

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

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Purpose: To examine the roles of oncology nurses in improving quality care for cancer survivors.

Data Sources: A content analysis of textbooks, journals, and key documents; surveys of graduate oncology nursing programs and the Oncology Nursing Society's Survivorship Special Interest Group; review of the nursing licensure examination and oncology nursing certification; review of undergraduate and graduate nursing standards; and review of currently funded nursing research.

Data Synthesis: Ten critical content areas of cancer survivorship were used for the analysis: description of population of cancer survivors, primary care, short- and long-term complications, prevention of secondary cancer, detecting recurrent and secondary cancers, treatment of recurrent cancer, quality-of-life issues, rehabilitative services, palliative and end-of-life care, and quality of care. Although findings within each source indicated significant information related to the roles of nurses in caring for cancer survivors, deficits also were identified.

Conclusions: Review of key literature and resources suggests significant contributions by oncology nursing over the past two decades to the area of cancer survivorship.

Implications for Nursing: Support is needed to expand education and research to ensure quality care for future cancer survivors.

Key Points . . .

- ▶ Oncology nurses have made significant contributions to the area of cancer survivorship.
- ▶ Increased attention to cancer survivorship is needed in basic and graduate nursing education, certification, research, and continuing education.
- ▶ Oncology nurses are central to all aspects of survivorship for patient care and family support.

such as pain, fatigue, sexuality, fertility, family coping, long-term sequela of treatment, and numerous other areas pertaining to survivorship (Brant, 1996; Ferrell, 1996; Grant, Padilla, & Greimel, 1996). Oncology nurses also have led important initiatives addressing psychosocial needs and have advocated for improved end-of-life care. Many of these educational efforts have been led by the Oncology Nursing Society (ONS), a national professional organization whose efforts have been especially important in raising awareness of survivorship concerns and providing extensive education to practicing nurses (Wilmoth & Sanders, 2001).

More than one million people will be diagnosed with cancer each year, and nurses will care for these individuals. Nurses will be integrally involved in all aspects of their care and across all settings, and they will tremendously affect the quality of care of cancer survivors and their families (Burke, 1998; Leigh, 1998, 2001).

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Nursing as a profession is dedicated to the care of patients and families throughout health and illness and across all settings of care. Nurses assess and plan care to address the multidimensional spectrum of needs for those faced with cancer. Nurses have been integrally involved in efforts focused on cancer prevention, and they also are pivotal in the emerging area of clinical genetics for prevention and early detection of cancer. From diagnosis through end of life, nurses play an intricate role in enhancing the quality of life (QOL) of their patients. Nurses are in a unique position to influence both the physiologic and psychological well-being of their patients, helping cancer survivors to cope with the immensity of their experience and its resulting impact on their lives (McCorkle, Grant, Frank-Stromborg, & Baird, 1996; Miaskowski & Buchsel, 1999).

Oncology nurses, individually and collectively, have led many initiatives that have resulted in attention to concerns

Oncology nurses have addressed many of the physical burdens associated with cancer survivorship. Fatigue, nutrition, sleep disturbances, menopausal symptoms, and short- and long-term sequela of treatment have been a key focus in oncology nursing. Efforts to better assess these symptoms and provide patient education have greatly enhanced comfort and QOL for survivors (Ferrell, Grant, Dean, Funk, & Ly, 1996; Ferrell, Grant, Funk, et al., 1996; Ganz, 2001).

Psychological concerns such as fear, anxiety, depression, and living with uncertainty have been addressed through model oncology nursing education, intervention, and research programs. Nurses assess psychological symptoms, offer supportive care and education, and are involved in coordination of interdisciplinary services by colleagues in social work, chaplaincy, rehabilitation, and psychology (Brant, 1996; Carroll-Johnson, Gorman, & Bush, 1998; Dow, Ferrell, & Anello, 1997; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997a; Quigley, 1989).

Social concerns emphasized in oncology nursing have included attention to sexuality, fertility, appearance, and counseling of partners and children. Recognition of the economic burden of cancer, employment concerns, and adjustment to life beyond cancer treatment have been important areas of contribution (Hoffman, 1991). Nurses have developed, implemented, and evaluated programs to support families through the cancer survivorship journey (Dow & Ferrell, 1998; Ferrans, 1994; Ferrell et al., 1997c; Ferrell & Hassey-Dow, 1998).

Spiritual care and attention to existential concerns also are within the domain of oncology nursing. Spiritual assessment, referral to chaplaincy, and respect for religious diversity have been common themes in oncology nursing education and practice. Attention to spirituality by oncology nurses has encompassed a broad view beyond religiosity to address issues such as hope, uncertainty, and meaning in illness (Ersek, Ferrell, Dow, & Melancon, 1997; Ferrell et al., 1997b; Ferrell & Hassey-Dow, 1998).

Oncology nursing is critical to quality care in cancer survivorship. This article describes key elements of oncology nursing as one essential discipline in the multidimensional care required in cancer. Although contributions by nurses have been significant, there are also gaps in care and serious needs to ensure the quality care of future survivors. This article is a summary of a report commissioned from the authors by the National Cancer Policy Board (NCPB) and Institute of Medicine (IOM). It was presented at a meeting of those organizations April 22, 2002. This article is limited to adult survivorship, whereas a separate review was commissioned for pediatric survivorship concerns.

Review of Key Oncology Nursing Standards

Four key ONS documents deemed as representative of the standard of oncology nursing care were evaluated for content pertaining to nursing care and cancer survivorship. Two monographs outlining oncology nursing standards, *Standards of Oncology Nursing Education, Generalist and Advanced Practice Levels* (ONS, 1995) and *Statement on the Scope and Standards of Oncology Nursing Practice* (Brant, 1996), as well as two psychosocial texts, *Psychosocial Dimensions of Oncology Nursing Care* (Burke, 1998) and *Psychosocial*

Nursing Care Along the Cancer Continuum (Carroll-Johnson et al., 1998), were included in the review. Ten critical content areas consistent with the outline of the overall NCPB/IOM report were considered: description of population of cancer survivors, primary care, short- and long-term complications, prevention of secondary cancers, detecting recurrent and secondary cancers, treatment of recurrent cancer, quality of life issues, rehabilitative services, palliative and end-of-life care, and quality of care.

Standards of Oncology Nursing Education (ONS, 1995) provided comprehensive guidelines for both generalist and advanced practice oncology nursing education. Key standards include the following.

1. Clinical experiences provide access to people across the life span and cancer continuum, including prevention and detection, treatment, rehabilitation, and/or supportive care.
2. Apply the physical, psychosocial, spiritual, and cultural aspects of prevention, early detection, treatment, rehabilitation, and palliation, and comfort people at risk for or experiencing cancer.
3. Develop an outcome-oriented care plan that is individualized, holistic, culturally sensitive, cost effective, and based on nursing diagnosis and incorporates cancer prevention, detection, treatment, rehabilitation, and supportive care.
4. Collaborate with the multidisciplinary team to assess, plan, implement, and evaluate across all levels of healthcare.
5. Apply research to oncology nursing practice.

Statement on the Scope and Standards of Oncology Nursing Practice (Brant, 1996) defined the practice of both generalist and advanced practice oncology nurses. This monograph identifies oncology nursing care as meeting “the needs of persons throughout the cancer experience, from prevention and screening through rehabilitation to end-of-life supportive care as needed” (p. 2). Providing quality oncology nursing care demands that even general oncology nurses require a cancer-specific knowledge base and demonstrate clinical expertise in cancer care beyond their basic nursing education. These standards require that oncology nurses provide competent and knowledgeable care to patients in all phases of the cancer trajectory. This text addresses both physical and psychosocial issues as they apply to all patients coping with cancer, from screening and diagnosis to rehabilitation and end-of-life care.

Two texts were reviewed that outline psychosocial aspects of oncology nursing. *Psychosocial Dimensions of Oncology Nursing Care* (Burke, 1998) addressed issues pertaining to the psychosocial care of cancer survivors, including patient and family coping, spiritual and psychological care, and end-of-life care. A chapter addressing the specific issues facing cancer survivors, “Survivorship” (Leigh, 1998), was included. The chapter defined cancer survivors and the different phases of cancer survivorship, as well as psychosocial needs of cancer survivors.

Psychosocial Nursing Care Along the Cancer Continuum (Carroll-Johnson et al., 1998) focused on psychosocial experiences that accompany a cancer diagnosis and the emotional and psychological responses to these experiences. A focus on nursing interventions provides a means to address and improve care for patients facing the psychosocial challenges that accompany survivorship. Many sections of the book also contain small sections on survivorship, which address specific issues that survivors face in regards to coping, support, fatigue, chronic illness, QOL, and oncology nursing care.

The incorporation of both physical and psychosocial oncology nursing care is stressed throughout each of these four publications. The role of both the general and advanced practice oncology nurse in caring for cancer survivors encompasses a broad range of care. Cancer survivorship is recognized as a complex issue requiring many facets of care, from prevention and screening through rehabilitation and end-of-life care. These texts encourage oncology nurses (particularly advanced practice nurses) to seek interdisciplinary collaboration in caring for cancer survivors in order to address their varied physical and psychosocial needs. Survivorship is an integrated component of oncology nursing. These documents stress the role of oncology nurses in executing care that addresses physical, psychological, social, and spiritual needs. Earlier documents often do not use the term “survivorship” but do discuss related concepts, such as rehabilitation and supportive care. Recent documents more uniformly address survivorship and acknowledge the entire cancer trajectory.

Survey of Members of the ONS Survivorship Special Interest Group

ONS has several special interest groups (SIGs) that provide a mechanism for members to network with colleagues in specific areas of practice. A survey of the ONS Survivorship SIG was conducted to assess these individual nurses who have a special interest in survivorship. A current list of the SIG members was obtained from ONS. The survey was prepared and sent to the 29 members of the Survivorship SIG; 22 members responded. Table 1 summarizes the results of the survey.

The respondents enthusiastically supported the need for greater attention focused on cancer survivors. Topics identified as currently the most adequate aspects of care included treatment of recurrent cancer, short-term sequela of treatment, pain, and palliative care. Aspects of care identified as least adequate included prevention of secondary cancer, general survivorship, long-term complications and trends, and access to health care. Respondents rated the need for survivorship education as very important and rated their practice setting as moderately effective.

Training of Nurses in Survivorship Issues Survey of Oncology Graduate Programs

The education of nurses specializing in a clinical area, such as oncology, occurs at a graduate level through master’s degree programs. At present, approximately 300 colleges and universities offer master’s degree programs in nursing, and, of these, ONS identified only 29 as offering a special oncology focus. To assess the training of nurses to provide appropriate care to cancer survivors, a survey was prepared and sent by e-mail to the 29 graduate nursing schools identified by ONS as offering an oncology emphasis. Responses were received from 20 of the 29 identified programs. Three schools responded that they no longer offered an oncology specialty. Table 2 summarizes the results of the survey from the 17 responding programs that still offer the oncology specialty.

Summary of Graduate Education

The Essentials of Master’s Education for Advanced Practice Nursing (American Association of Colleges of Nursing [AACN], 1996) outlines the nursing curriculum at the master’s

Table 1. ONS Survivorship Special Interest Group Survey Responses

| Variable | n | % |
|--|-----------|------|
| Position | | |
| Clinical RN | 6 | 27 |
| Coordinator/director | 9 | 41 |
| Educator | 6 | 27 |
| Not employed | 1 | 5 |
| Years in nursing | | |
| \bar{X} = 26.05 | – | – |
| SD = 7.02 | – | – |
| Range = 14–40 | – | – |
| Years in oncology nursing | | |
| \bar{X} = 19 | – | – |
| SD = 7.13 | – | – |
| Range = 8–35 | – | – |
| Education level completed | | |
| Associate | 1 | 5 |
| Bachelor’s | 5 | 23 |
| Master’s | 10 | 45 |
| Doctorate | 5 | 23 |
| Not reported | 1 | 5 |
| Assessment of the adequacy of care in clinical settings^a | | |
| | \bar{X} | SD |
| Aspects of cancer survivorship | | |
| Prevention of secondary cancers | 4.50 | 2.22 |
| General discussion of survivorship | 4.67 | 2.37 |
| Long-term complications/sequela of treatment | 6.95 | 2.13 |
| Trends, statistics, and healthcare access | 4.57 | 2.27 |
| Healthcare systems/QA/models of care | 3.90 | 3.05 |
| Rehabilitation services | 6.18 | 3.03 |
| Quality-of-life issues and survivorship | 7.32 | 2.34 |
| Detection of recurrent and secondary cancers | 5.82 | 1.97 |
| Pain management | 5.05 | 2.74 |
| Palliative care/end-of-life care | 6.60 | 2.27 |
| Short-term complication/sequela of treatment | 6.52 | 1.94 |
| Treatment of recurrent cancer | 4.67 | 2.65 |
| Personal factors | | |
| How effective did you feel as a new graduate of your most recent educational program in caring for cancer survivors? | 9.55 | 1.01 |
| How effective do you believe your clinical setting is in executing cancer survivorship content? | 5.60 | 2.84 |
| How receptive do you believe your clinical staff would be to increased cancer survivorship education? | 7.86 | 2.12 |
| As a clinician, how effective do you feel you are in executing cancer survivorship content in your care? | 8.31 | 1.25 |
| How important do you believe cancer survivorship education is to oncology nursing education? | 6.05 | 2.08 |

N = 22

^a0 = not adequate—10 = very adequate

level. This publication is divided into seven categories according to the graduate core curriculum content: research; policy, organization, and financing of healthcare; ethics; professional role development; theoretical foundations of nursing practice; human diversity and social issues; and health promotion and disease prevention. Survivorship is not specifically listed in

Table 2. Graduate Curriculum Survey Responses

| Variable | n | % |
|--|-----------|------|
| Respondents position | | |
| Associate professor | 6 | 33 |
| Professor | 1 | 7 |
| Director/manager of oncology program | 8 | 47 |
| Professor emerita | 1 | 7 |
| Years in nursing | | |
| \bar{X} = 18 | — | — |
| SD = 8.10 | — | — |
| Range = 2–30 | — | — |
| Assessment of areas in curricula where cancer survivorship is currently taught | | |
| Healthcare systems/QA/models of care | 2 | 12 |
| Rehabilitation services | 3 | 18 |
| Trends, statistics, and healthcare access | 4 | 25 |
| Other survivorship topics | 5 | 31 |
| Treatment of recurrent cancer | 6 | 37 |
| Detection of recurrent and secondary cancers | 9 | 50 |
| General discussion of survivorship | 10 | 56 |
| Prevention of secondary cancers | 10 | 56 |
| Quality-of-life issues and survivorship | 11 | 62 |
| Short-term complication/sequela of treatment | 12 | 68 |
| Long-term complication/sequela of treatment | 12 | 68 |
| Pain management | 12 | 68 |
| Palliative care/end-of-life care | 17 | 100 |
| Materials currently used to teach cancer survivorship content in curricula | | |
| Textbooks | 16 | 93 |
| Computer-assisted instruction | 1 | 7 |
| Audiovisuals | 8 | 47 |
| Speakers, experts | 12 | 73 |
| Clinical sites | 1 | 8 |
| Case studies | 12 | 73 |
| Standardized curriculum | 3 | 20 |
| Internet resources | 10 | 60 |
| Variable | \bar{x} | SD |
| Assess the quality of current content in your educational program in the following aspects of cancer survivorship^a | | |
| Healthcare systems/QA/models of care | 7.44 | 2.56 |
| Detection of recurrent and secondary cancers | 7.69 | 2.47 |
| Prevention of secondary cancers | 8.13 | 2.01 |
| Rehabilitation services | 7.56 | 2.09 |
| Treatment of recurrent cancer | 6.94 | 2.58 |
| General discussion of survivorship | 6.88 | 2.16 |
| Long-term complication/sequela of treatment | 6.94 | 3.10 |
| Trends, statistics and healthcare access | 7.88 | 2.29 |
| Quality-of-life issues and survivorship | 6.81 | 2.60 |
| Palliative care/end-of-life care | 7.88 | 2.56 |
| Short-term complication/sequela of treatment | 8.44 | 2.90 |
| Pain management | 6.63 | 2.20 |
| Personal factors^a | | |
| Overall, how important do you believe cancer survivorship content is to graduate nursing education? | 9.14 | 1.02 |
| How effective do you believe a new graduate of your program would be in caring for cancer survivors? | 7.46 | 1.81 |
| How receptive do you believe your faculty would be to increased cancer survivorship education? | 8.00 | 2.38 |
| As a faculty member, how effective do you feel you are in teaching cancer survivorship content? | 8.57 | 1.50 |
| How effective do you believe your school's curriculum is in teaching cancer survivorship content? | 7.50 | 2.38 |

N = 17

^a 0 = not adequate—10 = very adequate

any of these categories; however, the category “health promotion and disease prevention” discusses a key concept of nursing encompassing QOL—healthy lifestyle—and the maximization of QOL across the health-illness continuum.

The number of programs offering an oncology specialty has decreased from approximately 45 programs in 1990 to only 26 programs in 2002. Increased budgetary concerns have led to the consolidation of specialty programs into more generalized tracks (e.g., chronic illness, medical-surgical). This finding holds important implications for the quality of care provided to cancer survivors. Generalized master’s education tracks are less likely to provide adequate attention to the specific nursing care of cancer survivors. Oncology nursing as a specialty and the education of nurses in general master’s degree programs is essential to enhancing the quality of care provided to patients.

The quality of care to be provided to cancer survivors in the future will be greatly influenced by the preparation of nurses through graduate education. Nurses trained in master’s degree programs represent the leaders in oncology nursing, assuming positions as clinical nurse specialists, nurse practitioners, managers, and educators. Just as advanced practice nurses shaped the early care of patients receiving chemotherapy, radiation, and bone marrow transplants, in the decades ahead, graduate-prepared nurses will advance care in clinical genetics, cancer risk counseling, and long-term sequela of treatment.

Review of Cancer Nursing Texts

One means of evaluating the knowledge of nurses within a specific area is to evaluate the textbooks used within formal education programs. The authors of this article previously conducted a review of 50 leading nursing texts to evaluate the content on end-of-life care (Ferrell, Virani, & Grant, 1999). To provide similar information for this article, a review of five key oncology texts was conducted to assess the amount and level of survivorship content that was included.

The texts reviewed included *Cancer Nursing* (2nd edition) (McCorkle et al., 1996), *Cancer Nursing, Principles, and Practice* (Yarbro, Frogge, Goodman, & Groenwald, 2000), *Oncology Nursing* (4th edition) (Otto, 2001), *Oncology Nursing: Assessment and Clinical Care* (Miaskowski & Buchsel, 1999), and *Handbook of Oncology Nursing* (3rd edition) (Johnson & Gross, 1998). A master’s-prepared research nurse and a research coordinator conducted the review process. The 10 critical content areas noted earlier were used for this analysis. A grid format was prepared for use in the reviews of each text. The reviewers scanned the textbook table of contents and read each section for key content. Pertinent information then was tallied under each of the 10 categories.

Table 3 presents the overall quantitative findings of the total text review. Four of the books had content describing populations of cancer survivors. The most prevalent survivorship content areas present in all the books were primary care and quality of care. Content applying to short- and long-term complications, descriptions of populations of cancer survivors, QOL, palliative and end-of-life care, and detection of recurrent and secondary cancers also received adequate attention across the textbooks. Prevention of secondary cancers, treatment of recurrent cancer, and rehabilitative services received little attention in all the textbooks and were absent in several texts.

Only two textbooks had chapters with “survivor” in the title. “Survivorship and QOL Issues” (Grant et al., 1996) and

“Surviving Breast Cancer” (McCorkle, 1996) included content such as the definition of survivor, survivorship stages and phases, psychological and psychosocial aspects, QOL, economic issues confronting patients and family, and spiritual and ethical concerns. A section in *Cancer Nursing, Principles and Practice* (Yarbro et al., 2000) included three chapters specific to survivorship issues: “Psychosocial Responses to Cancer,” “Physical, Economic, and Social Issues Confronting Patients and Families,” and “Spiritual and Ethical End-of-Life Concerns.”

Although a key finding of this review was the lack of content on critical areas, including the prevention of secondary cancers, treatment of recurrent cancer, and rehabilitative services, content pertaining to cancer survivors was incorporated into each of the themes. Nursing care for cancer survivors occurs throughout all stages of the cancer experience, thus necessitating survivorship content across each of these themes. This review exemplifies the care that oncology nurses provide to cancer survivors throughout their disease while highlighting the existing deficits in nursing education. Each of the texts contained information regarding QOL issues, stressing the important role of the nurse in caring for patients across the physical, psychological, social, and spiritual domains.

Review of Nursing Literature in Journals

The oncology nursing literature, as published in leading journals, also was reviewed to assess survivorship content. Journals reflect current clinical practice and are the key source for published research. A total of 160 articles in the 2001 volumes of three leading oncology nursing journals (*Oncology Nursing Forum*, *Seminars in Oncology Nursing*, and *Cancer Nursing*) were reviewed for survivorship content. Table 4 presents the overall quantitative findings for the journal review. The same 10 topic areas were included in the journal review, and the articles were evaluated to determine if they were research based.

Sixty-six of these articles were found in *Oncology Nursing Forum*, the official journal of ONS. Two issues of the journal (vol. 28, issues 2 and 8) were not included in the review because they reported meeting proceedings rather than peer-reviewed articles. Of these 66 articles, 47 contained research-based information. The most common themes discussed in these articles were primary care and QOL issues. Slightly less prevalent, but still present, were themes concerning descriptions of populations of cancer survivors, short- and long-term complications from cancer treatments, and quality of cancer care systems. Palliative care, end-of-life care, and rehabilitative services received less attention in this journal, whereas the prevention of secondary cancers, detection of recurrent and secondary cancers, and the treatment of recurrent cancer were not identified.

Volume 17(1–4) of *Seminars in Oncology Nursing* contained 35 review articles. Only 2 of the 35 articles were primarily research based, although all papers in this theme-focused journal include references to current research. The most frequently occurring themes were quality of care and QOL. Descriptions of the population of cancer survivors, primary care, short- and long-term complications, and palliative and end-of-life care also were present throughout the volume. However, several themes received little to no attention in this journal. The detection of recurrent and secondary cancers, treatment of recurrent cancer, and rehabilitative services received three or less references throughout the volume,

Table 3. Textbook Review: Number of Topics Based on Survivorship Themes

| Survivorship Topic | McCorkle et al., (1996), <i>Cancer Nursing</i> | Yarbro et al., (2000), <i>Cancer Nursing</i> | Otto (2001), <i>Oncology Nursing</i> | Miaskowski & Buchsel (1999), <i>Oncology Nursing</i> | Johnson & Gross (1998), <i>Handbook of Oncology Nursing</i> | Totals |
|--|---|---|---|--|--|--------------|
| Description of population of cancer survivors | 16 | 35 | 41 | 61 | – | 153 |
| Primary care | 79 | 223 | 133 | 293 | 11 | 739 |
| Short- and long-term complications | 36 | 36 | 16 | 61 | 27 | 176 |
| Prevention of secondary cancers | 2 | – | – | – | – | 2 |
| Detecting recurrent and secondary cancers | – | 2 | 20 | 46 | – | 68 |
| Treatment of recurrent cancer | – | – | – | 1 | – | 1 |
| Quality-of-life issues | 55 | 11 | 23 | 8 | 2 | 99 |
| Rehabilitative services | 4 | 2 | 2 | 1 | – | 9 |
| Palliative and end-of-life care | 41 | 22 | 2 | 9 | 1 | 75 |
| Quality of care | 102 | 103 | 10 | 167 | 1 | 383 |
| Total number of survivorship content sections | 335 | 434 | 247 | 647 | 42 | 1,705 |

whereas no articles concerned the prevention of secondary cancers. One issue of this journal was dedicated solely to the dimensions of long-term cancer. This issue addressed each of the survivorship themes identified here: physiologic long-term and late effects, psychological and relationship issues, and transitions to palliative and end-of-life care.

Fifty-nine articles from volume 24 of *Cancer Nursing* were reviewed and of the 59 articles, 49 were based on research studies. The predominant themes discussed throughout these articles were QOL and quality of patient care. Descriptions of the population of cancer survivors and palliative and end-of-life care also were addressed in many of the articles. Topics that received limited attention were primary care and short- and long-term complications. This volume did not include articles concerning any of the following top-

ics: prevention of secondary cancers, detection of recurrent and secondary cancers, treatment of recurrent cancer, or rehabilitative services.

Although many of the themes received adequate attention throughout the three journals, several important topics were absent or limited. Of the articles that were reviewed from the three journals, only three articles related to the detection of recurrent and secondary cancers, two contained information regarding rehabilitative services, one addressed the treatment of recurrent cancer, and no information was included about the prevention of secondary cancers. The unique link between nursing care and QOL was recognized by the wealth of information regarding psychosocial and QOL issues after diagnosis and primary treatment. The results of the journal review reflect the similar strengths and deficits apparent in the textbook review.

Table 4. Journal Review: Number of Articles Based on Survivorship Themes

| Survivorship Themes | <i>Oncology Nursing Forum</i> (N = 66) | <i>Seminars in Oncology Nursing</i> (N = 35) | <i>Cancer Nursing</i> (N = 59) | Total (N = 160) |
|---|--|--|-----------------------------------|--------------------|
| Description of population of cancer survivors | 9 | 7 | 16 | 32 |
| Primary care | 26 | 10 | 10 | 46 |
| Short- and long-term complications | 15 | 7 | 5 | 27 |
| Prevention of secondary cancers | – | – | – | – |
| Detecting recurrent and secondary cancers | – | 3 | – | 3 |
| Treatment of recurrent cancer | – | 1 | – | 1 |
| Quality-of-life issues | 30 | 13 | 25 | 68 |
| Rehabilitative services | 1 | 1 | – | 2 |
| Palliative and end-of-life care | 2 | 7 | 13 | 22 |
| Quality of care | 17 | 16 | 25 | 58 |
| Based on research | 47 | 2 | 45 | 94 |

Review of Certification of Oncology Nurses and Advanced Oncology Nursing Certification

Demographics of Certified Nurses

Specialization in nursing is recognized through certification. An ONS-affiliated corporation, the Oncology Nursing Certification Corporation (ONCC) conducts the certification at two levels, including the Oncology Certified Nurse (OCN[®]) designation and the Advanced Oncology Nursing Certification (AOCN[®]).

At present, there are 19,021 OCNs[®]. Seventy-eight percent report full-time employment, and 20% report part-time employment. Eighty percent designate their functional area as patient care, while others function in administration, education, or research. Seventy percent work on oncology specialty units. There are also 1,269 AOCNs[®]. Eighty-two percent of these nurses are employed full-time, and 15% are part-time. Fewer (53%) are primarily focused on patient care, with more AOCNs[®] in administration, education, or research. Fifty-three percent of AOCNs[®] work on oncology units, with a wide diversity of other settings of practice.

OCNs[®] and AOCNs[®], and the certification process itself, are important factors in the quality of care of cancer survivors. These nurses have received specific training in cancer care and are experienced in issues confronting cancer survivors. Familiarity with issues ranging from chemotherapy side effects to complex psychosocial issues pertaining to cancer survivorship make these nurses invaluable resources to cancer survivors. These nurses are recognized leaders and mentors and often are in advanced practice roles directing programs targeting survivorship concerns.

Review of Test Blueprints

Test blueprints provide an outline of the content tested in the certification examinations. In reviewing the OCN[®] test blueprint guide for the OCN[®] examination, “survivorship issues” is found under the category of QOL. QOL content encompasses 27% of the OCN[®] test. QOL is divided into five categories: comfort, coping, sexuality, symptom management, and supportive care. “Survivorship issues” is 1 of 12 items under the category of coping. Review of the actual test would suggest that a major focus of the examination is on the active treatment phase, with less emphasis on survivorship.

The AOCN[®] test blueprint is divided into six sections that reflect role functions of direct caregiver, administrator, coordinator, consultant, researcher, and educator. The “direct caregiver role” section, which encompasses 63% of the test, is divided into seven categories. One of the subcategories is “comprehensive assessment and problems identification” regarding patients, families, and survivors, which includes psychosocial examples of spirituality, social support, financial aspects, and other topics of importance to survivorship. Survivorship also is mentioned under this subset of “direct caregiver role” within the discussion of “continuity of care.” Within “continuity of care,” subtopics include cancer survivorship rehabilitation and end-of-life care. Each of the role functions reflects aspects of survivorship, including genetic risk, psychosocial support, and the role of advanced practice nurses in achieving quality cancer care.

Review of Core Texts

ONCC recognizes a core text for each of the certification examinations. The two textbooks for the OCN[®] and AOCN[®] were reviewed for content on survivorship. The textbook for the OCN[®] examination was *Core Curriculum for Oncology Nursing* (Itano & Taoka, 1998). This book includes a chapter, “Coping: Survivorship Issues and Financial Concerns,” that focuses on theories of survivorship and defines cancer survivorship as the time of discovery of cancer and throughout the balance of life. Other highlights are stages of survivorship, which are categorized as acute stage, extended stage, and permanent stage. The chapter also explores the impact of survival, including the physical or physiologic, psychologic, social, and spiritual effects, thus addressing all QOL domains. Assessment of survivorship described in this chapter identifies the stages of survival and includes an evaluation of the cancer history of the individual, leading to the psychosocial interview(s) of the patient, family, and significant others. Also included are targeted outcomes and planning and implementation of care for survivors. The chapter describes long-time survivors of both pediatric and adult cancer and the development of guidelines for continued care by other care providers, such as primary care physicians and nurses.

The textbook for the AOCN[®] certification examination is *Advanced Practice in Oncology Nursing* (Lin, 2001). The book is divided into major disease sites and treatment modalities, according to diseases, diagnosis, and treatments (e.g., surgery, chemotherapy, radiation, biotherapy). Patient care issues are discussed, including psychosocial issues relevant to cancer survivorship. The psychosocial issues addressed are anxiety, depression, anger, pain, and family dysfunction. A genetics chapter provides an overview of a family history review.

Results of Role Delineation Studies

Similar to other professional certification processes, ONCC conducts periodic studies of the role function of the oncology nurse to ensure that certification and testing reflect actual practice (McMillan, Heusenkveld, & Spray, 1997; McMillan, Heusenkveld, Spray, & Murphy, 1999). The most recent OCN[®] study was conducted in fall 2001 (McMillan, Heusenkveld, Chai, Murphy, & Huang, 2002).

The authors conclude that the process of oncology nursing certification is an important contribution to quality care for cancer survivors. The certification process provides a means of promoting and testing competence in many areas of significance to cancer survivorship. The number of OCNs[®] and AOCNs[®] is very small, given the national need for nurses to address survivorship concerns and provide care for survivors. Promotion of certification is recommended and should be encouraged in cancer centers. Continued recognition of survivorship content in the certification examinations is recommended.

Review of Content of Basic Nursing Education on Survivorship Issues

Undergraduate Curriculum

The vast majority of RNs are prepared at a basic level of diploma/associate degree (42.8%) and baccalaureate degree (53.2%), whereas only 3.9% of nurses hold a master’s degree or higher. AACN (1998) reviewed and published a document that

provides direction for the preparation of professional nurses for practice at the baccalaureate level. This document does not use the term survivorship but covers many aspects relevant to survivorship, such as future trends in health care, technologic advances, and advances in genetic knowledge. One of the important trends included is the need to seek quality, accessibility, and cost-effectiveness in all aspects of health care and education.

The document is divided into the components of professional nursing education and preparation of professional nurses upon graduation. Graduates should be provided with the knowledge to assess factors that influence the health of patients and to foster strategies for health promotion, risk reduction, and disease prevention across the life span. QOL domains are discussed under the category of “illness and disease management.” Knowledge of social, physical, psychological, and spiritual responses of individuals and families or caregiver to disease and illnesses is required at the baccalaureate level. The goal is to maximize QOL and maintain an optimal level of functioning throughout the course of the illness, including end of life.

Although the undergraduate nursing curriculum provides a framework supportive of survivorship needs, the curriculum is broad and must serve as a general introduction to all aspects of nursing care from obstetrics, pediatrics, mental health, community health, and intensive care to numerous other aspects of nursing. The curriculum also is focused on the acquisition of basic nursing skills. Clinical time is focused in generalized care settings. Although some exposure to cancer care may exist in the classroom or clinical arena, in most instances, oncology is considered a specialized setting and not a focus of undergraduate education.

Licensure Review

The NCLEX-RN® licensure examination was established to test entry-level nurse performance. The test is divided into four major categories: safe, effective care environment; health promotion and maintenance; psychosocial integrity; and physiologic integrity. Although the term “survivorship” is not mentioned throughout the test plan blueprint, sections under the four major categories are relevant to survivorship. One such subcategory, “growth and development through the life

span,” which falls under the major “health promotion and maintenance” category, comprises 7%–13% of the examination content and could test survivorship knowledge. The major section, “psychosocial integrity,” which comprises 10%–22% of the examination content, would be an important area for testing survivorship issues. The two subcategories are coping and adaptation (5%–11%) and psychosocial adaptation (5%–11%). Many of the issues tested in this category are end of life, coping mechanisms, stress management, situational role changes, religious and spiritual influences on health, and sensory or perceptual alterations.

Overall, although undergraduate education provides a general framework for addressing cancer survivor’s needs, this basic preparation has not addressed survivorship in specific terms. This suggests a significant need for continuing education in survivorship for practicing nurses.

Nursing Research Related to Cancer Survivorship

ONS and the ONS Foundation

In addition to its role in education and practice, ONS has been a leading force in oncology nursing research, including pioneering research in cancer survivorship. Much of the research has been supported through the grants program of the ONS Foundation. Table 5 includes a listing of studies funded by the ONS Foundation from 2000–2001 that are related to survivorship. Table 6 presents a summary of all research funded by this organization from 1984–2001. These data indicate significant areas of survivorship addressed through oncology nursing research, such as long-term complications, survivorship concerns in ethnically diverse groups, screening for second malignancies, and supportive care. ONS Foundation resources are limited, and this program funds pilot projects, generally in the range of \$5,000–\$10,000. Much of the support is dependent on pharmaceutical funding. Additional support for this program to extend the number of small grant projects available, mentorship of grantees beyond these pilot studies to pursue future research, and availability of larger scale funding would be an important recommendation.

Table 5. ONS Foundation Cancer Survivorship Research (2000–2001)

| Title | Principal Investigator | Institution | Amount Funded (\$) |
|---|-----------------------------------|-------------------------------------|--------------------|
| African American Women: The Experience of Breast Cancer and Menopause (2000) | M. Tish Knobf, PhD, RN, FAAN | Yale University | 9,906 |
| Screening for Second Malignancies and Osteoporosis in Survivors (2000) | Suzanne M. Mahon, DNSc, RN, AOCN® | St. Louis University | 7,500 |
| 2000 Total | | | 17,406 |
| Menopause Symptom Management in Breast Cancer Survivors (2001) | Judith A. Berg, PhD, RNC, WHNP | University of Arizona | 10,000 |
| Surviving Prostate Cancer and Treatment: Impact on Couples (2001) | Michael A. Galbraith, PhD, RN | Loma Linda University | 10,000 |
| Long-Term Breast Cancer Survivors’ Experiences: A Secondary Analysis (2001) | Rose Utley, PhD, RN, CS | Southwest Missouri State University | 8,124 |
| Late Effects and Quality of Life in Long-Term Survivors of Testis Cancer (2001) | Linda A. Jacobs, PhD, CRNP, AOCN® | University of Pennsylvania | 8,000 |
| 2001 Total | | | 36,124 |

Table 6. ONS Foundation Projects Funded From 1984–2001 Categorized by Topic and Amount of Total Funding

| Topics Organized by 1994 ONS Research Priorities | 1984–1994 | | | | | | | | | | Total Number | Total Funding ^a (\$) |
|--|-----------|------|------|------|------|------|------|------|---|---|--------------|---------------------------------|
| | 1984–1994 | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | | | | |
| Pain | 14 | 3 | 4 | – | 3 | 1 | 3 | 1 | – | – | 29 | 216,411 |
| Cancer prevention | 1 | – | – | – | – | 1 | – | 1 | – | – | 3 | 20,992 |
| Quality of life | 19 | 7 | 5 | 4 | 2 | 6 | 5 | 5 | – | – | 53 | 387,344 |
| Risk reduction/screening | 3 | – | 3 | 4 | 1 | 3 | 4 | 1 | – | – | 19 | 132,806 |
| Ethical issues | – | – | – | – | – | 1 | – | – | – | – | 1 | 7,500 |
| Neutropenia/immunosuppression | – | 1 | – | – | – | 0 | 0 | – | – | – | 1 | 8,500 |
| Patient education | 4 | 1 | 1 | – | 1 | 0 | 4 | 1 | – | – | 12 | 88,523 |
| Stress, coping, and adaptation | 37 | 11 | 6 | 7 | 5 | 4 | 1 | 1 | – | – | 72 | 487,047 |
| Cancer detection | 4 | – | 1 | 1 | – | 1 | 0 | 1 | – | – | 8 | 53,750 |
| Cost containment/cost of care | – | 1 | – | 1 | – | 1 | – | – | – | – | 5 | 44,500 |
| Other Topic Areas | | | | | | | | | | | | |
| AIDS/HIV | 3 | – | 1 | – | – | 0 | – | – | – | – | 4 | 22,750 |
| Biophysical variables | 10 | 3 | 1 | 2 | – | 1 | 2 | – | – | – | 19 | 153,781 |
| Cancer genetics | 2 | – | – | 1 | – | 0 | 0 | 2 | – | – | 5 | 32,639 |
| Complementary therapies | 5 | 1 | 1 | – | 2 | 2 | 1 | 2 | – | – | 13 | 86,145 |
| Decision making | 2 | 1 | 1 | 1 | 4 | 0 | 2 | – | – | – | 11 | 76,056 |
| Exercise | 4 | – | 1 | – | 1 | 2 | 3 | 1 | – | – | 12 | 98,690 |
| Fatigue | 5 | 2 | 2 | 1 | 3 | 3 | 3 | 1 | – | – | 20 | 156,190 |
| Health beliefs | – | 2 | 1 | 5 | 1 | 4 | 0 | 1 | – | – | 16 | 112,875 |
| Home care | 2 | 2 | 2 | – | 4 | 0 | 1 | – | – | – | 11 | 98,960 |
| Hospice/terminal care | 1 | – | 2 | 2 | 3 | 1 | 2 | 1 | – | – | 12 | 96,145 |
| Informed consent | – | 1 | – | – | – | 0 | 0 | – | – | – | 1 | 7,500 |
| Intervention studies | 20 | 2 | 12 | 6 | 6 | 10 | 10 | 6 | – | – | 72 | 563,957 |
| Mucositis | 1 | – | 2 | – | – | 0 | 4 | – | – | – | 4 | 26,750 |
| Nausea and vomiting | 9 | – | 1 | 1 | – | 0 | 0 | – | – | – | 11 | 85,500 |
| Nutrition issues | 2 | – | – | 3 | – | 1 | 0 | 1 | – | – | 7 | 56,242 |
| Sexual functioning | 2 | – | 1 | – | – | 1 | 0 | – | – | – | 4 | 24,000 |
| Social support | 9 | 2 | 1 | 3 | 1 | 1 | 0 | 1 | – | – | 18 | 121,403 |
| Spiritual well-being | 1 | – | 1 | – | 1 | 1 | 1 | – | – | – | 5 | 34,470 |
| Symptom management | 12 | 1 | 7 | 3 | 4 | 1 | 2 | 3 | – | – | 33 | 244,694 |
| Vascular access device | 1 | – | – | – | – | 0 | 1 | – | – | – | 2 | 10,600 |

^a The total funding column cannot be summed across topics because studies may be categorized in several topic areas. Since 1984, the ONS Foundation's Small Grants Program has funded 240 studies for a total of \$1,706,053.

National Institute of Nursing Research

The National Institute of Nursing Research (NINR) is the primary source of research funding for nurses in the United States. NINR research funding must extend across all areas of patient care; thus, support for cancer research—and more specifically cancer survivorship—is limited. However, NINR has supported several very important areas of survivorship research such as pain, psychosocial support, coping, pediatric survivorship concerns, lymphedema, family coping, and other areas. Table 7 includes a list of grants funded by NINR from 1999–2001 related to cancer survivorship. Several of the projects are funded as R01s, the funding mechanism for major research projects.

In some instances, NINR has cofunded projects with the National Cancer Institute (NCI). In addition to the R01 mechanism, NINR supports training and fellowship grants and small grants to support pilot projects. NINR could be a very significant source for expanding the focus on quality care for cancer survivors. NCI also has supported nurse investigators in conducting research related to survivorship. Both NINR and NCI have funded research related to end-of-life care that was not included in this analysis. Additional support through each of these mechanisms, with attention to those areas that have not been addressed, could advance nursing science and care for patients and families across the cancer trajectory. Oncology nurses also have contributed significantly as research nurses in clinical trials and through cooperative groups. Increased nursing research performed in collaboration with clinical trials could provide an untapped potential for addressing survivorship concerns.

The field of nursing research continues to address topics focused on improving the quality of care for cancer survivors. These studies can be used to identify the major issues that affect QOL for cancer survivors, paving the way for future nursing interventions. The benefits that patients receive from qual-

ity nursing care often are highlighted as the nursing role in addressing physical and psychosocial care for cancer survivors is made evident throughout nursing research. Published qualitative studies share the voices of cancer survivors, allowing their thoughts and concerns to be heard by healthcare providers.

Conclusions and Recommendations

The following list of specific recommendations was presented to the NCPB/IOM based on this review of key oncology nursing literature and resources.

1. Increase the focus by the Oncology Nursing Society (ONS) and other professional nursing groups on survivors and survivorship issues.
2. Increase support for oncology specialty education within graduate programs, including the full spectrum of the cancer experience.
3. Evaluate and support oncology content in curricula, with emphasis on survivorship, which has received minimal attention in general oncology graduate programs.
4. Promote certification in oncology nursing through the OCN[®] and AOCN[®] examination process.
5. Explore opportunities to integrate survivorship content in basic nursing education (baccalaureate and associate degree) programs.
6. Increase support for oncology nursing research in survivorship, including
 - Support for expanded pilot funding through NINR, ONS, and the ONS Foundation
 - Targeted research for areas not addressed in current research.
7. Support extensive continuing education for clinical nurses regarding survivorship because of the limited exposure in this area in undergraduate education.
8. Explore opportunities for nursing research in cancer survivorship in conjunction with clinical trials and cooperative groups.

Table 7. National Institute of Nursing Research Cancer Survivorship Grants Selected, 1999–2001

| Principal Investigator | Institution | Mechanism | Study Title |
|------------------------|---|-----------|---|
| Ward, Sandra | University of Wisconsin Madison | R01 | Representational Intervention for Cancer Pain |
| Mishel, Merle | University of North Carolina at Chapel Hill | R01 | Managing Uncertainty in Advanced Prostate Cancer |
| Dalton, Jo Ann | University of North Carolina at Chapel Hill | R01 | Tailoring Cognitive Behavioral Treatment for Cancer Pain |
| Nail, Lillian | University of Utah | R01 | Postradiation Coping Processes—a Randomized Trial |
| Barsevick, Andrea | Fox Chase Cancer Center | R01 | Energy Conservation and Cancer Treatment-Related Fatigue |
| Hoskins, Carol | New York University | R15 | Breast Cancer—Education, Counseling, and Adjustment |
| Cimprich, Bernadine | University of Michigan | R29 | Nursing Therapy—Attentional Fatigue in Patients With Cancer |
| Kang, Duck-Hee | University of Alabama at Birmingham | R01 | Psychoimmune Outcomes: Intervention in Breast Cancer |
| Mock, Victoria | Johns Hopkins University | R01 | Mitigating Cancer Treatment-Related Fatigue by Exercise |
| Schwartz, Anna | University of Washington | R29 | Cancer, Catabolic Steroids, Exercise, and Quality of Life |
| Schwartz, Anna | Oregon Health Sciences University | R01 | Breast Cancer Survivors: Exercise and Raloxifene |
| Weitzner, Michael | University of South Florida | R01 | Longitudinal Study of Depression in Lung Cancer |
| Dow, Karen | University of Central Florida | R01 | Quality-of-Life Intervention in Breast Cancer Survivors |
| Armer, Jane | University of Missouri at Columbia | R01 | Prospective Nursing Study of Breast Cancer Lymphedema |
| Galbraith, Michael | Loma Linda University | R15 | Prostate Cancer: Acute and Extended Effects for Couples |
| Ingham, Jane | Georgetown University | R21 | Cohort Study of Patients With Cancer Caregiver Outcomes |
| Coward, Doris | University of Texas at Austin | R29 | Self-Transcendence in Breast Cancer Support Groups |
| Parker, Nadine | Oregon Health Sciences University | F31 | Quality of Life in Patients With Head and Neck Cancer and Their Spouses |
| Larson, Cheryl | University of Arizona | F31 | Elder's Spirituality Across Chronic Illness Experiences |
| Ridner, Sheila | Vanderbilt University | F31 | Lymphedema After Breast Cancer Treatment |

In summary, review of key literature and resources by the authors suggests very significant contributions over the past two decades by oncology nursing to the area of cancer survivorship. Models of clinical excellence exist in major cancer centers, and these exemplar projects should be disseminated to other settings. Nurse-directed programs to address pain, fatigue, lymphedema, psychological issues, and other QOL concerns could be replicated to greatly influence quality care.

Oncology nurses are central to all aspects of survivorship for patient care and family support. Extensive support is needed to expand education and research to ensure quality care for the future.

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For more information . . .

- ▶ Cancer Survivors Online
www.cancersurvivors.org
- ▶ Cancer Survivors Network
www.acscsn.org
- ▶ National Coalition for Cancer Survivorship
www.cansearch.org

Links can be found using ONS Online at www.ons.org.