This material is protected by U.S. copyright law. To purchase quantity reprints, e-mail reprints@ons.org. For permission to reproduce multiple copies, e-mail pubpermissions@ons.org.

Oncology Nurses' Perspectives on the State of Cancer Survivorship Care: Current Practice and Barriers to Implementation

Margaret Irwin, RN, MN, PhD, Jennifer R. Klemp, MA, PhD, MPH, Catherine Glennon, RN, MHS, BC, CAN, OCN®, and Linda M. Frazier, MD, MPH

he United States has an estimated 12 million cancer survivors (Altekruse et al., 2010). Cancer affects the well-being of survivors beginning at diagnosis and after the completion of acute treatment. During the transition from active treatment to post-treatment care, cancer survivors may be left without the resources, knowledge, or skills needed to manage the long-term consequences of their disease or treatment. Survivors also need routine health-promotion and disease-prevention management and education. As a result, survivorship care has emerged as a distinct focus within oncology.

Although survivorship has several definitions, the one most frequently used describes it as beginning at diagnosis (Hewitt, Greenfield, & Stovall, 2006). The National Coalition for Cancer Survivorship (NCCS) defines cancer survivorship as the state of living with the many challenges that come with a diagnosis of cancer, from the time of diagnosis and for the balance of life (NCCS, 2009). Both NCCS (2009) and the Centers for Disease Control and Prevention ([CDC], 2004) include family, friends, and caregivers in this definition.

Educating patients and caregivers about late and long-term physical and psychological effects that may occur is an important component of survivorship care. Survivorship care has improved outcomes in quality of life, early detection of late-onset sequelae of cancer treatment, reduction in the risks for new or recurrent cancers, and prevention of illness from comorbid conditions (Ganz, 2009; Landier, Wallace, & Hudson, 2006). Nursing professionals and researchers are exploring ways to integrate those findings into clinical practice and to empower cancer survivors to engage in healthy behaviors and obtain optimal care following treatment (Earle, 2007; Houldin, Curtiss, & Haylock, 2006).

Purpose/Objectives: To describe current survivorship care from the perspectives of oncology nurses.

Design: Descriptive.

Setting: E-mail invitation to Web-based survey.

Sample: 399 Oncology Nursing Society members providing care for patients initially treated more than one year previously.

Methods: An online survey was used to evaluate current aspects of survivorship care.

Main Research Variables: Practice settings, services provided, and barriers to delivering survivorship care.

Findings: Few nurses (27%) worked in settings with a formal survivorship program. Several program components were provided significantly more often in outpatient settings, pediatric facilities, and workplaces with a formal survivorship program. At the transition from acute to follow-up care, the survivorship nursing care provided most often was scheduling for ongoing monitoring (71%) and the least likely was assistance for employment or legal issues (16%). The greatest barriers to providing survivorship care were lack of time and funding (46%). Among nurses new to oncology (fewer than five years), 49% indicated they lacked sufficient knowledge compared to 36% of nurses with more than five years of oncology experience.

Conclusions: Findings describe current aspects of survivorship care across practice settings. Nurses reported that the greatest barriers are lack of time, funding, and lack of knowledge about survivorship issues.

Implications for Nursing: A need exists for education to enhance knowledge and skills of nurses who will provide survivorship care. Research is warranted to develop empirically supported guidelines and care-delivery models that address the barriers to providing survivorship services.

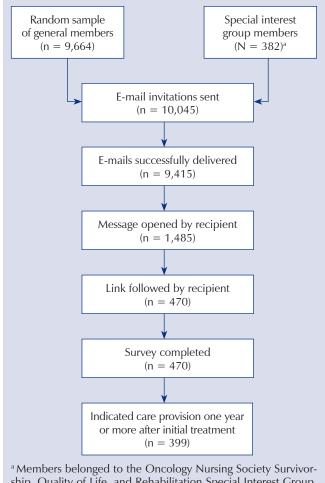
Cancer survivorship as a focus within oncology has gained momentum because of initiatives launched by advocacy groups, professional organizations, and government. NCCS, the Lance Armstrong Foundation, and the

American Cancer Society are the advocacy groups in the forefront of this movement. Professional groups such as the Oncology Nursing Society (ONS) and the American Society of Clinical Oncology are educating members and providing resources to establish and implement programs. Government groups such as the National Cancer Institute's Office for Cancer Survivorship, the Cancer Prevention and Control branch of the CDC, and the Institute of Medicine (IOM) also have raised awareness about patients' survivorship needs.

An event that brought broad attention to survivorship was the IOM report From Cancer Patient to Cancer Survivor—Lost in Transition (Hewitt et al., 2006), which highlighted cancer as a chronic condition that requires ongoing care and identified essential components of survivorship care. The report further summarized trends in cancer survivorship and enumerated late and long-term effects of cancer and antineoplastic therapies. A key emphasis within the report was that the transition from active treatment to post-treatment care is critical to long-term health. Post-treatment care was conceptualized as a unique phase of cancer care that should include prevention and surveillance for recurrence, detection and intervention for post-treatment symptoms, and coordination of care by primary and specialty providers who are caring for cancer survivors. The IOM panel identified several different models for providing survivorship care, as well as potential barriers for optimal care delivery.

Oncology nurses play a vital role in patient education, assessment of patients' current status, and facilitating the continuity of care needed to manage late and long-term effects of cancer (Hewitt et al., 2006; Houldin et al., 2006). In 2003, Ferrell, Virani, Smith, and Juarez (2003) reported on the critical role and contribution of nurses in the care of cancer survivors, pointing out that survivorship is an integral component of oncology nursing. They provided data from a survey of the ONS Survivorship, Quality of Life, and Rehabilitation Special Interest Group (SIG) that revealed the views of oncology nurses regarding the importance of professional education on survivorship issues and the need for more attention to cancer survivorship in clinical practice.

Cancer survivorship also has been identified as a priority area by the ONS Board of Directors (ONS, 2008). ONS periodically holds think-tank meetings to gain insights on a topic from its members and stakeholders and to develop plans for research and education. In 2008, the ONS Survivorship Think Tank led to the development of the ONS Cancer Survivorship Initiatives Roadmap, which included the plan to conduct a survey of ONS members to determine needs and practices related to survivorship care. In addition, the ONS Research Agenda for 2009–2013 includes late effects of treatment and long-term survivorship issues as an area of focus (Berger, 2008).



ship, Quality of Life, and Rehabilitation Special Interest Group. Membership volume data were extracted July 2009.

Figure 1. Survey Response Flow Chart

A comprehensive survey instrument was developed by ONS and the University of Kansas Cancer Center and sent to a random and purposive sample of oncology nurses across the United States. This article reports the findings of survey items related to services provided, barriers to providing survivorship care, and current practices of oncology nurses for cancer survivors.

Methods

A descriptive, cross-sectional study was conducted via an anonymous online survey. The study was approved by the institutional review board of the University of Kansas School of Medicine.

Survey Instrument

The questionnaire designed for this study addressed the major components of survivorship care recommended by IOM (Hewitt et al., 2006) and care needs outlined in the National Action Plan for Cancer Survivorship, which was developed with input from a wide variety of community, public health, and patient care organizations (CDC, 2004; Lance Armstrong Foundation & CDC, 2004). The results from the 39-item survey described the overall status of cancer survivorship care in the respondents' work settings (one item), provision of specific components of a survivorship program (eight items), and aspects of cancer care at the transition from acute to follow-up care (nine items). Program components that were assessed included referrals to specialists and other resources, follow-up assessment for recurrent or new cancers, promotion of healthy lifestyle practices, communication with primary care providers, screening for new cancers according to national guidelines, education to prevent health issues and maintain wellness, education about long-term effects, and provision of a written summary of treatments and recommenda-

written summary of treatments and recommendations. Barriers to establishing a survivorship program were assessed (eight items), and open-ended questions solicited additional input (five items). Descriptive information about the respondent and the work setting also was requested (eight items). No items were included that would identify any individual respondent. The final electronic survey was reviewed and accepted by ONS and University of Kansas professionals with expertise in the area of cancer survivorship.

Sample

The questionnaire was formatted and administered using the Zarca® electronic survey system. An e-mail invitation to participate, which included the survey link, was sent to randomly selected ONS members who had valid e-mail addresses and were identified in the membership database as working full or part time, as well as to all 382 members of the ONS Survivorship, Quality of Life, and Rehabilitation SIG (see Figure 1). The total ONS membership who met the initial inclusion criteria at the time of the survey was 27,617. The invitation informed potential participants of the survey purpose and guaranteed anonymity. The initial invitation was sent on July 23, 2009. A reminder e-mail was sent two weeks later to those on the initial mailing list who had not yet responded. The survey was closed on August 30, 2009.

Inclusion Criteria and Statistical Analysis

After all responses were collected, the Zarca system was used to export the data into a dataset that was then analyzed using Predictive Analytics Software®, version 17.0. Recoding was conducted to unduplicate any responses, such as description of a specific service or barrier in an open-ended "other" response that had been previously selected in a closed-ended item. Respondents were eligible

for the analysis if they answered yes to the question asking them if they see patients who received their initial treatment a year or more ago. For subgroup analyses, proportions were compared using Pearson's chi-square tests or with Fisher's exact tests when expected values in any cell were less than five. Characteristics of the respondents were compared to the ONS general members and to the ONS members who formed the Survivorship, Quality of Life, and Rehabilitation SIG as of July 1, 2009. Calculation of confidence intervals (CIs) around sample characteristics was used to determine any differences between respondents to this survey and the SIG and total memberships. All statistical tests were two tailed, and an alpha of 0.05 was used for all statistical calculations. Because of the large sample sizes, the 95% CI did

Table 1. Characteristics of Sample Compared to ONS General Membership and the Survivorship, Quality of Life, and Rehabilitation SIG

	Sample		ONS Men	nbers	SIG Members			
Characteristic	n	%	n	%	n	%		
Age (years) Younger than 40 40–49 50–54 55 or older Total	69 123 88 115 395	17 31 22 29 99	7,138 8,047 5,512 6,311 27,008	26 30 20 23 99	73 94 90 114 371	20 25 24 31 100		
Highest nursing degree completed Diploma Associate Bachelor's Master's Doctorate Total	31 77 149 119 17 393	8 20 38 30 4 100	2,949 7,441 11,576 4,906 441 27,313	11 27 42 18 2 100	36 65 112 116 30 359	10 18 31 32 8 99		
Primary work setting Outpatient Inpatient Other Total	186 85 121 392	47 22 31 100	15,048 10,198 2,122 27,368	55 37 8 100	205 91 86 382	54 24 23 101		
Primary functional area of work Patient care Education Administration Research Other Total	222 56 53 30 26 387	57 14 14 8 7 100	20,671 1,654 2,150 1,764 1,378 27,617	75 6 8 6 5 100	210 53 41 30 37 371	57 14 11 8 10		
Primary patient setting Adult Adult and pediatric Pediatric Total	359 19 18 396	91 5 5 101	25,769 1,323 248 27,340	94 5 1 100	332 29 6 367	90 8 2 100		

ONS—Oncology Nursing Society; SIG—Special Interest Group *Note*. Because of rounding, not all percentages total 100.

not overlap for most of the proportions when comparing the respondents to the ONS member groups, so the authors interpreted the clinical importance of any differences seen.

Results

Sample Characteristics

The overall response rate was 5% of ONS members who received the e-mail and 32% of those who opened the e-mail. In all, 83% of respondents were eligible for this analysis. The respondents had worked in oncology for a mean of 15.3 years (SD = 9.9), and their oncology experience ranged from 0-40 years.

Demographics of the respondent group were similar to that of the ONS general membership and the ONS Survivorship, Quality of Life, and Rehabilitation SIG (see Table 1). The respondents were slightly older than the general membership. Fifty-one percent of respondents were aged 50 years or older compared to 43% of the general membership. Respondents were more likely than the ONS general membership to have received at least a master's degree (34% compared to 20%, respectively). Respondents were similar to the survivorship SIG in age (53% were aged 50 years or older) and education (40% had at least a master's degree).

Survivorship Program Components

Ten percent of respondents said their workplace had a formal survivorship program for all types of cancer

Table 2. Current Status of Work Settings Regarding Provision of Care to Cancer Survivors

Status	n	<u>%</u>
We do not have a formal program but provide some services to patients and families that meet survivorship needs.	100	25
We have no plans to create a survivorship program at this time.	91	23
We have survivorship services for specific patient populations such as bone marrow transplantation, breast cancer, or prostate cancer survivors.	65	16
We are discussing creating a survivorship program.	46	12
We currently have a formal survivorship program in place for all types of cancer diagnoses.	41	10
We are in the process of planning a survivorship program.	41	10
We are in the process of opening our survivorship program.	11	3

N = 395

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

diagnoses, and 17% of respondents' workplaces provided such services for specific patient populations (total with a formal program: 106 respondents, 27%) (see Table 2). Twenty-three precent of respondents indicated that their work setting had no plans to create a survivorship program. Regarding specific components of a survivorship program that may be available in their workplace, only 22 respondents (6%) said that none of the eight program components were provided (see Table 3). The most frequently reported survivorship program components provided were referrals (69%) and follow-up assessments for recurrence (65%). In the open-ended item assessing other program components provided, the most frequently listed was provision of patient support groups.

The work setting appeared to affect the components of a survivorship program that were provided. In outpatient settings, a significantly larger percentage of nurses indicated that follow-up assessments, communication with primary providers, screening for new cancers, and education about long-term effects were provided. Four of the eight survivorship program components were significantly more common in outpatient settings, five components were more common in pediatric settings, and seven components were more commonly provided in settings with formal survivorship programs for some or all cancer survivors. Those differences were all statistically significant.

Barriers Encountered

Fourteen percent of respondents reported that their workplace had no barriers to establishing a survivorship program (see Table 4). Forty-six percent indicated that a lack of time and funding were barriers. Lack of interest by workplace leadership was cited by 20% of respondents. Among the open-ended comments about barriers, physician-related issues were described, including a lack of physician buy-in to the concept of a survivorship program, politics, individual oncologists and clinics wanting to "hold on" to their patients, and lack of clarity and coordination of responsibilities for follow-up care. Patient-related barriers were the least common of those encountered. Travel time or distance for patients living in rural areas were noted in two verbatim comments. Another respondent said, "Younger survivors are trying to get back to work and family life and don't have time or resources."

Lack of knowledge about survivorship needs as a barrier to establishing a survivorship program was associated with less oncology experience. Among those who had worked five or fewer years in oncology practice, 49% indicated a lack of knowledge as a barrier compared to 36% of respondents who had worked in oncology for more than five years (p = 0.028). A larger proportion of individuals whose primary work setting included pediatric patients (with or without adult patients) reported

Table 3. Survivorship Components of Care Provided

				Type	of Care		Pa	atient A	ge Gro	oup	Formal Program			
	Total (N = 399)		Inpatient (N = 85)		Outpatient (N = 186)		Adult (N = 359)		Pediatric (N = 37)		Absent (N = 289)		Present (N = 106)	
Program Component	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Referrals to specialists, resources, and services	275	69	57	67	138	74	245	68	28	76	187	65*	86	81*
Follow-up recurrence assessment	258	65	41	48**	143	77**	225	63*	31	84*	175	61*	81	76*
Promotion of healthy lifestyle practices	238	60	47	55	120	65	210	58	27	73	149	52**	86	81**
Communication with primary providers	216	54	36	42*	110	59*	192	53	22	59	149	52	65	61
Screening for new cancers according to national guidelines	210	53	34	40*	110	59*	180	50*	28	76*	133	46**	75	71**
Education to prevent new health issues and maintain wellness	198	50	42	49	97	52	170	47*	27	73*	121	42**	76	72**
Education about long-term effects	188	47	23	27**	108	58**	160	45**	27	73**	116	40**	69	65**
Written summary of treatments and recommendations	146	37	27	32	77	41	119	33**	26	70**	78	27**	66	62**
Other services	13	3	2	2	1	1	12	3	1	3	6	2	7	7
None of these services	22	6	6	7	7	4	20	6	2	5	21	7*	1	1*

^{*} p < 0.05; ** p \leq 0.001

Note. Because multiple choices could be selected, percentages do not total 100.

no barriers to survivorship program development (35% compared to 11%, respectively, p < 0.001).

Nursing Care at the Transition From Acute to Follow-up Care

Regarding what areas are incorporated into planning at the end of treatment or at discharge from the hospital, the service most frequently reported was scheduling follow-up visits for monitoring (see Table 5). The remaining services were provided by no more than 59% of the respondents. Areas least frequently provided were assistance with insurance issues, financial issues, and employment issues or legal rights. Seven percent of respondents stated that none of the listed services were included in their nursing care.

Some differences existed in the findings based on work setting. The outpatient setting was associated with a higher rate of scheduling patients for ongoing monitoring. When care was provided for pediatric patients, counseling about the risk for long-term effects was much more likely compared to only adult cancer survivors (76% versus 57%, respectively, p = 0.031), as was counseling about the signs of long-term effects and where to seek help for them (78% versus 53%, respectively, p = 0.004). The presence of a formal survivorship

program was significantly associated with providing six of the eight types of nursing care (all p < 0.05). Oncology nurses who had fewer than five years of experience in oncology were less likely to describe the signs of long-term effects or to tell patients how to seek help if they occur. Among the less experienced nurses, 45% reported providing this aspect of care, compared to 58% of the more experienced nurses (p = 0.041).

Discussion

The current study had several notable findings. The most striking was the significant differences in the types of care provided among specific patient care settings. In settings that provided pediatric care, a formal survivorship program or outpatient services that met the definition of survivorship care was more likely to be in place (Hewitt et al., 2006). Pediatric oncology has addressed long-term cancer survivorship over the past few decades, whereas the adult survivorship movement is relatively new (Jacobs et al., 2009). The differences between adult and pediatric settings seen in the current study likely reflect this.

Kolb (2009) looked specifically at the transition of care for pediatric patients with cancer as they become adult

Table 4. Barriers Encountered When Attempting to Establish a Survivorship Program

Barrier	n	%
Lack of time for current staff to incorporate these aspects of care into work	183	46
Lack of funding to support such a program	183	46
Lack of knowledge regarding survivorship issues and needs	151	38
Lack of staff to provide a program	150	38
Lack of interest in such a program by leadership in the work setting	81	21
Travel time or distance for patients to attend relevant program activities	72	18
No barriers; have a program or are in the midst of creating one	54	14
Lack of interest in such a program by patients or families	24	6
Other barrier	17	6

N = 395

Note. Because multiple choices could be selected, percentages do not total 100.

survivors. Her review identified barriers to obtaining the types of care that enable a successful transition to longer-term survivorship. Some barriers may be unique to the pediatric population, but many of the needs may remain unmet among pediatric and adult patients. For example, Kolb (2009) identified the importance of defining the roles of primary and specialty physicians, attending to insurance issues, and obtaining a treatment summary and recommendations from the primary oncologist. The current study found that those services are less likely to be provided for adult patients. For example, only 33% of nurses working in exclusively adult settings said that patients were provided a written summary and follow-up care plan, compared to 70% of those working in pediatric settings.

The current study also found opportunities for improvement in meeting other patient needs that others have identified (Jacobs et al., 2009; Kolb, 2009). Kolb (2009) listed employment and finances as one of five areas that are important in the transition that follows primary cancer treatment. In the current study, only 24% of respondents incorporated management of financial issues into nursing practice after initial acute treatment, and only 16% addressed employment issues. Practicing in a pediatric environment did not increase the delivery of those services. However, meaningfully higher rates of providing other types of survivorship care in pediatric oncology settings were found. Education about long-term effects, screening for recurrence, and wellness

strategies were exceedingly more likely to be covered by pediatric oncology providers compared to those practicing in adult-only settings.

Findings demonstrated significant differences in the components of survivorship care offered when a formal survivorship program was present, suggesting that a formal, programmatic approach may be more conducive to meeting the full range of survivor needs. When a formal cancer survivorship center was in place, written treatment summaries with recommendations, referrals to specialists, follow-up and screening for recurrence and new primary cancers, education on long-term effects and new potential health issues, promotion of healthy lifestyle behaviors, and psychosocial aspects of cancer were addressed more frequently.

Several models for survivorship care delivery have been described previously (Eiser et al., 2007; Gilbert, Miller, Hollenbeck, Montie, & Wei, 2008; Hewitt et al., 2006; Landier, 2009; Oeffinger & McCabe, 2006). They include nurse-led models; academic oncology-based models organized by disease or treatment type; communitybased models, in which survivorship care is provided by the primary care provider with referrals to specialists as needed; and shared care, in which combined services are provided by the primary care provider and a cancer center. Landier (2009) also described different systems of survivorship care: (a) the consultative system involving single or multiple visits for evaluation; (b) the ongoing care system, in which the patient is followed in a survivorship program; and (c) the integrated care system, in which survivorship care is incorporated into services provided by the primary oncology team. Little research exists to evaluate the outcomes of implementing various models (Earle, 2007; Ganz, 2009).

Ganz and Hahn (2008) reviewed the cancer survivorship clinic model. In this consultative model, experts in oncology educate and counsel patients on a variety of survivorship issues including the late and long-term side effects of cancer. The model can be implemented in tertiary care centers, such as in a pediatric late-effects clinic (Bowers, Adhikari, El-Kashab, Gargan, & Oeffinger, 2009) or in community settings where needed expertise is available.

Grant, Economou, Ferrell, and Bhatia (2007) described another approach to address survivor needs, consisting of an educational program to develop competency among a broad spectrum of professional staff to increase provision of survivorship care across multiple settings. Barriers were similar to those identified in the current study—lack of knowledge and funding, a staff philosophy that was not consistent with the view of survivorship as a distinct focus in cancer care, and lack of administrative support.

The finding that lack of time and lack of funding were the two greatest obstacles to delivering survivorship care identified by nurses in the current study is of concern. A lack of time hampers the provision of many aspects of nursing care, and patient education and meaningful discussion of psychosocial needs clearly require significant time to be spent with the patient (Hewitt, Bamundo, Day, & Harvey, 2007). However, a lack of time allocated in a healthcare system to provide a service often correlates with a lack of reimbursement for that service. When clinical practice guidelines are established and the recommended care is reimbursed, access to such services increases (Alexander, Kogan, & Nabukera, 2002; Szilagyi et al., 2006). The establishment of pediatric cancer long-term follow-up guidelines was associated with an increase in the number of such programs from 53%–70% among member institutions of the Children's Oncology Group in the United States (Bowers et al., 2009). For adults, survivorship care guidelines are available only for a few types of cancer (American Society of Clinical Oncology, 2009).

A lack of knowledge about survivorship issues was identified as a barrier to care by more than 33% of the respondents and by almost half of those with fewer than five years in oncology practice. The finding is consistent with previous research. For example, one study found that certain survivorship topics, such as prevention of secondary cancers and long-term complications, were less well addressed in nursing oncology textbooks and journal articles than topics such as quality of life (Ferrell

et al., 2003). Ferrell et al. (2003) recommended improvements in basic and graduate level nursing education programs and continuing education opportunities.

Limitations

The current study had a relatively low overall response rate (5%), but the response rate was better than is typically seen when using e-mail to contact potential respondents. In a benchmarking study assessing consumer response behavior, e-mails from nonprofit agencies had an average open rate of 16%, and only 2% followed the internal links to additional content (Matheson, Ruben, & Ross, 2009). The current study's e-mail open rate was similar (16%), but 32% of those who opened the e-mail followed the link to complete the survey. The characteristics of the current study's respondents on the whole were similar to the ONS membership, suggesting that selection bias was minimal.

Although the current study has shown that the existence of some type of formal program appears to be associated with increased provision of related services, the authors do not know whether all respondents defined a formal program in the same way and cannot identify the type of program provided. The findings can only suggest that formal attention to survivorship care, in whatever form, increases the provision of relevant care.

Table 5. Survivorship Care Incorporated Into Nursing Practice at Hospital Discharge or End of Initial Treatment

			Type of Care				Pa	atient A	ge Gro	up	Formal Program			
	Tot (N =		Inpatient (N = 85)		Outpatient (N = 186)		Adult (N = 359)		Pediatric (N = 37)		Absent (N = 289)		Present (N = 106)	
Aspect of Care	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Schedule for monitoring	285	71	54	64*	150	81*	255	71	28	76	202	70	81	76
Risk of long-term effects	236	59	50	59	113	61	206	57*	28	76*	157	54**	77	73**
Effects of cancer on emotions	227	57	45	53	103	55	201	56	25	68	153	53*	72	68*
Signs of long-term effects and where to seek help	222	56	47	55	103	55	192	53*	29	78*	140	48**	79	75**
Health promotion and cancer screening	206	52	41	48	102	55	182	51	23	62	129	45**	74	70**
Cancer's effects on relationships	174	44	34	40	77	41	154	43	19	51	114	39*	58	55
Insurance issues	132	33	31	36	59	32	115	32	16	43	89	31	43	41
Managing financial issues	94	24	18	21	39	21	84	23	9	24	62	21	32	30
Employment and legal rights	64	16	10	12	31	17	54	15	9	24	40	14*	24	23*
Other	6	2	1	1	3	2	6	2	-	-	2	1	4	4
None of these practices	26	7	4	5	13	7	25	7	1	3	21	7*	5	5*

^{*} p < 0.05; ** p \leq 0.001

Note. Because multiple choices could be selected, percentages do not total 100.

Conclusions and Implications for Nursing

This study's findings point to gaps in current oncology nursing practice related to the care of cancer survivors. ONS, other agencies, and a broad spectrum of healthcare providers are committed to providing comprehensive care for cancer survivors, but to do so, the educational needs of the providers must be addressed. The findings highlight the need for education about survivorship care for oncology nurses. Skills development is needed for other nurses and healthcare professionals as well, because care for survivors involves more than just nurses who work in oncology practice. Cancer survivors likely will have nononcology comorbid conditions that will be managed in primary care settings and by nonspecialty providers. Communication across practices or settings and coordination of nononcology and oncology care is essential to patients' quality of life. The growth in the number of cancer survivors suggests that skills in providing key aspects of survivorship care need to be gained by all healthcare providers, not just those who work in the specialty arena.

Nurses who encounter cancer survivors should be made aware of current resources so they can educate and assist survivors to meet their changing needs. As patient advocates, nurses should support efforts to continue to empower survivors and to obtain appropriate reimbursement for services that are essential for quality survivorship care.

Nursing care and nursing roles should continue to evolve to address the special needs of cancer survivors. Provision of more comprehensive care may be enhanced through development of relevant guidelines for nursing care. Nurses are an appropriate professional group to provide survivorship care, and they can be a catalyst for paradigm shifts in their institutions to address survivorship issues. Substantial evidence shows that nurse follow-up can be an efficient and effective way to address patient needs (Hewitt et al., 2006), and nursing has long provided leadership in defining, implementing, and evaluating models of care to advance survivorship research and clinical practice (Ruccione, 2009). Nurses have an opportunity to continue to provide leadership in this area to improve access to appropriate care and increase the collective understanding of survivorship issues through research.

Future Research

The field of survivorship care has significant clinical research needs. The identification of a lack of knowledge regarding survivorship issues in the current study points to the need for improving the understanding of specific educational needs for nurses in various practice settings. The effect of relevant educational programs and methods on actual practice and patient outcomes for nurses and

others should be examined. Similarly, strategies for empowering patients and others to advocate for and manage their own health care should be explored.

Ongoing research to identify and describe long-term effects of cancer and treatment should continue to expand. As cancer survival improves and new treatments are employed, additional late effects of cancer and its treatment are expected to emerge. A consistently growing body of knowledge regarding those effects is needed. Interventions to prevent and manage adverse long-term effects should be developed, and approaches to facilitate patients' ability to effectively cope with effects that may not be preventable should be studied. Related occupational health and employment issues warrant additional exploration, with identification of evidence-based cost-effective approaches to address return to work and associated disability concerns (Feuerstein & Harrington, 2006).

Research is needed particularly on models for delivering survivorship care that address the barriers identified in the current study and to develop empirically supported clinical care guidelines to increase survivorship care practices. Various models of survivorship care should be evaluated to determine which approaches achieve the best patient outcomes and are most cost effective. Such research should be patient focused, incorporating patient satisfaction with care and the full range of long-term patient outcomes. Potential disparities in access to services for survivorship care, such as differences between rural and urban settings, should be understood and addressed.

The authors gratefully acknowledge the support and expert input of Marcia Gruber, MS, MSN, RN, the vice president of Therapeutic Services at Roswell Park Cancer Institute in Buffalo, NY, and Deborah K. Mayer, PhD, RN, AOCN®, FAAN, an associate professor in the School of Nursing at the University of North Carolina at Chapel Hill and editor of the Clinical Journal of Oncology Nursing, in the design of this survey. The authors also acknowledge Dana Barkley, MS, the corporate relations manager in Corporate Support and Partnerships at ONS in Pittsburgh, PA, for her assistance in coordinating this project, as well as the many members who have participated in the ONS Survivorship Think Tank and Task Force.

Margaret Irwin, RN, MN, PhD, is a research associate in the Research Department at the Oncology Nursing Society (ONS) in Pittsburgh, PA; Jennifer R. Klemp, MA, PhD, MPH, is the managing director of the Breast Cancer Survivorship Center at the University of Kansas Cancer Center in Kansas City and an assistant professor in the School of Medicine at the University of Kansas in Lawrence; Catherine Glennon, RN, MHS, BC, CAN, OCN®, is the director of nursing for oncology at the University of Kansas Cancer Center; and Linda M. Frazier, MD, MPH, is a professor in the Department of Obstetrics and Gynecology in the School of Medicine at the University of Kansas. The views expressed in this article are those of the authors and do not reflect the official policy or position of ONS. Klemp is on the speakers bureaus for Myriad Genetic Laboratory and Pfizer Pharmaceuticals. Irwin can be reached at mirwin@ons.org, with copy to editor at ONFEditor@ons.org. (Submitted March 2010. Accepted for publication April 22, 2010.)

Digital Object Identifier: 10.1188/11.ONF.E11-E19

References

- Alexander, G., Kogan, M.D., & Nabukera, S. (2002). Racial differences in prenatal care in the United States: Are disparities decreasing? *American Journal of Public Health*, 92, 1970–1975.
- Altekruse, S.F., Kosary, C.L., Krapcho, M., Neyman, N., Aminou, R., Waldron, W., . . . Edwards, B.K. (Eds). (2010). SEER cancer statistics review, 1975–2007. Retrieved from http://seer.cancer.gov/csr/1975 2007
- American Society of Clinical Oncology. (2009). ASCO cancer treatment summaries. Retrieved from http://www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries
- Berger, A.M. (2008). Oncology Nursing Society 2009–2013 research agenda. Retrieved from http://www.ons.org/media/ons/docs/ research/2009-2013onsresearchagendaexecutivesummary.pdf
- Bowers, D.C., Adhikari, S., El-Khashab, Y.M., Gargan, L., & Oeffinger, K.C. (2009). Survey of long-term follow-up programs in the United States for survivors of childhood brain tumors. *Pediatric Blood and Cancer*, 53, 1295–1301. doi: 10.1002/pbc.22240
- Centers for Disease Control and Prevention. (2004). Overview: A National Action Plan for Cancer Survivorship: Advancing public health strategies. Retrieved from http://www.cdc.gov/cancer/survivorship/pdf/overview.pdf
- Earle, C.C. (2007). Long-term care planning for cancer survivors: A health services research agenda. *Journal of Cancer Survivorship*, 1, 64–74. doi: 10.1007/s11764-006-0003-9
- Eiser, C., Absolom, K., Greenfield, D., Snowden, J., Coleman, R., Hancock, B., & Davies, H. (2007). Follow-up care for young adult survivors of cancer: Lessons from pediatrics. *Journal of Cancer Survivorship*, 1, 75–86. doi: 10.1007/s11764-0006-1
- Ferrell, B.R., Virani, R., Smith, S., & Juarez, G. (2003). The role of oncology nursing to ensure quality care for cancer survivors: A report commissioned by the National Cancer Policy Board and Institute of Medicine [Online exclusive]. Oncology Nursing Forum, 30, E1–E11. doi: 10.1188/03.ONF.E1-E11
- Feuerstein, M., & Harrington, C.B. (2006). Recommendations for the U.S. national occupational research agenda: Research on cancer survivorship, musculoskeletal disorders, and work disability. *Journal of Occupational Rehabilitation*, 16, 1–5. doi: 10.1007/s1092 6-005-9004-1
- Ganz, P.A. (2009). Survivorship: Adult cancer patients. *Primary Care Clinics in Office Practice*, 36, 721–741. doi: 10.1016/j.pop.2009.08.001
- Ganz, P.A., & Hahn, E.E. (2008). Implementing a survivorship care plan for patients with breast cancer. *Journal of Clinical Oncology*, 26, 759–767. doi: 10.1200/JCO.2007.14.2851
- Gilbert, S.M., Miller, D.C., Hollenbeck, B.K., Montie, J.E., & Wei, J.T. (2008). Cancer survivorship: Challenges and changing paradigms. *Journal of Urology*, 179, 431–438. doi: 10.1016/j.juro.2007.09.029
- Grant, M., Economou, D., Ferrell, B., & Bhatia, S. (2007). Preparing

- professional staff to care for cancer survivors. *Journal of Cancer Survivorship*, 1, 98–106.
- Hewitt, M., Bamundo, A., Day, R., & Harvey, C. (2007). Perspectives on post-treatment cancer care: Research with survivors, nurses, and physicians. *Journal of Clinical Oncology*, 28, 2270–2273. doi: 10.1200/ JCO.2006.10.0826
- Hewitt, M., Greenfield, S., & Stovall, E. (2006). From cancer patient to cancer survivor—Lost in transition. Washington, DC: National Academies Press.
- Houldin, A., Curtiss, C.P., & Haylock, P.J. (2006). Executive summary: The state of the science on nursing approaches to managing late and long-term sequelae of cancer and cancer treatment. *American Journal of Nursing*, 106, 54–59.
- Jacobs, L.A., Palmer, S.C., Schwartz, L.A., DeMichele, A., Mao, J.J., Carver, J., . . . Meadows, A.T. (2009). Adult cancer survivorship: Evolution, research, and planning care. CA: A Cancer Journal for Clinicians, 59, 391–410. doi: 10.3322/caac.20040
- Kolb, M. (2009). Life after pediatric cancer: Easing the transition to the adult primary care provider [Online exclusive]. Clinical Journal of Oncology Nursing, 13, E30–E40. doi: 10.1188/09.CJON.E30-E40
- Lance Armstrong Foundation & Centers for Disease Control and Prevention. (2004). A National Action Plan for Cancer Survivorship: Advancing public health strategies. Retrieved from http://www.cdc.gov/cancer/survivorship/pdf/plan.pdf
- Landier, W. (2009). Survivorship care: Essential components and models of delivery. Oncology (Williston Park), 23(4, Suppl.), 46–53.
- Landier, W., Wallace, W.H.B., & Hudson, M.M. (2006). Long-term follow-up of pediatric cancer survivors: Education, surveillance, and screening. *Pediatric Blood Cancer*, 46, 149–158.
- Matheson, K., Ruben, M., & Ross, H. (2009). 2009 eNonprofit benchmark study: An analysis of online messaging, fundraising, and advocacy metrics for nonprofit organizations. Retrieved from http://www.e-benchmarksstudy.com/pubs/2009_eNonprofit_Benchmarks_Study.pdf
- National Coalition for Cancer Survivorship. (2009). NCCS the organization. Retrieved from http://www.canceradvocacy.org/about/org
- Oeffinger, K.C., & McCabe, M.S. (2006). Models for delivering survivorship care. *Journal of Clinical Oncology*, 24, 5117–5124.
- Oncology Nursing Society. (2008). ONS launches survivorship initiative. Retrieved from http://www.ons.org/Newsroom/Press/media/ons/docs/newsroom/survivorshipdraftlh.pdf
- Ruccione, K. (2009). The legacy of pediatric oncology nursing in advancing survivorship research and clinical care. *Journal of Pediatric Oncology Nursing*, 26, 255–265. doi: 10.1177/1043454209343179
- Szilagyi, P.G., Dick, A.W., Klein, J.D., Shone, L.P., Zwanziger, J., Bajorska, A., & Yoos, H.L. (2006). Improved asthma care after enrollment in the State Children's Health Insurance Program in New York. *Pediatrics*, 117, 486–496. doi: 10.1542/peds.2005-0340