# Oncology Nurses' Knowledge of Survivorship Care Planning: The Need for Education

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ancer survivorship care is a concept highlighted in a report by the Institute of Medicine (IOM) (Hewitt, Greenfield, & Stoval, 2005). In that report, cancer survivors described feelings of loss at the end of acute treatment, lack of attention to long-term sequelae of treatment, and a physical and emotional toll from their cancer diagnosis (Hewitt et al., 2005). In response to these concerns, the IOM challenged healthcare providers to establish cancer survivorship planning as a routine part of cancer care (Hewitt et al., 2005).

The IOM cancer survivorship initiatives have been embraced by oncology professionals at many academic medical centers; however, the work has been somewhat fragmented, perhaps from the lack of empirical evidence and widespread professional education (Klemp, Frazier, Glennon, Trunecek, & Irwin, 2011). The need for institutional and professional support of a survivorship paradigm shift is evident (Earle & Ganz, 2012; Ganz, Earle, & Goodwin, 2012). Barriers to high-quality survivorship care include issues of reimbursement, resources, time, communication, coordination of care, and evaluation of results (Stricker et al., 2011). Some issues remain with the term survivor (Khan, Rose, & Evans, 2012). Survivorship care encompasses all patients, including those with metastatic disease and at the end of life (Lester & Schmidt, 2011).

Oncology care providers are accustomed to providing expert care, but the establishment of cancer survivorship care as a distinct phase remains a relatively new concept to most healthcare providers (Lester & Schmidt, 2011). A conceptual model of adult survivorship is not well described (Howell et al., 2012), and the operational model continues to evolve (McCabe & Jacobs, 2012). Oncology professionals typically discuss several of the recommended components of survivorship care planning with survivors (Haylock, Mitchell, Cox, Temple, & Curtiss, 2007). However, that occurs over a period of time, not in a concise package or at a designated time point in the cancer trajectory. The familiarity of survivor-

**Purpose/Objectives:** To survey nurses about their knowledge of cancer survivorship care.

Design: Descriptive, cross-sectional.

**Setting:** Midwestern comprehensive cancer center.

Sample: 223 registered and advanced practice nurses.

**Methods:** Online survey of survivorship knowledge using a 50-item questionnaire derived from the Institute of Medicine report and related publications.

**Main Research Variables:** Concepts of survivorship care and common long-term symptoms.

Findings: Most nurses reported having knowledge about healthy lifestyle habits; more than 50% of nurses reported having knowledge about chemotherapy, surgery, and radiation therapy, as well as side effects of fatigue, depression, limitations of daily activities, and weight gain; less than 50% of nurses reported having knowledge of impact on family, biologic agents, lymphedema, immunizations or vaccinations, and osteoporosis screening; less than 40% of nurses reported having knowledge about marital and partner relationships, osteoporosis prevention and care, sexuality, side effects of bone marrow transplantation, employment issues, and angiogenesis agents; and less than 25% of nurses reported having knowledge on genetic risks, as well as fertility, financial, and insurance issues.

**Conclusions:** Oncology nurses at an academic comprehensive cancer center reported gaps in knowledge consistent with previous studies about knowledge of survivorship care.

Implications for Nursing: The Institute of Medicine has challenged oncology providers to address cancer survivorship care planning. Gaps in cancer survivorship knowledge are evident and will require focused education for this initiative to be successful.

**Key Words:** late effects of cancer treatment; rehabilitation; survivorship; undergraduate nursing education; continuing education

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ship care planning to nurses who worked at the James Cancer and Solove Research Institute, a National Cancer Institute-designated comprehensive cancer center in Columbus, OH, was relatively unknown. The institution was beginning to provide survivorship care plans, but common barriers were met in the startup phase. The purpose of the current study was to assess the familiarity of oncology nurses with survivorship care planning. The primary aims of the study were to measure oncology nurse knowledge about cancer survivorship concepts, comfort in explaining pathology reports, and knowledge and comfort in discussing multiple side effects and survivorship issues. The nurse researcher particularly was interested in the pathology report issue because multiple nurses had anecdotally described their fear of survivorship care plans because patients would be receiving treatment summaries, including pathology reports. The outcome goal of the survey was to identify knowledge gaps that could guide future education endeavors to advance nursing knowledge and enhance survivorship care planning.

## **Literature Review** Survivorship Care Plans

As recommended by the IOM, the cancer survivorship care plan is comprised of the treatment summary and a care plan for the period after active treatment (Howell et al., 2012). The treatment summary provides records of the primary cancer diagnosis, diagnostic test results, cytology or pathology findings, dates of treatment, complications, a medication list, summary reports from the oncology providers, and contact information for the treating practitioners (Lester & Schmidt, 2011). Psychosocial, nutritional, and other supportive interventions are provided in a second section (Ganz, Casillas, & Hahn, 2008; Hewitt et al., 2005; Lester & Schmidt, 2011).

The care plan is created from data in the medical record as well as professional interactions with the patient and family. It provides a timeline for primary and preventive cancer care, frequency of examinations, and responsible healthcare providers. Personalized, evidence-based recommendations guide interventions and evaluations of symptoms, including psychosocial care (Lester & Schmidt, 2011). Information about persistent symptoms, healthy lifestyle recommendations, rehabilitative needs, referrals, and resources are provided with discussion of potential long-term side effects. The patient contextual understanding of the plan and personal goals should be considered (Lester & Schmidt, 2011).

The treatment summary and survivorship care plan serve as communication tools, education, and future care directives. The documents should be stored in the electronic or paper oncology medical record, and copies should be provided to the patient and primary care provider (PCP). Keeping the documents in the oncology medical record would ensure that patients have access to a copy in case of damage, loss, or absence of medical

records by the treating facility (e.g., from environmental disasters) (Lester & Schmidt, 2011). Barriers to completion of survivorship care plans include payment and completion of the care plan, particularly in the absence of electronic medical records.

#### **Transition to Survivorship Care**

In a study of breast cancer survivors, oncology specialists, and PCPs to explore the transition to survivorship, healthcare providers and patients cited issues such as communication, patient needs, provider roles, and ambivalence over discharge (Kantsiper et al., 2009). PCPs reported that additional training and communication were necessary to provide disease-related information, as well as information on current treatment and integrated care. The PCPs voiced concern over the multiple comorbid patient, which would include time-consuming oncology care (Kantsiper et al., 2009).

In a study of LIVESTRONG Survivorship Centers of Excellence and their corollary community settings, five de-identified treatment summaries and survivorship care plans were requested from each setting (N = 16)to determine concordance with IOM recommendations, and 13 centers participated. Several sites demonstrated 75% or greater concordance between treatment summaries and IOM recommendations for hormone therapy, surgical treatment, staging and tumor characteristics, and treatment toxicities (Stricker et al., 2011). Less than 50% of sites reached 75% concordance with lapses in documentation of diagnostic information, details about the treating physician, and specific treatment details. No site reached 75% concordance for clinical trial information, genetic testing, supportive therapy, or overall treatment summary (Stricker at al., 2011).

In the same study, the degree of concordance between survivorship care plans and IOM recommendations was less than 75% for more than half the sites, with missing documentation of cancer and noncancer surveillance, recurrent and secondary signs of cancer, familial cancer risk, prevention and health promotion, psychosocial effects, and overall survivorship care plan (Stricker et al., 2011). Other underaddressed items included information about insurance and the provider responsible for cancer surveillance tests (Stricker et al., 2011).

In a Canadian study, cancer survivors (N=14) revealed intense feelings about the loss of influential healthcare relationships formed during cancer treatment (Thorne & Stajduhar, 2012). The transition from active cancer treatment to care from a PCP was fraught with anxiety, uncertainty, and gaps in communication. Patients sensed the PCP's insecurities with their responsibility for ongoing oncology care in a system that may have missed the initial signs of cancer (Thorne & Stajduhar, 2012). The authors concluded that targeted knowledge must be provided for the oncology and primary care teams to

understand the complex patient communication issues that can occur during this transition and across the cancer continuum (Thorne & Stajduhar, 2012).

Data from four focus groups with minority breast cancer survivors revealed the race-specific needs of survivors and deficits with regard to the readability and comprehension of the American Society of Clinical Oncology's breast cancer survivorship care plan, as well as patient-perceived gaps for follow-up care, surveillance tests, resources, and wellness guidelines (Burg, Lopez, Dailey, Keller, & Prendergast, 2009). The authors discussed the potential use of survivorship care plans in primary care and conceded that training opportunities must be expanded for PCPs to have confidence in the provision of survivorship care (Burg et al., 2009).

#### **Nurse Survivorship Knowledge**

In a study of patient preferences about survivorship care plans, oncology nurses were identified as critical to the development, education, and implementation of a survivorship program (Marbach & Griffie, 2011). The authors suggested that research is necessary to determine the learning needs of nurses for survivorship education and posed the question of whether it was realistic to expect nurses to possess that knowledge (Marbach & Griffie, 2011).

Australian nurses were asked to complete a survey to determine whether evidence existed that cancer nursing education influences the planning of care in patients with cancer (Howell, 2002). Most nurses claimed some form of related cancer nursing education; however, this education was not evident in written care plans (Howell, 2002). Topics to augment their practice included pain knowledge, assessment, and interventions, as well as management of symptoms and side effects of treatment (Howell, 2002).

Brixey and Mahon (2010) published a self-assessment tool for oncology nurses to evaluate their knowledge and skills based on 14 categories, with 139 items to assess competency. Nurses in Texas were surveyed in 2000 and again in 2010, and their top 10 educational needs were compared. Five oncology-related deficits still remained (i.e., pain management, cancer genetics, survivorship, tobacco cessation, and clinical trials) (Volker, Watson, Becker, & Scott, 2011). Findings from the Texas study suggested similar deficits related to survivorship care between the two time periods. Competency surveys may be helpful for staff to identify educational opportunities as survivorship programs commence.

Ferrell, Virani, Smith, and Juarez (2003) published an extensive report on the role of education to empower the oncology nurse to provide improved quality of care for cancer survivors, and 10 content areas were examined relative to the IOM recommendations. The researchers

reviewed undergraduate and graduate nursing programs across the country, cancer-related nursing texts, nursing journal publications, oncology certification examinations, and funded research. This review revealed positive and negative findings (Ferrell et al., 2003). Focused curricula on topics related to cancer survivorship care were lacking in professional nursing programs. In addition, a concomitant decline of oncology specialty graduate programs was noted (Ferrell et al., 2003). That review illustrated multiple gaps and identified the need to develop comprehensive oncology and survivorship education for working RNs and advanced practice nurses (APNs), as well as undergraduate and graduate programs.

In 2010, a descriptive cross-sectional study was conducted by the Oncology Nursing Society to determine needs and practices of nurses in survivorship care. A 39item online survey was constructed based on the IOM components to gather data about cancer survivorship care in specific work settings, aspects of care provided from active treatment to follow-up, and components of survivorship programs (Irwin, Klemp, Glennon, & Frazier, 2011). Respondents (N = 395) reported having a formal survivorship program for all cancer types (10%) or survivorship services for specific populations (17%). Twenty-three percent said their institution had no plans for a survivorship program (Irwin et al., 2011). One reported barrier to providing survivorship care was a lack of knowledge (49%), which was associated with five or less years of oncology experience, as compared to 36% of nurses who had more than five years of oncology experience (Irwin et al., 2011). The authors concluded that to provide cancer survivorship care, providers must be educated and learn skills.

An educational initiative to prepare professional staff to care for cancer survivors commenced in 2006, with a total of four three-day courses planned through 2009 (Grant, Economou, Ferrell, & Bhatia, 2007). Competitive applications were sought for two-person teams of nurses, social workers, physicians, directors, administrators, and psychologists. Content for education was obtained from the IOM report and the Declaration of Principles from the *Imperatives for Quality Cancer Care* by the National Coalition of Cancer Survivorship (Grant et al., 2007). Results of a survey given before the workshop documented institutional barriers to effective survivorship care, including lack of knowledge (81%), financial constraints (62%), lack of survivorship philosophy (14%), and no administrative support (10%) (Grant et al., 2007). Of those attending, 86% reported administrative support, 81% reported receptiveness of staff to survivorship care, 56% were comfortable with survivorship care, and 48% thought survivorship care was effective (Grant et al., 2007).

The data from those studies supported that nurses have self-reported educational needs about survivorship care and care planning. The majority of the physical care and long-term survivorship follow-up likely will be provided by an RN or APN. Nurses must be surveyed in multiple settings to determine overall educational needs and to develop an interdisciplinary team that can address the physical and psychosocial needs of survivors with integrated care that accomplishes the IOM goals.

#### Methods

#### Design

The purpose of the current study was to examine oncology nurse knowledge about cancer survivorship care using a self-report questionnaire. A descriptive cross-sectional design was used.

#### **Procedure**

Development of the questionnaire began with a review of literature, item generation, and consultation with an expert review panel. A 32-member interdisciplinary survivorship care advisory board was created to guide a survivorship grant. Members included RNs, APNs, social workers, physicians, and cancer survivors that were knowledgeable and passionate about survivorship care. The advisory board members received the questionnaire to review and score. The questionnaire included definitions of survivorship concepts. Members were asked to associate questionnaire items with the concepts of survivorship care and to score their appropriateness and accuracy from 0-1. Comments were returned on the questionnaires with associated scores. The first content validity index (CVI) score was 0.89, and then adjustments in wording, readability, and context were made to the items. The revised questionnaire was distributed to the expert panel with the same instructions. The second CVI score was 1 without additions, deletions, or corrections.

#### Survey

The survey was conducted from July to August 2009, after approval from the Ohio Nurses Association (ONA), the chief nursing officer, and the university's cancer institutional review board (IRB). The questionnaire was built, secured, and distributed by an administrative employee outside the Department of Nursing Excellence using an electronic survey system (i.e., SurveyMonkey®) and institutional master email lists. All RNs and APNs in the institution were invited to participate in the online survey via an IRB- and ONA-approved invitation that included an implied consent statement for participation in the study. Reminder emails were sent at 14 and 28 days, and the survey was closed at 35 days. The survey administrator used properties of the survey system to download de-identified survey results into Microsoft Excel® spreadsheets that were given to the principal investigator. The computer Internet protocol addresses

were destroyed by the survey administrator to ensure anonymous and confidential information.

#### Sample and Setting

The survey was conducted at a comprehensive cancer center in the midwestern United States. Inclusion criteria included participants aged 18 years or older who were part- or full-time RNs at the institution.

#### Measurement

The survey was based on concepts in the IOM report, as well as common cancer survivorship symptoms observed in practice and as noted in the literature. The survey consisted of seven demographic items about the current age range of the nurses, nursing-related education level, number of years in nursing and in oncology nursing, job title, work setting, and primary cancer focus, as well as six multiple-choice items about cancer survivorship concepts, two true-or-false items about pathology reports, and 35 variables that required a response of yes or no for self-assessed knowledge and comfort about survivorship issues related to healthy lifestyle and possible long-term side effects.

#### **Statistical Analyses**

A power analysis for the sample size was not calculated by the statistician because no comparable studies of survivorship care knowledge in oncology nurses were published at the time of the study. Therefore, a sample (N = 150) was recommended to represent a population of about 700 RNs and APNs working at the institution in 2009.

Following the survey, responses from the Microsoft Excel spreadsheet were exported into SPSS®, version 18.0. Descriptive analyses were conducted; response rates were reported in sums and percentages. Comparisons between demographic groups and survey items were analyzed with Pearson's chi-square test. Small group responses (e.g., cell values of less than 5) were analyzed using a Monte Carlo approximation to the true value. Analysis of variance (ANOVA) provided comparisons of items between and within groups; the Monte Carlo two-sided model was used to aggregate results (e.g., cell values of less than 5). The statistical tests were calculated with a 95% confidence interval, two-tailed model, and alpha of 0.05.

#### Results

#### **Demographic Data**

A 31% institutional response rate was obtained (N = 223) with completed surveys from staff RNs, nurse practitioners, clinical nurse specialists, management or administration, research or education, and other, which presumably identified RNs with other working titles

such as patient care resource managers, care coordinators, disease team leaders, or specialty nurses. Respondents described their demographic characteristics based on work setting, highest level of nursing education, years of nursing experience and cancer nursing experience, primary role, age in years, and primary cancer focus (see Table 1). The sample was representative of the institution's distribution of nurses in inpatient, outpatient, and combined inpatient/outpatient settings, as well as educational preparation and age. Many nurses reported working with leukemia or lymphoma diagnoses. However, nurses (n = 85) frequently listed other cancers as their primary cancer focus, which most likely defined multiple cancer types on a mixed inpatient unit or in a multisite outpatient setting.

#### **Survivorship Concepts**

Respondents were asked to choose one multiple-choice answer that defined the timing for designating the title of cancer survivor, the definition of cancer survivor, the familiarity with the term *cancer survivorship care planning*, the timing for implementation of cancer survivorship care planning, the components of a cancer survivorship care plan, and nursing responsibilities (see Table 2).

Chi-square analysis was used to determine groups that were familiar with cancer survivorship care plans and included nurses with master's and doctorate degrees ( $\chi^2$  [(5, N = 220) = 22013.32, p = 0.02]), 16–20 years of nursing experience ( $\chi^2$  [(6, N = 220) = 14.12, p = 0.028]), and 60–69 years of age ( $\chi^2$  [(5, N = 219) = 25.73, p = 0]), which indicated that the more educated, more experienced, and older nurses were correct more frequently in their responses about the components of survivorship care plans when compared to their younger counterparts.

#### **Pathology Reports**

Nurses answered two true or false questions about the benefit of cancer survivors receiving pathology reports and comfort in explaining the report (see Table 3). Significant relationships were demonstrated with chi-square analysis for comfort in explaining a pathology report with the nurse practitioner role ( $\chi^2$  [(27, N = 221) = 131.1, p = 0]) and with master's and doctorate degrees ( $\chi^2$  [(15, N = 217) = 95.26, p = 0]), a response that indicated that more educated nurses and nurse practitioners were most comfortable explaining pathology reports to survivors.

# **Knowledge About Survivorship Symptoms** and Issues

Participants were asked to respond yes or no to their knowledge and comfort in discussing 35 cancer symptoms and issues, as listed in the literature and IOM report (see Table 4). At least 70% of the nurses felt knowledgeable about healthy lifestyle habits (e.g., skin protection, diet, exercise, fatigue). More than 50% of the nurses felt

knowledgeable about discussing smoking cessation, routine cancer screening, chemotherapy short- and long-term side effects, medications, short-term effects

Table 1. Sample Characteristic	.3 (14 — 223)	<u>'</u>
Characteristic	n	%
Work setting		
Inpatient	104	47
Outpatient	84	38
Combined	30	13
Other	5	2
	3	4
Nursing education Diploma	30	13
Associate	30 37	17
Bachelor's		
	95 53	43
Master's	52	23
Doctorate	2	1
Missing data	7	3
Years of nursing experience	4.6	24
1–5	46	21
6–10	30	13
11–15	31	14
16–20	28	13
21–25	23	10
More than 25	62	28
Missing data	3	1
Years of cancer nursing experience		
1–5	85	39
6–10	51	23
11–15	24	11
16–20	24	11
21–25	13	6
More than 25	22	10
Missing data	4	2
Primary role in cancer care		
Staff ŘN	113	51
Nurse practitioner	23	10
Administration	10	4
Clinical nurse specialist	9	4
Management	9	4
Research	7	3
Education	5	2
Other	45	20
Missing data	2	1
Age (years)		
18–29	32	14
30–39	48	22
40–49	61	27
50–59	61	27
60–69	18	8
Missing data	3	1
Primary cancer focus	3	
Brain and central nervous system	5	2
Breast	10	4
Gastric and colorectal	11	5
	2	1
Gynecologic		
Head and neck	18 57	8
Leukemia and lymphoma	57 10	26
Lung	18	8
Skin	5	2
Urologic and prostate	8	4
Other	85	38
Missing data	4	2

Note. Because of rounding, percentages may not total 100.

Table 2. Nurse Responses to Survivorship Concepts (N = 223)

Item	n	<b>%</b>
A patient with cancer is termed a		
survivor		
At the time of diagnosis	77	35
At the end of treatment	28	13
At the two-year mark	7	3
At the five-year mark	89	40
I do not know.	22	10
A cancer survivor is		
The patient with cancer	97	43
The patient and spouse	2	1
The caregiver	_	_
Family and friends	_	_
All of the above	119	53
I do not know.	4	2
Missing data	1	1
I am familiar with the term cancer		
survivorship care planning.		
Yes	112	50
No	111	50
Cancer survivorship care planning		
should be implemented		
At the time of diagnosis	161	72
Upon completion of active treatment	32	14
At the two-year mark	1	1
At the five-year mark	2	1
I do not know	27	12
A cancer survivorship care plan		
consists of		
A treatment summary and survivorship	140	63
care plan		
A care plan about the chemotherapy	1	1
regimen		
A care plan about survivorship needs	36	16
I do not know.	45	20
Missing data	1	1
It is a nursing responsibility to		
address cancer survivorship issues.		
Yes	197	88
No	23	10
Missing data	3	1

Note. Because of rounding, percentages may not total 100.

of surgery, as well as common symptoms (e.g., dental or oral care, depression, limitations of daily activities, weight gain or loss).

Less than 50% of the nurses felt knowledgeable about the impact of cancer on family and children, biologic agents, lymphedema, routine immunizations and vaccinations, osteoporosis prevention, short-term side effects of radiation therapy, and long-term side effects of surgery. Less than 34% of the nurses felt knowledgeable about marital/partner relationships, osteoporosis screening, long-term side effects of radiation therapy, sexuality, short-term side effects of bone marrow transplantation, and employment issues. No more than 25% of the nurses felt knowledgeable about discussing osteoporosis treatment, anti-angiogenesis side effects,

long-term side effects of bone marrow transplantation, genetic risks, fertility preservation, fertility after cancer treatment, financial challenges, and insurance issues.

Chi-square analysis was used to determine differences between nurse demographic characteristics and various survivorship issues. In most cases, the BSN, MSN, and PhD education tracts were indicative of improved knowledge of survivorship issues when compared to diploma and associate degree nurses. Some survivorship issues were indicated as educational needs for all nurses, as shown in Table 4.

#### **Discussion**

The desired level and complexity of knowledge necessary for providing cancer survivorship care planning pose an educational challenge for oncology nurses, as evidenced by the survey. Oncology nurses often are specialized in their cancer type, which is ideal for the development of survivorship care planning in their specific population, but it may narrow their scope about common survivorship issues. Although all patients do not experience every treatment-related symptom, some patients do experience an extraordinary number of symptoms that may persist into long-term survivorship. Therefore, oncology nurses must be aware of common survivorship-related symptom side effects and should have a repertoire of evidence-based interventions or services for referral. Disease teams that are focused on specific cancer types, treatment, and pertinent side effects can reduce the burden of learning for interdisciplinary members. However, the oncology RN and APN require a wide range of knowledge as leaders of survivorship care.

Various statistics were used, including chi-square, ANOVA, and linear regression analysis. Because of conflicted means for pooled age ranges, years of nursing experience, and years of oncology nursing experience, regression analyses were not helpful. ANOVA demonstrated statistical significance, although they were

Table 3. Nurse Responses About Comfort With Explaining Pathology Reports (N = 223)

Item	n	%
Cancer survivors would benefit from having a copy of the pathology report.		
True	189	85
False	28	13
Missing data	6	3
In my role, I feel comfortable		
explaining a pathology report.		
True	61	27
False	157	70
Missing data	5	2

Note. Because of rounding, percentages may not total 100.

limited in differentiation between or within groups for the demographic characteristics.

The more educated (i.e., BSN, MSN, and PhD degrees), more experienced (i.e., 16 years or more), older nurses (i.e., aged at least 40 years), and those in the roles of nurse practitioner and research nurse provided the correct responses about survivorship symptoms more often than nurses who were younger, less experienced, not graduates of a college program, and who were not in specialist or advanced practice roles. Staff RNs accurately self-reported knowledge about a number of symptoms, but the nurse practitioners were more likely to provide the correct answers. This may have been indicative of the emerging role of the nurse practitioner in 2009 with survivorship care planning and extensive symptom identification and management experience. Oncology nursing experience did not demonstrate an advantage over years of general nursing experience.

#### **Nursing Education Issues**

Nursing education at the undergraduate and graduate levels teaches components of chronic illness, but it often falls short for cancer-related education (Ferrell et al., 2003). Nursing programs and guidelines for the National Council Licensure Examination for RNs test plan do not provide faculty direction for the curriculum or amount of time to spend on specific disease processes (Volker et al., 2011). Future oncology education for nurses is essential to create a successful program of survivorship care that aligns with the IOM recommendations.

Marbach and Griffie (2011) suggested that nurses should not be required to possess all the knowledge related to survivorship care planning. The lack of nursing knowledge about survivorship care planning and related issues is evident in the current survey results and can likely be generalized to institutions of a similar type and size (Stricker et al., 2011). RNs and APNs must possess more knowledge about survivorship care planning and elements of chronic disease management. Findings from the current survey and the survey of members of the Oncology Nursing Society are similar in many ways, with few survivorship programs noted for all cancer types and populations (Irwin et al., 2011). Multiple barriers exist, including lack of institutional support, lack of guidance, and expectations beyond usual educational preparation.

Improved curricula are necessary in nursing programs, but topics and programming continually compete with few openings in academic schedules. The deficits and barriers related to the absence of targeted education significantly limit the widespread practice of cancer survivorship care (Ferrell et al., 2003; Grant et al., 2007; Lester & Schmidt, 2011). The educational need can be broadened to discuss complex chronic symptoms, a topic that embraces all program interests and covers concomi-

Table 4. Nurse Responses to Knowledge and Comfort With Patient and Family Discussion About Survivorship Issues (N = 223)

Issue	n	%
Skin protection	166	74
Diet	163	73
Exercise	157	70
Fatigue	155	70
Smoking cessation	147	66
Routine cancer screening guidelines	140	63
Chemotherapy agents, short-term side effects	139	62
Other medications the patient may be taking	126	57
Depression or anxiety	125	56
Limitations of daily activities	118	53
Weight gain or loss	118	53
Chemotherapy agents, long-term side effects	117	53
Surgical short-term side effects	115	52
Dental and oral care	113	51
Radiation therapy, short-term side effects	99	44
Impact of cancer diagnosis on children	88	39
Biologic agents, side effects	86	39
Lymphedema	86	39
Routine adult immunizations and vaccinations	84	38
Osteoporosis prevention	81	36
Surgical side effects, long-term	81	36
Marital, partner, and relationship com- munication	75	34
Osteoporosis screening	75	34
Radiation therapy, long-term side effects	70	31
Sexuality	64	29
Bone marrow transplantation, short-term side effects	60	27
Employment issues	57	26
Osteoporosis treatment	56	25
Anti-angiogenesis agents, side effects	49	22
Bone marrow transplantation, long-term side effects	48	22
Fertility preservation	41	18
Financial challenges from cancer and treatment	40	18
Genetic risks	39	17
Insurance issues	35	16
Fertility after cancer treatment	26	12

tant topics within common comorbid conditions (e.g., cardiac and pulmonary diseases, cancer, diabetes). Perhaps that approach would encompass a greater amount of education that can be translated to specific cancers with crossover psychosocial needs and interventions. A short graduate elective for undergraduate and graduate students that uses creative interventions in urban and rural hospitals has been effective at the Ohio State University (Lester & Schmidt, 2011).

#### **Current Status of Survivorship Care**

Nurse practitioners still are the providers of survivorship care planning, beginning with initiation, the first two years of the American Society of Clinical Oncology's urge for oncologists to complete survivorship care planning, the failure of that initiative, and reorganization (Lester & Schmidt, 2011). RNs can participate in survivorship care planning by helping with care plans as the nurse practitioner embraces the role of provider for long-term survivorship care. RNs could compile and check information for accuracy, develop care plans based on patient issues, and discuss the care plan with the APN or physician to validate referral orders. RNs also could review survivorship care plans with the patients and document ongoing progress or redirection of goals during subsequent visits. The incorporation of electronic medical records in major health systems has streamlined survivorship care planning and will continue to do so as software becomes more sophisticated. Centralized survivorship clinics continue to exist, but the primary model includes disease- and provider-specific clinics (Howell et al., 2012; Lester & Schmidt, 2011). The oncology nurse remains central to patient care and survivorship care.

#### **Limitations**

The study limitations included a survey at one institution, which limits generalizability. An online survey was conducted as opposed to interviewing techniques with the difficulty that 20% (n = 45) of respondents answered "other" with regard to their job title. In addition, the instrument was developed for the sole use of the current study; a reliable and validated instrument was not available in the literature. Preliminary psychometric properties were ascertained, but the overall instrument has not been tested. This survey also was conducted in 2009, and survivorship care planning has changed since then.

## **Implications for Nursing**

The results of the current study and the studies reviewed cause concern about nursing professionals' knowledge of cancer survivorship care and the intended initiation and use of survivorship care plans. Reported gaps in communication between the oncologist, patient, and the PCP are troublesome, as well as perceived and verified competency for long-term care of cancer survivors. An interdisciplinary team with trained, competent, and confident professionals is an excellent model for adult survivorship care. Nurses are integral to this paradigm shift and can provide the necessary leadership to move the survivorship initiative forward. Education and ongoing communication are essential to the success of this endeavor.

Most healthcare professionals will need to obtain additional education to ensure knowledge of cancer survivorship care. Curriculum changes in nursing schools should occur, although the greater need is to

#### **Knowledge Translation**

Evidence exists that rehabilitation and survivorship goals improve outcomes and are important to successful management of chronic disease.

Oncology nurses must provide cancer survivorship care in a way that ensures education and communication for the patient and primary care provider.

Fragmented survivorship care will continue unless focused education is provided to professionals.

educate professionals who already have completed formal training. Pediatric oncology APNs have been instrumental in defining, implementing, and evaluating survivorship models of care and educating professionals through conferences, continuing education offerings, publications, and mentorship (Ruccione, 2009).

The Oncology Nursing Society offers an annual conference as well as multiple regional courses, webinars, online offerings, books (e.g., *Cancer Rehabilitation and Survivorship: Transdisciplinary Approaches to Personalized Care*), and peer-reviewed, evidence-based research journals with many survivorship offerings (Lester & Schmidt, 2011; Oncology Nursing Society, 2013). The National Cancer Institute has sponsored development of an online community to provide continuing education, training tools, and resources for professionals that offers a universal method of online learning (www.cancersurvivor shiptraining.com).

The American College of Surgeons soon will require screening for psychosocial distress and searching for evidence of referrals for psychosocial care (Wagner, Spiegel, & Pearman, 2013), which are essential elements of survivorship care plans. Instruments such as the Distress Thermometer from the National Comprehensive Cancer Network ([NCCN], 2013a) and James Supportive Care Screening questionnaire (Wells-Di Gregorio et al., 2013) are useful tools to obtain self-reported patient distress. Algorithms to navigate the new language are helpful. The NCCN (2013b) survivorship guideline includes algorithms to address anxiety, depression, cognitive function, exercise, fatigue, immunization, infections, pain, sexual function, and sleep disorders. Likewise, the NCCN (2013a) distress management guideline provides information about patients at risk for distress and describes periods of increased vulnerability.

#### **Conclusion**

The role of the oncology nurse continues to evolve with regard to survivorship care, in part because of changing models of care (Klemp et al., 2011). The original depiction of the shared care model for cancer survivorship

care did not include the RN or APN, but now nurses are the backbone of advancing survivorship care (Lester & Schmidt, 2011). To increase knowledge of survivorship care, nurses should participate in continuing education classes, conference offerings, online courses, and journal clubs. Healthcare institutions should address these learning needs, and educational institutions should incorporate increased segments of cancer survivorship care into undergraduate and graduate programs (Lester & Schmidt, 2011). The NCCN (2013b) released the Clinical Practice Guidelines in Oncology for Survivorship that cover eight distinct areas related to survivorship. Institutions could incorporate these guidelines for survivorship

care to provide better care for patients throughout the cancer continuum.

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