriptions of their current health status was that they felt less healthy than their peers and less healthy at present than they had before Hodgkin disease developed. Survivors reported feeling "non-normal" (n = 79) or sensing that their bodies were dysfunctional (n = 34) because of changes in organ functioning (e.g., decreased thyroid function, infertility). One participant lamented, "There are so many things you can't do. . . . You can't do the daily

**Table 1. Description of Health Status and Future Health Risks (Most Commonly Reported Themes)**

Code	Description	n	%
Feeling “non-normal”	Being different from others, sensing a loss, and noting changes in body habits and mental health since diagnosis; they report being identified as different by people who stare or express pity.	79	31
Experiencing fatigue	Being unable to resist falling asleep when still; they struggle with diminished energy needed for participation in everyday activities.	36	14
Sensing their body is dysfunctional or going wrong	Their organ function is failing or breaking down. Abnormalities include abnormal heart rate, poor thyroid function, or weight gain.	34	13
Waiting, worrying, wondering, and fearing	Uncertainty about how healthy they are physically, now or in the future; even a careful checkup is limited by what is known and unknown.	29	11
Fearing second malignancies	Being frightened by their family histories of cancer, certain symptoms, and the knowledge that they are at risk of relapse or another cancer	29	11
Fearing for the next generation	Being afraid that offspring may inherit or develop cancer or might be damaged by their therapy.	16	6
Finding it often too hard to take care of themselves	Being tired of practicing good health habits or lacking knowledge	12	5
Worrying about fertility issues	Being concerned about hormonal changes caused by therapy and about their ability to have children	12	5
Experiencing health-related limitations	Wanting to do what they want to do rather than having limits imposed on them; limits include having to take thyroid medication, not using tanning beds, and not playing sports they want to play.	7	3
Not being taken seriously by healthcare providers	Perceiving that local physicians think they are paranoid about their health and will not give them needed attention even in light of a symptom, such as a fever	4	2

N = 258

*Note.* Because of rounding, percentages do not total 100.

things like everybody else does . . . can’t tan, can’t be in a crowd.” Survivors especially struggled with differing from others when that difference made them the object of pity. One participant noted, “You’re in the . . . grocery store, trying to shop . . . and they’re over there with tears in their eyes saying, ‘I understand what you’re going through. Oh, let me pray for you.’ I’m like, ‘Get away!’” Many participants described an emotional chasm between them and their friends and extended family; because of this chasm, participants were unable to talk about cancer or survivor issues with those who were close to them.

Experiencing fatigue (n = 36) was noted by many and was associated with weight gain that prevented a return to previous levels of activity. “Sleep all the time—that’s all I want to do is sleep,” shared one survivor. Participants often referred to “losing their health” as though they had lost a possession that they hoped might be recovered.

All groups expressed anxiety about future health risks. Survivors were concerned about second malignancies (n = 29). Participants were aware of and fearful about their risk of developing breast cancer. However, only 10 of the 20 participants practiced breast self-examination, even though all but two

**Table 2. Fear of Medical Care Extremes and Current Health Protective Behaviors (Most Commonly Reported Themes)**

Code	Description	n	%
Desiring competent and caring medical care after completing therapy	Needing knowledgeable, personal, balanced health evaluations and treatment after regular visits to their oncologists are unnecessary	48	21
Practicing various health behaviors	Doing specific things, such as applying sunscreen, not smoking or drinking, washing their hands, or pacing activities to keep themselves well	36	16
Trusting their oncologist to do a thorough checkup	Feeling that an annual physical examination done by a cancer doctor will be more accurate and thorough than one done by a primary doctor; they have close relationships with their cancer doctors, who can anticipate problems survivors might have.	35	15
Having internal reasons for practicing or not practicing health behaviors	Various incentives for doing or not doing things to protect themselves, such as knowing their body, personal knowledge, fear, habit, or taking personal responsibility for their health.	33	15
Having reasons external to themselves for practicing or not practicing health behaviors	Family-related or connectedness-related incentives for doing or not doing things to protect themselves, such as observing a relative struggle with cancer, harassment by family, positive modeling by a health professional, a requirement for school, or an external reward or recognition.	25	11
Feeling that surviving cancer positively motivates good health behaviors	Experiencing cancer encouraged them and others close to them to practice better health habits.	23	10
Continuing bad health habits	Engaging in poor nutrition or not exercising because of the influence of poor appetite and little activity when on therapy	15	7
Receiving or not receiving needed medical care	Feeling at risk to get too much or too little attention from primary care clinicians	6	3
Using self-talk to calm their health concerns	Being able to comfort themselves regarding what is normal in the face of a worrisome symptom	5	2

N = 226

**Table 3. Effective Methods and Optimal Timing for Breast Health Teaching (Most Commonly Reported Themes)**

Code	Description	n	%
Preferring certain methods of teaching	Favoring one-on-one instruction offering health information, such as breast self-examination, nutrition, symptom management, or insurance issues; customized written material given at the time of discharge would be helpful. Individualized pace is important, as is showing an interest, but pressuring the patient is not helpful. Peer support is vital. An Internet page or chat room would be helpful.	65	24
Getting support	Various healthcare professionals, teachers, family, friends, and community support groups were or were not helpful during and after treatment.	57	21
Wanting time to talk to others like me	Desiring an opportunity to talk with other patients who are a similar age and have had a similar diagnosis	56	21
Desiring guidance on managing side effects and looking for second malignancies	Wanting descriptions of the toxic effects of treatment and medication; the information should include details about the management of long-term problems and about monitoring themselves for signs of other cancers.	40	15
Perceiving treatment, care setting, and activities are too juvenile	Feeling that hospital and survivor programming in general are for younger patients and that staff, friends, and family treat them as children	21	8
Preferring certain timing of teaching	Good times for communicating information vary with each patient. Especially valuable times would be at landmarks, such as the first off-therapy visit. Information needs to be given gradually, with time for assimilation.	21	8
Emphasizing emotions behind the message is important.	When medical results are being shared, keeping in mind the feelings that may be associated with hearing results is important.	6	2

N = 266

*Note.* Because of rounding, percentages do not total 100.

understood that they had an increased risk of breast cancer. Reasons for neglecting this practice ranged from being too busy to being terrified that an abnormality might be found. Several were fearful that they might miss something and then blame themselves or be blamed by others for not being cautious enough. “I think there is a lot of mystery, like you have a symptom . . . and you’re like, ‘Is this because of what I’ve been through that I am experiencing this, or is it like something really bad?’” worried one survivor. Many found it hard to take care of themselves (n = 12); they expressed being overwhelmed and frustrated by their responsibility to be vigilant about their health. “You can give up on yourself. You get so aggravated. This is wrong. That’s messed up. This ain’t right, blah, blah, blah,” said one participant.

**Current health protective behaviors and fear of extremes of medical care:** Survivors consistently related their concerns about receiving too much or too little scrutiny or concern from local healthcare providers (n = 48). One survivor said, “Since I’ve come off therapy, I’ve had back trouble. I went to the emergency room, and the doctor never even touched me. He just stuck his head in the door and goes, ‘You had cancer, didn’t you? You need to see that doctor. . . . It’s probably come back.’” In contrast, another reported, “Every time I go to my doctor with a sinus infection, he wants to do a full-body MRI. I tell him it’s only a cold, but he orders tons of blood tests.” Survivors expressed the most confidence in health evaluations done by their oncologists (n = 35).

The practice of various health behaviors (n = 36) varied greatly. Some reported continuing to struggle with bad habits (n = 15) acquired during therapy (e.g., eating junk food, shunning exercise). However, 18 study participants (90%) actively practiced health promotion behaviors, including regular hand-washing and applying sunscreen.

External forces that prompted the practice of health promotion behaviors (n = 25) included being harassed by a family member, receiving an award (e.g., an athletic award), or observing a relative’s struggle with cancer. Survivors with a

child consistently credited their love for their child as a powerful motivation that encouraged them to take care of their own health. “I look at [my son] and I say, ‘That’s why I’m going to do it’ . . . Our husbands can take care of themselves, but our kids can’t.” Internal motivators for practicing good health habits (n = 33) included participants feeling that they had beaten cancer and now just had to “finish the job” and the belief that they alone could discern physical changes that might go unnoticed by a physician.

**Effective methods and optimal times for breast health teaching:** Three findings emerged from the discussions about effective methods and optimal times for teaching about breast health. First, survivors desired opportunities to talk with others who were similar ages and had similar diagnoses (n = 56). Topics for such counseling included shared experiences of past treatment and methods of promoting good health. “You wouldn’t feel so alone. . . . It wouldn’t just be fictional to that other person. [Hodgkin disease and treatment] will have happened to them, and I can ask anything and they’ll know for a fact how it is,” said a participant. Other effective teaching methods (n = 65) that were mentioned included Web sites, videos, and individualized teaching during clinic visits. Written material was felt to be helpful only in reinforcing instruction. Finally, survivors stated that the optimal times for teaching about breast health (n = 21) were at various therapy-related landmarks: the beginning of chemotherapy, the beginning of radiation therapy, the end of radiation therapy, the end of therapy, and once each year after the completion of all therapy. The gradual dissemination of information about long-term effects of therapy and future health threats would prevent survivors from feeling overwhelmed and allow time for assimilation.

### Exploratory Model Development

Similar patterns emerged from each focus group session in terms of the most frequently reported codes and how the codes were related to each other. Field notes from the focus group facilitators were reviewed to illuminate further

the relationships among codes. Codes naturally clustered by subject areas of interest. Then, they were grouped into constructs (see Table 4). Definitions of each construct were induced from the words of the focus group participants. Using an inductive method of model development, these themes were combined to note the relationships among abstract concepts that convey how female survivors of Hodgkin disease described their current health status and motivation for practicing breast health behaviors. The resulting exploratory model (see Figure 2) illustrates this relationship and highlights interventions that encourage behaviors promoting breast health.

For survivors, an anticipation of dangerous health risks evolved from a sense that disease and therapy damaged their organ function. This anticipation of danger resulted in survivors practicing some health protective behaviors and fearing extremes of medical care. Anticipating danger also contributed to the survivors' perception of their current health status and motivation for practicing breast health behaviors. Effective interventions noted in the focus groups included creating a positive listening environment, providing adequate information, offering opportunities for peer counseling, and providing personal instruction and multimedia health promotion.

## Discussion

As a result of the steady improvement in survival rates, cure in patients with Hodgkin disease has come to mean more than just the eradication of cancer. Oncology nurses' focus now must include the promotion of future health and the lessening of the impact of late effects of therapy. As nurses create partnerships with patients to accomplish these additional goals, they must listen to patients and provide adequate information so that survivors can feel well informed and secure performing self-care activities, such as participating in a program of breast health. Encouraging survivor compliance with recommendations for heightened surveillance for breast cancer is challenging (Dershaw, 2000). Balshem, Amsel, Workman, and Engstrom (1988) asserted that cancer screening programs for asymptomatic individuals are especially problematic, even if the individuals have a documented and well-known increased risk of cancer. The current study supported Balshem et al.'s conclusion that health promotion interventions will not be successful until the social, nonhealthcare meaning of cancer and cancer control is understood. Data revealed that survivors are aware of health threats and feel vulnerable to breast cancer. This awareness does not always translate into health promotion activities. Participants indicated that the effectiveness of educational programs depends on programs' sensitivity to variations in learning readiness and differences in preferred learning style. Establishing a relationship in which patients believe that they have been heard is essential for creating a positive learning environment. The perspective of a survivor of Hodgkin disease must be understood before an effective intervention can be implemented.

The desire to be heard and have others appreciate the impact of cancer on survivors' current lives was highlighted by the unexpected narratives that preceded each session. These narratives communicated participants' thoughts and most pressing concerns. Their personal histories communicated the loneliness survivors feel as they struggle to find peace and security after their illness. Even when therapy was completed several years previously, survivors categorized their

lives into the dyads of "before cancer" and "after cancer." In addition, the narratives suggested that survivors felt that only those with common experiences could understand their grief over personal losses and their struggle with current challenges.

Personal narratives were more brief in the third group than the first two. Participants in the third group shared fewer intimate details about diagnosis and spoke predominantly in concrete terms about risks to their future health. This difference between the third group and the other two may have been because participants in the third group were younger than those in the first two: The median age of participants in the third group was 20.8 years, whereas the median age in the first two groups was 22.6 years. Those in the third group generally had lower stages of disease (IA–IIB compared with IA–IVA). Crom, Chathaway, Tolley, Mulhern, and Hudson (1999) found that advanced stage of disease and the resulting increased rigor of therapy adversely influenced the health status and quality of life of adult survivors of childhood solid tumors.

The survivors' need to share their stories of diagnosis and treatment with other survivors of the same disease reminded the researchers that talking about difficult times during diagnosis and treatment is crucial to learning readiness. Patients must sort out complex, confusing reflections before they can internalize new information. Astute oncology nurses must pay attention to what is being said and not rush to deliver educational instruction until survivors are ready to focus on what is being taught.

Study participants were aware of their risk of secondary breast cancer; however, they indicated that presentations of information regarding breast health must be provided in personal and multimedia formats if good health practices are to be undertaken. Time for questions and to practice breast self-examination should be provided to calm survivors' fears that they may not identify abnormal lesions. Finally, effective programs must incorporate peer counseling.

## Limitations and Directions for Future Research

Participatory research methods, or focus group formats in this study, provide opportunities to explore experiences and attitudes and investigate preferences for the best timing and methods for teaching survivors about breast health. The results of this study must be evaluated in light of its purpose. Expected limitations exist in the generalizability of the findings. Study participants were not randomly chosen, and most were Caucasian. Ethnic and cultural variations limit the extrapolation of these findings to other target populations. Additional limitations associated with focus group research also were applicable to the present analysis: Some themes were discussed in greater detail by one group (Krueger & Casey, 2000), and extraneous variables, such as age at diagnosis, stage of disease, and intensity of treatment, were beyond the control of the investigators.

These limitations, as well as the study results, point to future research directions. The exploratory model suggests themes and relationships that are crucial to encouraging better self-care practices in female survivors of Hodgkin disease. Additional investigations refining the model are warranted. Specifically, the influences of socioeconomic status, ethnic origin, and cultural variations would be of interest. Research initiatives investigating the efficacy of

**Table 4. Constructs and Definitions Emerging From the Codes**

Codes	Construct	Definition	Quotations
Feeling "non-normal" Sensing their body is dysfunctional or going wrong Experiencing fatigue Experiencing health-related limitations Finding it often too hard to take care of themselves	Feel damaged	Female survivors perceive themselves to be different from others because of poor bodily functions or decreased endurance; this awareness results in a heightened need to take care of their health and is a source of stress.	"It's that you're always special from then on. You're not just a, the daily thing like everybody else does. You just can't be normal." "Every time I turn around, something else is wrong. Something else—chemo caused this, radiation caused that." "All the time, sleep all the time—that's all I want to do is sleep." "After radiation, they kind of hit me with it, that you can't tan anymore, and I was like, 'Huh? Are you crazy?' You know what I am saying? Maybe if I knew at the beginning that I couldn't do some of that, it would be easier." "I don't know, I just don't. I'm just bad. I don't have time to do it."
Fearing second malignancies Worrying about fertility issues Waiting, worrying, wondering, and fearing Fearing for the next generation	Anticipate danger	Female survivors think it is likely they will experience health problems because of their diagnosis and treatment, either in themselves or in their children.	"I think that I'm scared about increased chances of other types of cancer, and I haven't reached the five-year mark yet, and so, I'm still kind of, I'm waiting for that day, as well." "I have to be honest. I don't do breast exams. . . . I'm scared to death I'm going to find out that I have something else, and if it does, I will have a nervous breakdown. I mean, I'm scared to death. . . . I just want to go to a doctor once a month and get checked." "I feel better since I've been able to have a baby. That's been a huge difference for me, and I don't know, maybe that's just me, but I've felt a lot better since I've been able to have a baby. That was one of my major concerns." "I think there is a lot of mystery, like, you have a symptom of some sort and you're like, 'Is this because of what I've been through that I'm experiencing this?' And you don't really know for sure. . . . There is so much that cancer doctors know and a lot they don't know, so that is scary." "My worst concern is like, once I get older and I decide to have kids, if it will affect the child or if it could cause relapses."
Having reasons external to themselves for practicing or not practicing health behaviors Having internal reasons for practicing or not practicing health behaviors Practicing various health behaviors	Practice some health behaviors	Female survivors participate in self-care behaviors because of their own anxiety about being at risk for health problems and so that they can be alive to continue caring for loved ones.	"Our husbands can take care of themselves. Your kids can't take care of themselves. I don't care how old they are. . . . My kids are why I do it." "I would say that one thing would be, you think if you take care of yourself, I don't know, I guess like fear, in a way, makes you take care—makes me take care of myself." "I do do some stuff. I use, like, sunscreen and wash my hands often, and I always wear a seat belt."
Trusting their oncologist to do a thorough checkup Desiring competent and caring medical care after completing therapy Receiving or not receiving needed medical care	Fear extremes of medical care	Female survivors value an astute healthcare provider who understands their potential future health problems and knows how to monitor them for those problems.	"We feel like we have a relationship with [the cancer doctor] and he knows who we are, so, no matter what, even if it isn't cancer-related or a postcancer problem, this is the first place we think to call or to contact and ask." "My veins are so bad after chemo. At home, they have to have the doctor stick me, and he is a real digger. His policy is stick first, then look for the vein." "They load you up with antibiotics and given all this crap that I don't even need or sometimes it is the direct opposite. You don't either get enough or they do too much. I've gotten both extremes." "My doctor at home thinks I am a nutcase. I will be telling him something that I am worried about, like a lump in my neck, and he will just look at me like, 'Okay, what else?'"
Perceiving treatment, care setting, and activities are too juvenile Emphasizing emotions behind the message is important.	Create a positive listening environment	Female survivors desire an opportunity to have their concerns taken seriously and the chance to help pace information they are given.	"Speak to us, don't look through us." "When teaching, I think they ought to watch more. Just because I say I want to hear, it don't mean I want to hear it. If I start crying, watch what you say."
Desiring guidance on managing side effects and looking for second malignancies	Provide adequate information	Female survivors want to participate in their care after completing treatment, but they need to know what their future health risks are so they can self-monitor wisely.	"They ought to have classes that make you feel better, so you feel like you're more prepared. When you're not coming every month, so you're not so paranoid. I mean, if they prepare you better to leave here, then you don't feel it was all their responsibility."

*(Continued on next page)*

**Table 4. Constructs and Definitions Emerging From the Codes (Continued)**

Codes	Construct	Definition	Quotations
Wanting time to talk to others like me	Offer opportunities for peer counseling	Female survivors would profit from interaction with other female survivors of Hodgkin disease so that they can compare experiences and share concerns for the future.	"No one understands, no one, even my family. . . . My dad, still today cannot say, 'You got cancer. You had cancer.'" "I had so much support from friends and everything at the school, and friends from the family and stuff like that."
Preferring certain methods of teaching Preferring certain timing of teaching	Provide personal instruction and multimedia health promotion	Female survivors need many interactions with staff and written or visual information on how they can best care for themselves, and this information needs to be offered during and after their therapy.	"They should have both one-on-one and group education, because everybody is different." "You have too much to think about when you're going through treatment to think about what's going to happen to you down the road."

Internet-based communication methods that provide survivor information also are needed. Survivors could receive individualized risk information that is based on their specific diagnosis, disease stage, age at diagnosis, and treatment. Similarly, investigation is needed to evaluate the effectiveness of novel peer-counseling formats, such as Internet chat rooms. The impact of self-care interventions should be measured by intermediate outcomes, such as knowledge acquired and increases in self-care practices, as well as the more important long-term outcomes of survival. Such research studies will provide a blueprint that can be used to improve the care of all adult survivors of childhood cancer.

### Nursing Implications

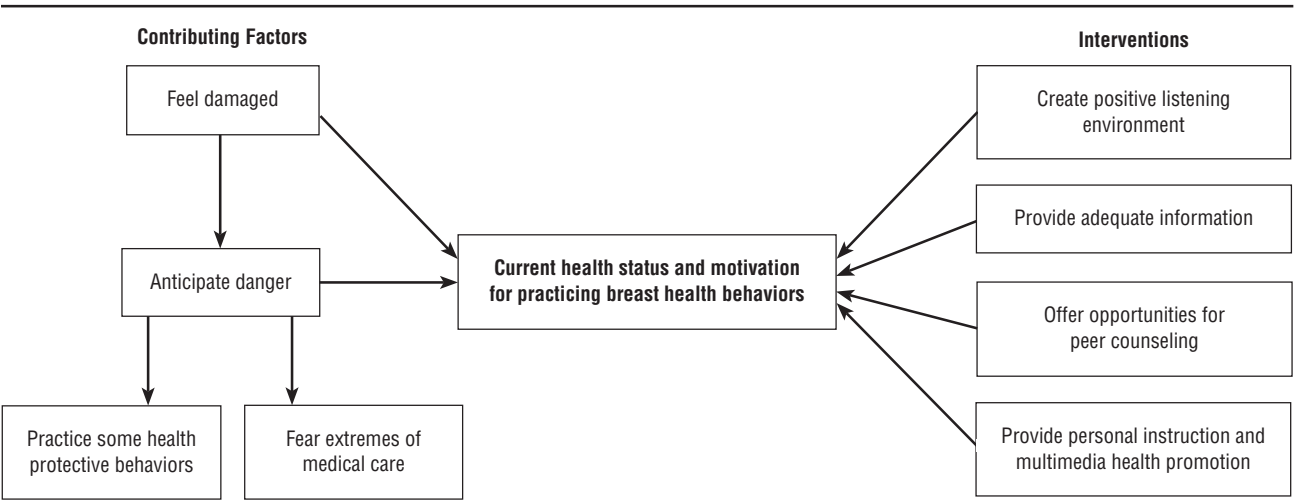
Although the importance of listening to patients may seem intuitive to oncology nurses, this study is a valuable reminder that patients long to be heard. Moreover, patients must be heard before they can be taught effectively. The intimacy achieved through empathetic listening offers nurses unique opportunities for educating survivors about future health risks and supporting self-care practices.

Survivors at high risk for developing breast cancer experience much anxiety about their vulnerability (Nikoletti, Kristjanson, Tataryn, McPhee, & Burt, 2003). Understanding risk factors and screening recommendations that promote early diagnosis can be beneficial in alleviating some feelings of anxiety. Nurses can facilitate informal communication between patients with similar risks to lessen feelings of isolation.

Priority areas for research in breast cancer risk reduction education for survivors of Hodgkin disease through self-care include

- Longitudinal studies evaluating factors influencing survivors' identification of potential breast cancer risk, their intention to seek medical care, and possible barriers to seeking care
- Investigations confirming optimal timing and methods for disseminating risk reduction education.

This study has increased awareness that, although survivors of childhood cancer experience increased future morbidity, they are not informed adequately about future health risks, are not equipped to incorporate self-care practices into daily living, or are not invested in the importance of



**Figure 2. Exploratory Conceptual Model Suggesting Contributing Factors and Interventions to Promote the Effectiveness of a Breast Health Program**

self-care. Increasing awareness of the need to recruit and educate survivors regarding self-care practices is challenging. During and after therapy, nurses need to assess patients' knowledge about future health risks and assist in formulating plans for care. Advanced practice oncology nurses need to work to expand current national promotion initiatives for breast health, such as the Breast Cancer Education and Risk Assessment Program (Snyder et al., 2003), to include survivors of childhood cancer who received thoracic irradiation as a part of their therapy. Future work in this area will move

oncology nurses closer to incorporating such assessments and interventions into the care of all survivors of childhood cancer.

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