

ONCOLOGY NURSING SOCIETY 2005–2009 RESEARCH AGENDA

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I. EXECUTIVE SUMMARY

A. Project background

The research agenda for the Oncology Nursing Society (ONS) is the product of a multimethod, stakeholder consensus-building effort. With the support of the National Cancer Institute (NCI) and the National Institute of Nursing Research (NINR) (1 R13 CA101305-01), the 2002–2005 Research Agenda has been updated and revised with regard to the original six priority research content areas. As we seek to meet ONS’s mission to promote excellence in oncology nursing and quality cancer care, we realize that new knowledge is needed to further define and expand the scope of excellence and quality. The agenda’s focus is on areas where gaps exist in the knowledge base for oncology nursing practice. This document is not intended to set priorities for the Society for any other initiatives, such as education or policy. High-priority topics are specified for each of six content areas.

B. How to use this document

This document can be used to inform the Society’s own planning for its research enterprise and to inform external individuals and groups regarding the scientific priorities of the ONS membership.

The ONS research agenda is submitted as a mechanism to achieve that mission with the goals to (a) increase the knowledge base for oncology nursing practice through funding cutting-edge and critical priority areas of oncology nursing research, (b) prepare future oncology nurse researchers who will be well trained and equipped to implement ongoing programs of research and to seek support from major sponsors such as the National Institutes of Health (NIH) and the American Cancer Society (ACS), and (c) prepare clinical nurses as critical consumers of research findings that can be applied to practice.

C. Common themes and fundamental strategies

As you read this research agenda, you will note particular commonalities among the recommendations from the experts. The recommendations tend to focus on resources needed and include the following strategies.

- Increased attention to priority populations common to many topics
- Collaborative networks of researchers and clinicians that provide incentive to partner scientists and clinical oncology nurses
- Application of standardized approaches to research methods and procedures

D. Content areas with rationales and priority topics

1. Research in cancer symptoms and side effects

Rationale: The number of people with cancer who are affected by neurologic effects is increasing. Some of the symptoms experienced with neurologic effects can occur concurrently with additional effects and form a symptom cluster. Symptom clusters, or the experience of concurrent related symptoms, is not limited to neurologic effects but can vary widely across cancer diagnoses and treatments. A growing body of evidence suggests that these symptoms significantly impact quality of life.

Priority topics

1.1 Neurologic effects

- 1.1.1. Cognitive impairment or mental status changes
- 1.1.2. Peripheral neuropathy
- 1.2 Symptom clusters and associated outcomes

2. Individual and family-focused psychosocial and behavioral research

Rationale: The delivery of cancer treatment has shifted from acute care to ambulatory care and the home, necessitating the involvement of families and caregivers. Cancer occurs in the context of family. Interventions targeted to individual family members have the potential to benefit the family as a whole. Existing models of psychosocial care largely are deficit based but need to shift to a focus on positive health and strength-based variables. Little attention is given to the impact of inherited susceptibility on the family.

Priority topics

- 2.1 Research focused on the family system to sustain core family functions while managing the demands of illness, including decision making
- 2.2 Studies on the impact of inherited cancer risk on families

3. Research in health promotion: Primary and secondary prevention

Rationale: In the 20th century, tobacco use emerged as the leading cause of preventable death in the United States and around the world. Tobacco use contributes to more than 30% of cancer deaths. Almost 90% of lung cancers are attributed to tobacco use and could be prevented with interventions to eliminate tobacco uptake, support smoking cessation, and reduce exposure to second-hand smoke. Smoking cessation is the most cost-effective intervention for adults, more so than mammograms, Pap tests, and screening for colorectal cancer or hypertension.

Colorectal cancer presents a unique opportunity for primary and secondary prevention. Current research with mammography screening adherence has demonstrated that interventions targeting women and providers have resulted in significant increases in the number of women undergoing screening.

Priority topics

- 3.1 Test risk-based interventions for prevention of tobacco uptake, smoking cessation, and decreasing exposure to secondhand smoke.
- 3.2 Develop and test cost-effective interventions to increase evidence-based screening (cervical, breast, colorectal, prostate) based on individual cancer risk assessment.

4. Research that considers the late effects of cancer treatment and long-term survivorship issues for patients and their families

Rationale: Cancer has become a chronic illness. For the most part, even individuals who ultimately die from their disease live years past the initial diagnosis. The use of intensive multimodal treatment regimens also contributes to an increasing incidence, or perhaps awareness, of deleterious physiologic and psychosocial treatment complications called long-term or late effects. Appropriate medical, behavioral, educational, and psychosocial

interventions for adult cancer survivors experiencing late effects of diagnosis and treatment, such as premature menopause, peripheral neuropathies, decline in sexual functioning, stress incontinence, cardiac damage related to anthracyclines, cognitive changes, and the effect of these issues on family functioning, must be researched and developed.

Priority topics

- 4.1 Describe the full range of late effects of cancer treatment: Are they physiological, psychosocial, existential, or economic? What are the risk factors for second malignancies? What is the impact on quality of life?
- 4.2 Identify modifiable factors that can be targeted with interventions to reduce the late effects of cancer treatment.

5. Research in nursing-sensitive patient outcomes (NSPOs)

Rationale: The demand for professional accountability regarding outcomes dictates that nurses are able to identify and document outcomes that are attributable to nursing care.

Priority topics

- 5.1 The effectiveness and quality of nursing care on NSPOs within the context of the healthcare system to prevent adverse events
 - 5.1.1 Infection
 - 5.1.2 Prevention of adverse events related to cancer treatment modalities
 - 5.1.3 Workforce issues that promote or threaten quality care
- 5.2 The effectiveness and quality of nursing care on NSPOs within the context of health management for individuals
 - 5.2.1 Maintain or promote physical function, functional status, or functional ability of individuals who receive cancer treatment
 - 5.2.2 Nursing interventions to prevent or decrease fatigue in individuals with cancer

6. Translational research to develop, test, and evaluate strategies designed to determine which system- and clinician-related factors affect the clinical application of already created evidence-based guidelines; in situations where it is possible, to determine whether patient outcomes are improved as a result of the clinical use of the guidelines.

Rationale: Since the 1980s, ONS has supported the development of new knowledge for oncology nursing practice. We have witnessed that the investment of dollars spent on research endeavors has increased the number of completed studies and the number of publications in scientific journals. By necessity, more attention has been given primarily to the generation of new knowledge than to the translation and use of that knowledge. The lag time between the generation of new knowledge and the translation of that knowledge into evidence-based practice guidelines must be kept to a minimum. Findings of the most rigorous and well-conducted studies will have insufficient impact unless used to advance patient care.

Priority topics

- 6.1 Identify barriers and facilitators in the clinical practice setting for translational research.
- 6.2 Create and implement methods to translate the research into the practice setting.
- 6.3 Compare implementation methods in a variety of practice settings.

E. Priority populations for study—All priorities

Notable populations are relevant for study in all research priorities (see Figure 1).

- Research in the populations across the lifespan, particularly pediatrics, young to middle-aged adults, and older adults
- Research in the area of family caregiving and the family group as a research participant across the cancer continuum
- Research in vulnerable populations, including access to care and other factors related to health disparities

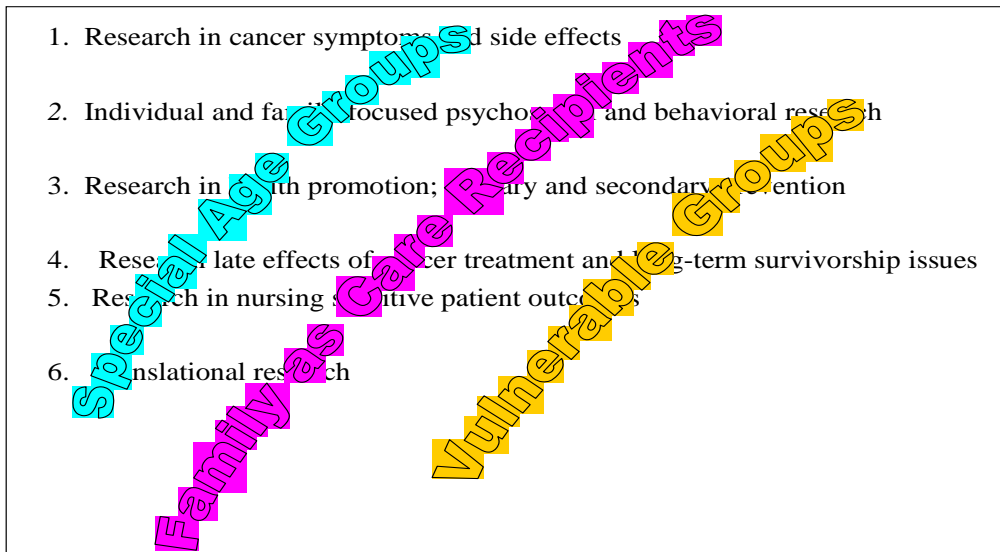


Figure 1. Special populations for inclusion in research priorities

F. Mechanisms for funding

The allocation goal should be \$500,000 for an individual priority topic. All of the research priority areas should be considered when the ONS Foundation Board seeks research sponsorship because some potential donors may be more interested in one priority than another. A variety of funding mechanisms should be used for each priority area to achieve the goals of building new science, developing new researchers, and, particularly, applying new knowledge to practice. Many of the research priority strategies address the need for funded clinician-scientist teams. These recommendations are aligned closely with the 2005 ONS Strategic Plan strategy, implement professional partnership models in research.

G. Relationship to strategic plan

One of the 2003–2005 ONS strategic goals is to generate and disseminate new knowledge gained through oncology nursing research. In keeping with this, the purpose of the research agenda is to identify key areas of science in which ONS can take a leadership role in supporting, through funding, the advancement of oncology nursing science. The knowledge acquired from this research can be integrated into practice to influence quality of cancer care.

H. Risk and reward

The major rewards possible through the effective use of this proposed agenda are the contributions that new knowledge can provide to the care of people with cancer, development of oncology nurse researchers who can go on to obtain support from other funding agencies, continued development of the evidence base for clinical practice, and creation of an infrastructure that will support and develop nurse researchers.

The major risk is that the agenda will not be used and/or that it will not be evaluated and revised on an ongoing basis. An additional risk may be that the selection of targeted areas of research funding needs will limit and possibly cause donors who are interested in other topics to fund research through research grants directly to investigators. The benefits of funding research through the ONS Foundation can far outweigh the potential risks.

II. INTERNAL/EXTERNAL ASSESSMENT

A. Internal

The 2004 ONS Research Priorities Survey results were used as the guide for the development of the Research Agenda priority areas. Specific priority areas were selected based on the (a) Research Priorities Survey, (b) feedback from the synthesis of the outcomes, neutropenia, biotherapy and symptom management expert panels of ONS, and (c) the Research Agenda Project Team members' assessment of cutting-edge topics in cancer care. ONS has limited resources for oncology nursing research; thus, it should not duplicate what is available from large federal and other funding agencies but rather provide a "stepping stone" toward larger funding.

A yearlong, systematic priority setting process involving various stakeholders was implemented in late 2004 and early 2005, updating the previous agenda. The updated priorities are included in this report. A group of 25 nursing research experts and clinician experts and members of the ONS Research Team participated in the priority setting process.

B. External

The chosen content areas also were guided by a review of areas targeted for research by the NCI, NINR, Department of Defense (DOD), Susan G. Komen Breast Cancer Foundation, and ACS.

III. AGENDA DESIGN/MAIN COMPONENTS

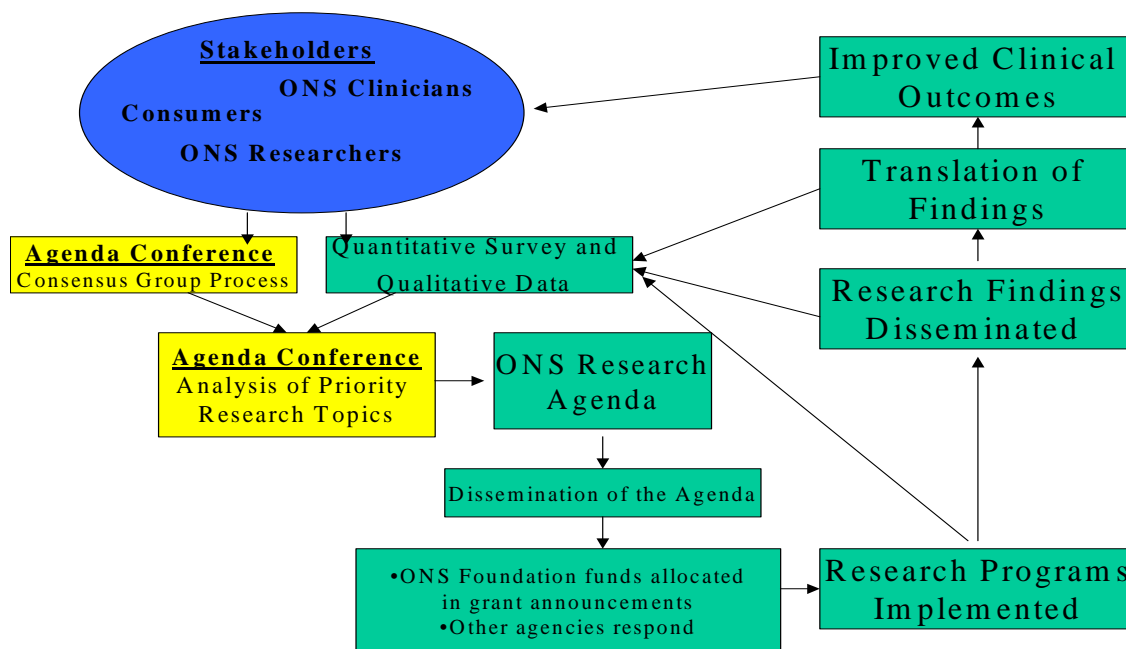


Figure 2. Framework for priority setting: The ONS Research Agenda

A. Research agenda prioritization every four years

These priority areas will be identified through the results of the ONS Research Priorities Survey (conducted every four years), other funding agencies' priorities (NINR, NCI, DOD, ACS, other private foundations, etc.) and the state of the science, determined via an assessment of current practice and research knowledge needs and gaps by oncology nursing research experts, clinical experts and consumer advocates (see Figure 2). The input of oncology nursing research experts in the development of these priority areas is essential because cutting-edge, state-of-the science topics may not be identified through general survey methods. The perspectives of clinical experts and consumers also are essential because the issues and problems they experience in day-to-day living with cancer are the driving forces for this research agenda. All of these research priority areas should be considered when the ONS Foundation Board seeks research support because some potential sponsors may be more interested in one priority than another priority.

B. Allocation of funds for each of the top priority areas should be \$500,000.

This funding goal for major grants will enable the ONS Foundation to support a variety of mechanisms to facilitate all three goals of "building the science," "developing new researchers" and "creating critical clinician consumers." The fundraising goal should be \$500,000 for each priority area in addition to funding for the small grant awards.

C. ONS Foundation Small Grants Program remains separate from the targeted priority areas for major grants.

The continuation of the ONS Foundation Small Grants and Fellowship Program as a separate program from the Major Grants Program will facilitate the generation of new areas of research and/or the development of new researchers. Even though the number and quality of applications for small grants have been variable in the recent past, small grants are an essential component of the ONS Research Agenda. Strategies to improve the quality and increase the number of

applications need to be ongoing. The following recommendations are made for the Small Grants Program.

- Small grant submission should not be targeted to the priority areas or areas of science but rather should reflect investigator-initiated topics. This will provide opportunities for innovative research to be developed in all areas.
- The funding level for small grants should be a minimum of \$10,000.
- Detailed review and follow-up of small grant recipients should be included in the program.
- All applicants must include a specific plan for the submission of their supported research project for presentation and publication.
- All recipients of ONS Foundation Small Grants are expected to present and publish from their work (acknowledging ONS Foundation support) as an outcome of their research.
- Funding should be for two years with a progress report submitted after one year.
- All small grant applications must have an experienced researcher as a consultant or as a part of the research team.

D. Review, evaluation, and revision of topics

The review, evaluation, and revision of specific priority topics will occur at two-year intervals at the time of the Biennial National Conference on Cancer Nursing Research (next in 2007). The ONS Research Priorities Survey should be conducted every four years (next one should be conducted in 2008 to have the results available for the 2009 National Conference on Cancer Nursing Research).

IV. AREAS OF SCIENCE FOR ONS RESEARCH 2005–2009

The content areas of science listed in section IV C are those areas identified by the 2005 Research Agenda Project Team. These content areas reflect priorities for which more knowledge currently is needed.

A. Common themes and fundamental strategies

As you read this research agenda, you will note particular commonalities among the recommendations of the experts. The recommendations tend to focus on resources needed and include the following strategies:

- Increased attention to priority populations common to many topics
- Collaborative networks of researchers and clinicians that provide incentive to partner scientists and clinical oncology nurses
- Application of standardized approaches to research methods and procedures

B. Content areas of science

1. Research in cancer symptoms and side effects

Priority topics

- 1.1. Neurologic effects
 - 1.1.1. Cognitive impairment and mental status changes
 - 1.1.2. Peripheral neuropathy
- 1.2. Symptom clusters and associated outcomes

Rationale and background

Neurologic effects: The prevalence of the understudied symptoms of neurologic effects (from cancer, treatment, or both) is not known. The clinical manifestations of neurologic effects have been reported and appear to be highly variable. Some of the symptoms experienced in neurologic effects can occur concurrently and form a symptom cluster. Symptom clusters, or the experience of concurrent related symptoms, is not limited to only neurologic effects but can vary widely across cancer diagnoses and cancer treatments. A growing body of knowledge suggests that neurologic effects and symptom clusters adversely affect physical functioning and quality of life in people with cancer.

Neurologic effects produce some of the most devastating symptoms faced by people with cancer (Wen & Plotkin, 2005). They can occur from the disease and its treatment and are prominent in every phase of illness from diagnosis until death. Neurologic symptoms result from damage to the central (CNS) and/or peripheral nervous systems (PNS), causing fundamental alterations in patients' physical (sensation and ambulation) and mental (cognition and mental status) function and quality of life. Research has begun to shed light on the magnitude of the problem caused by selected treatments and in various cancer subtypes; however, a critical mass of information and skilled researchers and teams will be needed to fully articulate the problem and to develop interventions that will impact the quality of patients' lives.

Cognitive effects: Cognitive decline is one of the major CNS effects of cancer treatment. The largest body of cognitive effects research with the highest-quality research designs has been conducted in children diagnosed with acute lymphocytic leukemia treated with combinations of chemotherapy, CNS radiation, and/or intrathecal therapy (Espy et al., 2001; Walch, Ahles, & Saykin, 1998). Research about these same issues in adults has lagged behind (Olin, 2001). Cognitive deficits from cancer chemotherapy (primarily in breast cancer) are just beginning to be described. Deficits include memory decline and decreased concentration and attention (Ahles & Saykin, 2002; Partridge, Burnstein, & Winer, 2001; Schagen et al., 1999; van Dam et al., 1998; Wieneke & Dienst, 1995). These effects persist in survivorship and can be so severe that they interfere with a patient's ability to return to previous role function (Ahles & Saykin, 2002; Ahles, Tope, Furstenberg, Hann, & Mills, 1996; Ahles & Whedon, 1999; Olin, 2001; Whedon & Ferrell, 1994; Whedon, Stearns, & Mills, 1995).

Mental status changes (e.g., delirium) are a relatively unexplored, high-incidence neurologic effect of cancer and its treatment (Passik & Kirsh, 2005). The etiology of delirium in people with cancer is commonly multifactorial (e.g., brain metastasis, treatment-related, opioid-induced, paraneoplastic syndromes, polypharmacy, electrolyte imbalances). Despite its prevalence and devastation to patients and their families, little is known about prevention and/or management strategies.

Peripheral neuropathy and neuropathic pain (NP): Peripheral neuropathy is a common but poorly understood neurologic effect with few options for prevention or management (Postma et al., 1999; Quasthoff & Hartung, 2002; Verstappen, Heimans, Hoekman, & Postma, 2003; Visovsky, 2003). In chemotherapy clinical trials, incidence ranges from 10%–100%, depending on the drug(s), dose(s), patient factors, and measurement strategies (Bakitas, Smith, Cohen, & Fadul, 2004). Although chemotherapy-induced peripheral neuropathy (CIPN) is regularly noted in reports of cancer clinical trials, little attention has been paid to

describing its specific nature, scope, symptom pattern, and impact on function or quality of life. Such information is needed to determine the extent of the problem and how to best manage it in clinical practice.

Initial information about neuropathy came primarily from case reports and small investigational phase I and II drug toxicity studies in the 1980s of two neurotoxic agents: cisplatin (Ostchega, Donohue, & Fox, 1988) and vinca alkaloids (Brenner, Magill, Wissel, & Sordillo, 1983; Gralla et al., 1981; Kelsen et al., 1982; Thant et al., 1982). More recently, the introduction and widespread use of newer, effective neurotoxic agents (e.g., taxanes, oxaliplatin) has created a renewed interest in the assessment and management of neuropathy (Almadrones, McGuire, Walczak, Florio, & Tian, 2004; Cella, Peterman, Hudgens, Webster, & Socinski, 2003; Chaudhry, Rowinsky, Sartious, Donehower, & Cornblath, 1994; Rowinsky, Chaudhry, Cornblath, & Donehower, 1993; Vahdat et al., 2001; Verstappen, Postma, Hoekman, & Heimans, 2003).

Not all CIPN causes pain; however, NP (defined as pain that arises from injury, disease, or dysfunction of the CNS or PNS) is also a common neurologic sequelae of cancer and its treatment. Estimates suggest that it affects more than two million Americans (Foley, 2003), but evidence indicates that NP incidence is unknown because it has been assessed inadequately by healthcare professionals and reported inconsistently by patients (Smith, Whedon, & Bookbinder, 2002).

CIPN and NP can be difficult to evaluate because they produce a range of symptoms and signs. Patients often perceive vague or unusual sensations, such as numbness, prickling, burning, and tingling, but these may not be experienced or described as “painful.” As such, clinicians and patients may perceive that these symptoms are less important than ones that clearly are described as “painful” (Senneff, 1999; Smith et al., 2002). In clinical trials, descriptions of neuropathy symptoms and their impact on function and quality of life typically are reduced to a numerical score (grade 0–4). These scores provide little information about a patient’s specific symptom pattern or the larger realm of the impact of neuropathy on his or her quality of life.

Unless the condition presents with a significant motor component, it may be invisible to clinicians in the typical busy clinical encounter and may go unrecognized. Currently, prevention and treatment of CIPN and NP are challenging and mostly ineffective at providing patients with adequate relief (Dworkin et al., 2003).

Relationship between PNS and CNS: Although PNS and CNS effects often are studied separately in clinical trials, some suggest that neurologic insults to either system may be related (e.g., in ways such as etiology, mechanism, pattern, or vulnerability) or possibly synergistic (DeLeo, Colburn, & Rickman, 1997; Dickenson, Matthews, & Suzuki, 2001; Sommer, 2001). Theories for the latter were proposed in a recent review article referring to the idea that peripheral nerve injury, transmitted to the CNS, ultimately may cause changes in both systems (Dickenson et al.). Complex cytokine mechanisms being studied in animal models may provide some explanation for the connection between the development of PN and cognitive deficits (DeLeo et al.; Sommer). Studies that evaluate CNS and PNS effects simultaneously and prospectively may help to describe how these two components occur or relate.

Symptom clusters: In 2001, Dodd, Miaskowski, and Paul defined the concept of a symptom cluster as three or more concurrent symptoms (e.g., fatigue, depression, and sleep disturbances) that are related to each other. These authors also proposed that a synergistic adverse effect of selected symptom clusters may exist on patient outcomes. Many investigative teams are working in this area and addressing the methodologic and statistical issues related to symptom clusters. This empiric work will result in refinement of the original “working” definition and further the understanding of the clinical manifestations and consequences of symptom clusters. To date, several funding institutes, foundations, and agencies have had targeted calls for research proposals involving symptom clusters. These initiatives should continue because work in this area is early in its development and holds the promise of making important advances in clinical care. Symptoms in a cluster are related to one another, but the suggested strength of those relationships has not been specified. Clearly, patterns of association and possible synergy among the multiple symptoms need to be described. Symptoms in a cluster are not required to have the same etiologies or mechanisms; however, knowledge regarding etiologies is essential to the understanding of assessment, symptom prevention, and interventions (Dodd et al., 2001; Dodd, Miaskowski, & Lee, 2004).

Future research recommendations

Cognitive impairment and mental status changes

- Descriptive studies to characterize scope of the problem from various cognitive impairments (including various cancer diagnoses; patient-based, qualitative investigations of the experience of cognitive dysfunction; exploration of opioid-induced delirium)
- Identification or development of reliable and valid measurement strategies of cognitive impairment or mental status changes, quality-of-life or “real-world” impact on patients’ everyday lives, and appropriate outcome targets
- Methodologic issues should pay special attention to measurement, the desirability of longitudinal designs, the need for cross-cultural studies, and language and translation issues.
- Evidence-based interventions to address prevention, treatment, cognitive rehabilitation, and family impact
- Development of criteria for clinically significant change in cognitive function
- Important predictor and outcome variables could include types of chemotherapy, genetic factors, hormonal factors, prior brain trauma, and symptom clusters, especially fatigue and depression.

Peripheral neuropathy and NP

- Descriptive studies to characterize epidemiology and scope of the problem
- Methodologic studies focused on subjective assessment and quality-of-life or “real-world” impact on patients’ everyday lives
- Evidence-based interventions to address safety, rehabilitation, improvement in functional status, and self-care management
- Development of criteria for clinically significant change in performance status
- Important predictor and outcome variables could include performance status, type of chemobiotherapy, hormonal influences, preexisting neuropathy, and comorbidities (e.g., diabetes, chronic pain syndromes).

Symptom clusters and associated symptoms

- Identify the temporal dimension of the onset of each of the symptoms in the cluster. What symptom is antecedent to the others, and does it make a difference in patient outcomes? Understanding the temporal sequence of onset of symptoms could provide new insights as to possible underlying physiological or psychological mechanisms (may be shared or unique). Describe the symptoms in the cluster, their patterns of association, and how these change over time.
- The amount of time that all of the symptoms within the cluster need to be present to be considered a "cluster" has not been specified.
- The issue of measuring one dimension on multiple symptoms or using instruments developed to measure a specific symptom, yielding multiple dimensions of the symptom, should be studied.
- Determine which analytic strategy to use that best fits the purpose of a specific study, such as factor analyses (grouping by symptoms) (Gift, Jablonski, Stommel, & Given, 2004), cluster analyses (grouping by patients who are similar in their symptom experience or symptom combinations), path analysis (examining the processes by which symptoms influence one another), and structural equation modeling (examining direct and indirect effects of symptoms and related variables).
- Develop middle-range theories to describe the complex relationship among symptoms in a cluster.
- Test the timing of simultaneous, multidimensional interventions targeted at symptoms in a cluster.
- Explore strategies for obtaining a broad range of symptoms across studies, practice settings, populations, cancer treatments, and phases of the cancer experience (e.g., minimum data set, data repository).
- Identify biomarkers in symptom clusters (e.g., to select candidate genes, to identify phenotypes of specific symptom clusters), which may in turn lead to screening patients who are at greater risk for developing a particular symptom cluster.

Resources for priority

- Develop ONS-sponsored request for application (RFA) for a partnership grant between advanced practice nurses and clinician or nurse researchers and basic or behavioral scientists to identify ways to link mechanism work with clinical neurological phenomena.
- Identify grant mechanisms at NIH and relevant institutes to have as a priority for funding elegant descriptive studies, animal studies, and clinical trials of relevance to neurotoxic effects.
- Pursue industry or private sector funding from companies developing neurologic toxicity prevention and treatment agents for educational and research activities.
- Develop RFA in the topic area from the ONS Foundation, NIH, NCI, and NINR for symptom cluster work.
- Develop cosponsored NIH and ONS Foundation state-of-the-science summits, conferences, and consensus panels (in time, once much more is known).
- Establish a minimum data set or data repository for investigators to send their symptom data, perhaps similar to the NIH's policy for sharing data.

2. Individual and family-focused psychosocial and behavioral research

Priority topics

- 2.1 Research focused on the family system to sustain core family functions while managing the demands of illness, including decision making
- 2.2 Studies on the impact of inherited cancer risk on families

Rationale and background

Focus on family system: The primary psychosocial and behavioral research to date has focused on descriptive studies of the psychosocial impact and morbidity in individuals. Nursing research in this area has spanned more than four decades, with many excellent summaries and literature reviews, including several in the nursing literature, in just the past five years (Lin & Bauer-Wu, 2003; Rustoen & Begnum, 2000; Sammarco, 2001; Woodgate, 2000; Zebrack, 2000; Ziegler, Newell, Stafford, & Lewin, 2004). We recommend a shift in focus to understudied subgroups, including individual family members and those within vulnerable and special populations (Lewis, 2004).

Cancer occurs in the context of family: Family concerns have been examined across cancer diagnoses (Germino, 1984; Given et al., 1993; Lewis, 1993; Manne, Alfieri, Taylor, & Dougherty, 1999; Manne & Glassman, 2000; Northouse, 1984; Northouse & Peters-Golden, 1993; Rodrigue & Park, 1996) and focused on specific types of cancers, especially breast cancer (Baider & Kaplan De-Nour, 1988, 1999; Ben-Zur, Gilbar, & Lev, 2001; Given & Given, 1992; Hilton, 1993a, 1993b, 1994; Hoskins, 1995; Issel, Ersek, & Lewis, 1990; Lewis, 1996, 1999; Lewis & Bloom, 1978; Lewis & Deal, 1995; Lewis, Ellison, & Woods, 1985; Lewis & Hammond, 1992; Lewis, Hammond, & Woods, 1993; Lewis, Zahlis, & Issel, 1988; Northouse, 1984, 1988, 1989, 1992; Northouse, Laten, & Reddy, 1995; Northouse & Swain, 1987; Northouse, Templin, Mood, & Oberst, 1998; Ptacek, Ptacek, & Dodge, 1994; Shands, Lewis, & Zahlis, 2000). Families experiencing prostate cancer also have been examined (Baider, Ever-Hadani, Goldzweig, Wygoda, & Peretz, 2003; Banthia, Malcarne, Varni, Ko, Sadler, & Greenbergs, 2003; Boehmer & Clark, 2001; Germino, Mishel, & Longman, 1998; Harden et al., 2002; Kornblith, Herr, Ofman, Scher, & Holland, 1994; Maliski, Heilemann, & McCorkle, 2002). Despite the fact that lung and colorectal cancer are two of the top three cancers diagnosed each year and that colorectal cancer has a high family risk, limited research on family responses to these cancers was found (Abernethy, Chang, Seidlitz, Evinger, & Duberstein, 2002; Baider, Perez, & Kaplan-DeNour, 1989; Northouse, Mood, Templin, Mellon, & George, 2000; Persson, Severinsson, & Hellstrom, 2004). Additionally, some research has been done on family adjustment to cancer in pediatric, adolescent, and young adult populations (Herman-Stahl & Petersen, 1999; Kazak & Meadows, 1989; Madan-Swain et al., 1994; Rait et al., 1992; Trask et al., 2003; Zeltzer et al., 1996). The body of research represented by these studies on family responses to cancer in general indicates (a) strong evidence of family distress exists, (b) multiple factors influence couple and family adjustment, (c) family distress negatively influences several quality-of-life-related patient outcomes, and (d) evidence of predicted morbidity exists in family members affected by cancer in a member. Issues about which families express concern include those related to fear of recurrence, emotional states (depression and anxiety), interpersonal relationships (spouse, children, friends, and coworkers), and health and physical complaints. In addition, strong evidence supports increased demands and expectations for family, including caregivers, to absorb the costs of caregiving (Given et al., 2004; Hilton, Crawford, & Tarko, 2000; Stommel, Given, & Given, 1993).

Within this priority, family member involvement in decision making about treatment and end of life is understudied. Oncology nurses have an ethical responsibility to ensure that family involvement and impact are considered in the decision-making process (Meeker, 2004; Wideheim, Edvardsson, Pahlson, & Ahlstrom, 2002; Zhang & Siminoff, 2003). In addition, existing models of family functioning emphasize deficits. However, research is showing that positive health and strength-based variables are important predictors of individual and family system functioning (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Efficace & Marrone, 2002; Haase & Phillips, 2004; Holland et al., 1999; Jenkins & Pargament, 1995; Moadel et al., 1999; Mytko & Knight, 1999; Ryff & Singer, 2003; Schnoll, Harlow, & Brower, 2000; Schulz & Mohamed, 2004; Sears, Stanton, & Danoff-Burg, 2003; Stanton et al., 2002; Stewart, Wong, Duff, Melancon, & Cheung, 2001; Wenzel et al., 2002; Zebrack & Chesler, 2002).

Interventions targeted to individual family members have the potential to benefit the family as a whole and specifically the patient with cancer (Blanchard, Toseland, & McCallion, 1996; Bultz, Speca, Brasher, Geggie, & Page, 2000). The aims of family interventions are to sustain family function and serve as a form of primary prevention of psychosocial morbidity in patients and family members. However, such interventions are not aimed to provide family therapy for preexisting family dysfunction. We recommend research on family interventions that target the impact of cancer on the primary relationships in a household, the core functions of the family as a whole, and family members' skills to manage the illness (Lewis, 2004). Targeted interventions are recommended that assist families to (a) alter their coping in response to illness-related pressures, (b) learn necessary skills to manage illness-related concerns, (c) gain skills in communication to increase responsiveness to each other's thoughts and feelings about cancer and decrease marital tension from cancer, and (d) understand ways children are affected by cancer and help them adjust (Lewis, 2004).

A variety of family-targeted interventions has been studied. These are targeted primarily toward uncertainty management, communication and interaction, education, and emotional expression via individual counseling and support groups (Cochrane & Lewis, 2005; Goldberg & Wool, 1985; Manne, Babb, Pinover, Horwitz, & Ebbert, 2004). These interventions frequently are long and fairly complex. A need exists to develop cost-effective, brief, delimited, and easily translated nurse-directed interventions targeted to the family household. Such interventions should be interactive to give voice to family members' struggles and to help families develop a plan. Anticipatory interventions for dealing with chronic disease, including cancer, such as preparatory counseling and experience mapping, are promising (Bultz et al., 2000; Lorig et al., 1999; Lorig, Gonzalez, Laurent, Morgan, & Laris, 1998) to prevent psychosocial adjustment problems. Studies of skill-based interventions to increase problem solving (Toseland, Blanchard, & McCallion, 1995) and interaction skills that give voice to all family member experiences also are recommended. Skill-based interventions should focus on maintaining family control of decision-making and include uncertainty management for family members that extends beyond problem solving (e.g., fear of recurrence). Family-centered end-of-life interventions are an ethical responsibility to ensure that the family is on board with decisions. Additionally, interventions should be studied that target skills to reduce the burden of care for school age, adolescent, and spouse or partner family members. Some intervention delivery approaches, including informational and emotional support groups and individual telephone, in-person, or combination delivery, have been explored minimally (Donnelly et al., 2000; Hoskins et al., 2001; Kozachik et al., 2001; Northouse & Peters-Golden, 1993), but additional study is recommended.

Source Documents of Major Policy and Content Implication

Report from the Institute of Medicine report on families and health (Weihs, Fisher, & Baird, 2002)

NCI Office of Special Projects on caregiver and child-focused new generation of educational materials (personal communication, E. Becze, Dec 1, 2004)

Impact of inherited cancer risk on families: Genetic diseases are family diseases in a biologic and psychosocial sense. The primary psychosocial research emphasis on inherited risk to date has been on perceptions and behaviors individuals who are contemplating or actively seeking information about inherited susceptibility to cancer (e.g., through genetic counseling, genetic testing), primarily hereditary breast, ovarian, and colorectal cancer syndromes (Braithwaite, Emery, Walter, Prevost, & Sutton, 2004; Butow, Lobb, Meiser, Barratt, & Tucker, 2003), with limited research on individuals from specific racial or ethnic groups (Donovan & Tucker, 2000; Matthews et al., 2000). Studies have indicated that those who seek genetic counseling often do so to help family members (Armstrong et al., 2000; Lerman et al., 1996; Lynch et al., 1997; Vernon et al., 1999). Friends or family members, particularly spouses, may be involved in the decision-making process about genetic counseling, although their roles in and perceptions of the process largely are unstudied (Bluman et al., 2003; Coyne & Andersen, 1999; Mahon & Casperson, 1995b). In addition, the possibility that minor children may have an inherited risk, even if the disease is not manifested until adulthood, sometimes poses a decision-making dilemma for parents (and counselors) (Wilfond, Rothenberg, Thomson, & Lerman, 1997).

Recommendations for carrying out genetic counseling and testing include preparatory and follow-up guidance to patients about communications with families (Jenkins, Dimond, & Steinberg, 2001; Mahon & Casperson, 1995a; Tranin, Masny, & Jenkins, 2003; Trepanier et al., 2004), yet little attention is given to the impact of inherited susceptibility on the family. Research studies have indicated that individuals receiving genetic counseling and testing do heed counselors' advice to inform family members; studies consistently show that as many as 80% of individuals inform at least one family member of their genetic testing results within the first week after the counseling session (Bonadona et al., 2002; Croyle & Lerman, 1999; Hughes et al., 1999; Julian-Reynier et al., 2000; Peterson et al., 2003). In fact, when asked their preference for informing family members themselves or having a healthcare provider or some other person inform them, they generally prefer to relay the information themselves (Bonadona et al.; Croyle & Lerman).

Individuals' understanding of their inherited risk varies a great deal, and very little research exists on what information is particularly difficult to understand (e.g., inconclusive test results (Hughes et al., 2002), subgroups of individuals who may have difficulty understanding this information (e.g., younger children [Tercyak et al., 2001]), and ways to enhance understanding (e.g., use of specific visual aids [Lipkus & Hollands, 1999])). No research describes how this information is conveyed from individuals to their family members, beyond which family members are informed and factors that influence why results are disclosed to some family members, including children, and not others (Bonadona et al., 2002; Claes et al., 2003; Costalas et al., 2003; Dugan et al., 2003; Foster, Eeles, Ardern-Jones, Moynihan, & Watson, 2004; Hughes et al., 1999; Kenen, Ardern-Jones, & Eeles, 2004; Peterson et al., 2003; Tercyak et al., 2001). The content of and context for these important family communications (including patterns of communication and cultural contexts) and family members' responses to receiving (or not receiving) these communications are unknown. Given the legal and ethical mandates around inherited risk (e.g., the patient's right to privacy in healthcare encounters and the family's need

to know about their risk for cancer), information about these communications within families is critical so that interventions can be developed to facilitate and enhance family communications and understanding regarding inherited risk, particularly in those who might be vulnerable to having adverse psychosocial responses (Biesecker & Brody, 1997; Costalas et al., 2003; Foster et al., 2004; Hopwood, 1997; Mahon & Casperson, 1995b; Peterson et al., 2003; Wilfond et al., 1997). This research knowledge is important to generate for nurses engaged in general oncology clinical practice, as well as those with advanced practice roles and advanced specialization in genetics, all of whom are faced with these issues on a day-to-day basis and need evidence-based information to respond appropriately to patients and family members (Mahon & Casperson, 1995a and 1995b; Tranin et al., 2003).

Source documents of major policy and content implication

American Society of Clinical Oncology Policy Statement Update: Genetic Testing for Cancer Susceptibility (2003)

Ethical and Policy Implications from the Cancer Genetic Studies Consortium National Institutes of Health (Wilfond et al., 1997)

ONS Cancer Predisposition Genetic Testing and Risk Assessment Counseling position statement (2004)

Recommendations from the National Society of Genetic Counselors (Trepanier et al., 2004)

Future research recommendations

Focus on family system

- Descriptive studies to characterize the illness trajectory within the family system
- Description of the positive factors or strengths that sustain the family system across the illness trajectory
- Descriptive studies on cultural influences on family experiences, including descriptive studies specifically focused on ethnic, cultural, or other subpopulations that currently are understudied
- Development of measures that are sensitive to differences in family developmental stage (e.g., young survivors)
- Development of brief interventions focused on delimited interventions to the family household
 - Anticipatory: preparatory counseling and experience mapping
 - Skill-based (Lorig et al., 1998, 1999): includes caregiving and family self-care, interaction skills that give voice to all family members' experiences. Skill-based interventions should include uncertainty management for family members that extends beyond problem solving (e.g., fear of recurrence).
- Important predictor and outcome variables
- Perceived illness experience rather than objective qualities
- Positive health concepts, including resilience as a predictor and outcome

Impact of inherited cancer risk on families

- Descriptive studies to characterize family member involvement in seeking information about inherited susceptibility to cancer
- Descriptive research on family communications about inherited risk, including patterns of and contexts (e.g., cultural) for these communications
- Descriptive studies of family members' understanding of their risk for cancer and psychosocial and behavioral responses related to inherited susceptibility to cancer (e.g., guilt, conflict, diminished cohesiveness, engagement in appropriate screening behaviors)

- Evidence-based interventions that facilitate and enhance family communications, including guidance offered to individuals about family communications and resources (e.g., visual aids) that enhance an accurate understanding of inherited risk.
- Evidence-based interventions to address distress and concern about prevention and lifestyle management. Based on the current state of the science, this might be best targeted in breast, prostate, and colorectal cancer.

Resources

Focus on family system

- Core grants from ONS Foundation with three to five substudies on the development or pilot testing of family-focused interventions or methods development studies. Core elements should be scripted by ONS and “bid” on by investigators.
- Supplemental grants for phase I, II, or III clinical trials that do not currently contain a family component
- Targeted partnership with drug companies and ONS Foundation for family-focused intervention studies, including media development and pilot studies to minimize distress and enhance functioning of patients and family members during particularly stressful times in the illness trajectory
- ONS-funded workshops on developing interventions
- Development of Centers of Oncology Nursing Research Excellence
- Partner ONS special interest groups with research priorities: Let the clinicians tell the researchers what they need to know.
- NIH funding mechanisms—explore new mechanisms for structures development
- Development of nursing-sensitive patient indicators in a database
- ONS leadership conference and workshops to disseminate translation research

Inherited family risk

- Core grants from ONS Foundation that examine the family experiences related to inherited susceptibility and genetic testing for cancer
- ONS Foundation-supported supplemental grants for currently funded genetic counseling studies beyond risk assessment that do not contain a family component
- Descriptive studies of understudied subgroups, including vulnerable and special populations as well as family members
- Targeted partnership with commercial enterprises and ONS Foundation for funding evidence-based, family-focused studies and development of appropriate visual aids to enhance family members’ understanding of communications about inherited susceptibility to cancer
- Development of formal partnerships of researchers with appropriate ONS special interest groups to address the research priorities

3. Research in health promotion, primary and secondary prevention

Priority topics

- 3.1 Test risk-based interventions for prevention of tobacco uptake, cessation, and decreasing exposure to secondhand smoke.
- 3.2 Develop and test cost-effective interventions to increase evidence-based screening (cervical, breast, colorectal, prostate) based on individual cancer risk assessment.

Rationale and background

Prevention and early detection has great potential to decrease morbidity and mortality from cancer. Primary prevention is the prevention of disease through activities such as smoking cessation, chemoprevention, and genetic counseling. Secondary prevention is the early detection of cancer before signs or symptoms are apparent (“American Society of Clinical Oncology Policy Statement Update,” 2003). The priority for primary prevention will focus on tobacco exposure. The priority for secondary prevention will focus on breast and colorectal cancer screening. Included in the primary and secondary priorities are the identification of risk status through heredity, gene-environment interactions, and biomarkers.

Tobacco use

Tobacco use is the major cause of preventable cancer and contributes to more than 30% of cancer deaths (IARC, 2004; Wingo et al., 1999). Lung cancer, almost entirely caused by tobacco use, continues to be the most common cause of cancer death for men and women, resulting in more deaths each year than from breast, prostate, and colon cancer combined. Lung cancer deaths among American women surpassed breast cancer deaths in the mid-1980s (U.S. Department of Health and Human Services, 2005) and now constitute 40% more deaths than from breast cancer. Tobacco-attributable cancers include cancers of the lung, oral pharynx and larynx, esophagus, stomach, bladder, kidney, pancreas, and cervix, as well as acute myeloid leukemia, and tobacco is related to increased risk of endometrial, colon, and liver cancer (U.S. Department of Health and Human Services, 2005). Other forms of tobacco use, such as cigars and chewing tobacco, also are associated with increased risk of oral cancers, along with other cancers and diseases.

Tobacco use negatively impacts cancer treatment side effects, outcomes, and quality of life. The inclusion of smoking history and tobacco use as core data in all oncology clinical trials is being recommended to allow for interpretation of the impact of tobacco use on clinical outcomes (Gritz, Dressler, & Sarna, in press), and efforts are needed to ensure that this critical information is included in oncology nursing research as well.

Prevention: One of the most effective strategies to prevent cancer is to prevent the uptake of tobacco among youth (DiFranza & Wellman, 2003). Although tobacco use rates have declined, one out of five (22.1%) Americans continues to smoke (Centers for Disease Control and Prevention [CDC], 2004a), far above the Healthy People 2010 goal of no more than 12%. Smoking prevalence varies among the population, with the highest among American Indian/Alaska Natives (40.4%) as well as among Puerto Rican (30.4%), Korean (27.2%), and Vietnamese (26.5%) adults (CDC, 2004b). Smoking among high school students has significantly declined with the lowest prevalence (21.9% current use and 9.7% current frequent use) since the mid-1990s (CDC, 2004c). However, the percentage among some youth (aged 12–17) continues to be high, including American Indian/Alaska Natives (27.9%) and non-Hispanic white youth (16%). Rates among non-Hispanic girls now exceeds that of boys (17.2% versus 14.9%) (CDC, 2004c).

As smoking patterns have changed, tobacco-attributable cancers such as lung cancer have increased in impoverished, poorly educated, and ethnic minority communities, contributing to health disparities (Hutchinson & Froelicher, 2003; Wingo et al., 1999; Wong et al., 2002). Forty percent of cancer deaths among African American men have been attributed to tobacco

use (Leistikow, 2004). With the decline in cigarette smoking in the larger population, tobacco companies have moved to target special segments of the population, including women, young people, and those with low incomes (U.S. Department of Health and Human Services, 2005).

Tobacco control is a critical issue for reducing the cancer burden for all oncology health professionals (American Society of Clinical Oncology, 2003; Sarna & Bialous, 2004). As demonstrated in California with the reduction of lung cancer, tobacco control policies can result in fewer cancer deaths (CDC, 2001).

Research has supported the efforts of nurses in educating both adults and children about the tremendous health risks posed by tobacco use, improving their understanding of the benefits of smoking cessation, and increasing awareness of available local resources (Rice & Stead, 2005). More research is needed to examine the role and contributions of oncology nurses in testing strategies and policies in implementing tobacco control efforts.

Tobacco cessation: Smoking cessation is the most cost-effective intervention to reduce death and disease for adults, more cost-effective than mammograms, Pap tests, and screening for colorectal cancer or hypertension (Coffield et al., 2001). Although the U.S. Public Health Service issued a scientifically based clinical practice guideline, *Treating Tobacco Use and Dependence* (Fiore et al., 2000), which describes scientifically based tobacco cessation treatments and the efficacy of all health professionals in engaging interventions, few nurses are aware of the guideline and limited study has investigated the best strategies to incorporate it in oncology nursing practice (Browning & Wewers, 2003; Sarna, Brown, Lillington, Wewers, et al., 2000; Sarna, Brown, Lillington, Rose, et al., 2000). Tobacco use is a chronic, relapsing condition (Fiore et al.). Even after a diagnosis of cancer, some patients still will have difficulty quitting, and use during treatment has been linked to increased side effects and diminished quality of life (Browning & Wewers, 2003; Garces et al., 2004; Gritz, 2000). Additionally, patients with lung cancer report stigma, blame, and inferior quality of care that they attribute to healthcare professionals' views of their tobacco use (Chapple et al., 2004). Further research is needed to explore the efficacy of current cessation treatment in people with cancer (Lerman, Patterson & Berrettini, 2005), especially the "added value" of oncology nursing efforts in supporting cessation.

Continued tobacco use among cancer survivors has been linked with increased risk of cancer recurrence, increased risk of second tobacco-attributable malignancies, increased risk of tobacco-attributable comorbid diseases such as cardiovascular disease, decreased overall survival, and diminished quality of life (Cinciripini et al, 1997; Gritz, 2000; Mazzone & Arroliga, 2004; Wong et al, 2002). Smoking cessation for patients who have been diagnosed and treated for cancer has received some attention (e.g., Gritz, 2000), but the nursing literature in general, and specifically oncology nursing literature, is very limited in this area (Browning et al., 2000; Sarna, Brown, Lillington, Wewers, et al., 2000). Although a diagnosis of cancer may be a "teachable moment" for family members who smoke as well, few studies have examined this problem (Schilling et al., 1997). Also of concern to oncology nurses is smoking by survivors of childhood cancer (Emmons et al., 2003).

A review of nursing interventions for smoking cessation found that the provision of cessation advice by nurses significantly increases the odds of quitting in a variety of healthcare settings (Rice & Stead, 2005). In a national survey of oncology nurses, few nurses actively engaged in smoking cessation interventions (Sarna, Brown, Lillington, Wewers, et al., 2000). A number of

barriers to nursing involvement in tobacco reduction exist, including lack of knowledge and lack of skills (Sarna, Brown, Lillington, Wewers, et al., 2000; Sarna, Brown, Lillington, Rose, et al., 2000). Nurses, along with other health professionals, are not immune to tobacco addiction, and their smoking affects their involvement in tobacco control (Sarna et al., 2001; Sarna et al., 2005).

Exposure to secondhand smoke: Secondhand smoke is a carcinogen attributed to more than 3,000 deaths from lung cancer each year, as well as other cancers and many other diseases such as heart disease (California Protection Agency, 1999; IARC, 2004). Secondhand smoke also may increase symptom distress (Sarna & Bialous, 2004). Minimal nursing research has been conducted in this area (Chan & Lam, 2003).

Breast and colorectal cancer screening

Breast and colorectal cancer are the second and third causes, respectively, of cancer deaths in women (Jemal et al., 2005). In 2005, 145,290 colorectal cancer cases and 211,240 breast cancer cases are projected to occur. Regular colorectal and breast cancer screening has the potential to save more than 95% of these women by facilitating early diagnosis (American Cancer Society, 2003). On average, 95% of women diagnosed with localized-stage colorectal or breast cancer have at least a five-year survival, whereas those diagnosed with distant disease have only a 20% chance of living five years (Jemal et al., 2005). Removal of adenomatous polyps, the precursors to colorectal cancer, provides the additional benefit of decreasing the incidence by 75%–90% (Winawer et al., 1997).

Fortunately, screening for colorectal and breast cancer offers excellent protection against mortality. Scientists estimate that deaths from colorectal cancer could be reduced by 50% if current screening guidelines were implemented properly (Colorectal Cancer Progress Review Group, 2004). The five-year survival rates for people diagnosed with stage I (Duke's A) disease is approximately 95% (Jemal et al., 2005), making early detection paramount. Randomized trials have demonstrated the efficacy of screening with fecal occult blood tests (FOBTs) in reducing mortality by more than 30% (Mandel et al., 1993). This mortality reduction was achieved primarily because FOBT led to endoscopic screening with flexible sigmoidoscopy or colonoscopy.

Similarly, the potential for mammography to decrease mortality through early detection has been demonstrated through breast cancer screening studies conducted since the 1970s. Eight major randomized controlled trials have been conducted for breast cancer screening, collectively including more than 500,000 women (Andersson et al., 1988; Frisell et al., 1991; Miller, Howe & Wall, 1981; Miller et al., 1992a; Miller et al., 1992b; Nystrom et al., 1993; Shapiro, 1997; Shapiro et al., 1982; Tabar et al., 1985; Tabar et al., 1987; Tabar et al., 1992; Roberts et al., 1990). Although a 2001 study questioned the benefit of mammography (Gotzsche & Olsen, 2002), the NCI and U.S. Preventive Services Task Force quickly refuted this data and strongly endorsed routine screening for women aged 40 years and older based on a meta-analysis that found a sizable benefit in mortality reduction (Agency for Healthcare Research and Quality, 2002; Quigley et al., 2002). When women aged 50 and older were routinely screened by mammography, a 30% reduction in mortality was demonstrated.

Despite screening recommendations, adherence to colorectal and breast cancer screening is inadequate. From 1987–1998, rates of screening FOBT rose in women from 21%–26%, whereas rates of recent endoscopic screening rose from 6%–10% (Breen et al., 2001; CDC, 2001; Ries et al., 2000). At the same time, screening rates for colorectal cancer with either

FOBT or endoscopy rose more than twice as much for men (15% increase) as for women (6% increase) (Breen et al.; CDC). The most recent data from the National Health Interview Survey show that 35%–46% of women aged 40 or older have not had a mammogram in the past two years (Eastman, 1997), and 60% report no mammogram in the past 12 months. A workshop convened by NCI acknowledged the low rates of colorectal cancer screening and indicated that a research challenge for the next five years must be interventions to increase adherence to guidelines (Anderson et al., 2002). Additionally, implementation of methods to increase screening must be cost-effective for healthcare providers and be endorsed by women.

Managed care plans encourage use of and pay for colorectal and breast cancer screening, yet levels of adherence to national screening guidelines fall far short of desired levels. Nationally, only 44% of people report ever having had a sigmoidoscopy and only 34% report having had a sigmoidoscopy or colonoscopy within the past five years (CDC, 2001). Furthermore, a group of women who never have been screened by mammography still exists, and the rate of repeat mammography screening that will produce further mortality reductions is poor (Champion et al., 2000).

Concern about adherence to colorectal and breast cancer screening has been highlighted by two NCI Progress Review Groups. The Colorectal Cancer Progress Review Group (1998) highlighted raising awareness of colorectal cancer screening and developing interventions to facilitate the informed utilization of screening tests as a priority. The Breast Cancer Progress Review Group (2004) encouraged healthcare professionals to make effective use of new information technologies to reach large population segments with educational messages that facilitate breast cancer screening.

Guidelines for colorectal cancer screening and mammography: Guidelines for colorectal screening recently were revised by the U.S. Multidisciplinary Task Force on Colorectal Cancer and endorsed by ACS (Winawer et al., 2003). This expert group recommended that screening programs begin by classifying an individual's risk based on personal and family medical history to determine the appropriate screening approach. For people with average risk, colorectal cancer screening starts at age 50 and includes four options (a) annual FOBT, (b) flexible sigmoidoscopy every five years, (c) double contrast barium enema every five years, and (d) colonoscopy every 10 years. For people at increased risk for colorectal cancer, colonoscopy is the recommended screening test (Winawer et al., 2003). Because guidelines vary based on risk, healthcare providers first must assess risk status for colorectal cancer and then tailor the intervention to average or higher-than-average risk so that the appropriate option is recommended. Breast cancer screening guidelines endorsed by ACS and NCI emphasize yearly screening for women aged 50 and older (ACS, 2001).

Prior experience with colorectal cancer screening may impact a current decision to screen. For instance, an unpleasant sigmoidoscopy experience may influence future choice of colorectal cancer screening. Because people at average risk will be given their choice of the recommended screening methods, they may be more likely to undergo screening again. Although theoretically people at average risk could have a colonoscopy, this decision would be influenced by the policy of their healthcare plans. Many healthcare plans will not pay for a person at average risk to have the more expensive colonoscopy. The program will provide people at average risk with the option of FOBT, sigmoidoscopy, or both. The colonoscopy option will be explained as a procedure usually reserved for those at higher risk for colorectal

cancer. For people who have a higher-than-average risk for colorectal cancer, the program will mention FOBT and sigmoidoscopy but recommend colonoscopy.

Research on colorectal cancer has found that tailoring health promotion interventions to attitudes and beliefs increases the efficacy of interventions, allowing tailored interventions to emerge as a promising strategy for influencing attitudes and behaviors. Tailored interventions are defined as “any combination of information and behavior change strategies intended to reach one specific person, based on characteristics that are unique to that person. Messages are also tailored to the outcome of interest, and assess individuals prior to delivering the message” (Kreuter et al., 1998, p. 5).

Research on colorectal cancer screening has identified perceived risk, benefits, and barriers to screening and physician recommendation as important predictors of screening. Several studies have shown the importance of physician recommendation for colorectal cancer screening participation (Friedman et al., 1999; Gordon, Rundall, & Parker, 1998; Holt, 1991; Leard, Savides & Ganiats, 1997; Lewis & Jensen, 1996; McCarthy & Moskowitz, 1993; Paskett, 2000; Rawl et al., 2000). Beeker et al. (2000) conducted 14 focus groups to identify knowledge, attitudes, and beliefs about colorectal cancer and screening. Respondents had little knowledge about their own risk or the benefits of screening. Barriers such as embarrassment, inconvenience, physical discomfort, and concern about being able to actually complete screening tests were cited. Knowledge about cancer and knowing someone who had colorectal cancer consistently have been related to adherence to FOBT (Farrands et al., 1984; Myers et al., 1990; Price, Colvin, & Smith, 1993) and flexible sigmoidoscopy (Brown et al., 1990; Price et al.). Manne et al. (2002) studied the relationship of the Transtheoretical Model and Health Belief Model variables to stage and adherence for colorectal cancer, finding that perceived risk, benefits, and barriers, among other variables, were related to stage and adherence. Colorectal cancer screening intervention trials are relatively new, but several have been reported in the literature. Vernon (1997) reviewed studies of behavioral interventions to increase colorectal cancer screening, ranging from mailed letters and screening kits to short educational conversations with a nurse. Most interventions significantly increased FOBT screening, but adherence still was below 50%. In prospective studies of patient or community populations, the demographic characteristics of being older than age 70, being male, having less education, and having low income consistently were associated with nonadherence to FOBT. Adherence was lowest in people aged 70 or older with one exception: Age was not associated with FOBT participation among first-degree relatives of patients with colorectal cancer (Sandler et al., 1989). For sigmoidoscopy, studies have found that men are more likely to be screened than women (Myers et al., 1994; Polednak, 1990). Authors of one study even suggested a gender bias against women in relation to sigmoidoscopy (Herold et al., 1995).

For breast cancer screening, tailoring interventions to a woman’s belief system and stage of mammography adoption facilitates screening. Champion and Huster (1995) demonstrated that personal counseling tailored to individual beliefs effectively increased mammography adherence (odds ratio [OR] = 5.27, $p = 0.001$), and findings from other studies suggest that the strengths of such face-to-face individualized interventions can be approximated by tailored interventions delivered via other media. King et al. (1994), Marcus et al. (1993), Rimer et al. (2002), and Champion et al. (2002) have delivered tailored mammography counseling interventions by telephone and found significant increases in mammography use. A recent innovation is using computer-tailored print materials created specifically for individual recipients based on their responses to particular questions (Kreuter et al., 2000).

Randomized controlled intervention trials comparing tailored and nontailored print communications (Skinner et al., 1999) have demonstrated that tailoring materials enhances their efficacy in promoting mammogram use. For example, Skinner, Strecher, and Hospers (1994) found, among low-income women nonadherent at baseline but considering a mammogram, that those who received tailored communications subsequently were much more likely to have had a mammogram than those whose print communications were not tailored (75% versus 32%). Lipkus et al. (2000) and Rakowski et al. (1998) also found an advantage in tailoring mammography interventions. Most recently, Clark et al. (2002) demonstrated the advantage of stage-matched tailoring as compared to non-stage-matched tailoring. In addition, some studies have suggested that interactive tailored interventions have an advantage over noninteractive tailored print materials.

The focus on comprehensive screening for cancer is emerging as the model for health care. Theoretically based research concepts such as risk, benefits, and barriers apply to colorectal and breast cancer screening. Benefits of screening for both cancers involve early discovery and treatment to prevent progression of disease. Some barriers to screening may differ between colorectal and breast cancer screening and will need messages specific to each cancer.

Cancer risk assessment in primary and secondary prevention

Susceptibility to cancers in large part is determined by complex interactions of genes and multiple environmental exposures to mutagens or carcinogens. These interactions are evident in sporadic and familial cancers, as well as in inherited cancer syndromes. Discoveries of gene-environment and gene-gene interactions have further defined specific risk factors for cancer occurrence and recurrence. However, these discoveries also have added to the complexity of cancer risk assessment, the fundamentals of which are based on gene-gene and gene-environment interactions.

Cancer risk assessment is an integral component of cancer primary and secondary prevention (Mahon, 1998). Cancer risk assessment can be viewed as a process that involves not only querying about exposure to modifiable and nonmodifiable risk factors but also assessing perception or misperception of cancer risk (Joy, Penhoet, & Petitti, in press) and identifying and measuring the impact of modifiable risk factors (e.g., diet, tobacco use, drugs) that possibly interact with known gene variants (Khoury, 2002). Another part of the risk assessment process is communication of cancer risk (Croyle & Lerman, 1999), ideally using messages that employ tailored information (Lipkus & Hollands, 1999; Rimer & Glassman, 1999). Although only 10% of cancers are genetically predisposed, all cancer risk assessment should take into account the potential for inherited risk along with other risk factors.

ONS's position on cancer risk assessment is evident in statements addressing prevention and early detection of cancer and cancer predisposition testing and genetic counseling (ONS, 2004). These statements support obtaining, documenting, and interpreting cancer risk assessments along with recommending appropriate cancer early detection and prevention strategies. These position statements distinctly call for developing a research plan that evaluates the efficacy of prevention and early detection programs (including genetic testing programs), the psychological impact of cancer prevention and detection strategies, promotion of participation in prevention and early detection activities, and long-term outcomes of risk management strategies. Although these position statements were authored several years ago and recently were revised, much of the research has not occurred. ONS encourages nurses to broaden their knowledge base to be able to conduct sophisticated cancer risk assessments.

Yet, in the nursing literature, little evaluation of models is used to conduct risk assessments, few proposed instruments are used to measure risk, and reports of the quality and outcomes of cancer risk assessments are insufficient.

Greater knowledge of genetic and environmental cancer risk factors has spawned cancer risk assessment technologies and products. Internet-based interactive tools—for example, the NCI/National Surgical Breast and Bowel Project Breast Cancer Risk Assessment Tool (<http://bcra.nci.nih.gov/brc/start.htm>) or Harvard's Your Disease Risk (www.yourdiseaserisk.harvard.edu)—are disseminated widely to healthcare professionals and the public alike. To educate nurses about cancer risk and risk assessment, ONS developed a Cancer Genetics and Cancer Care Tool Kit, which is available online at www.ons.org/clinical/documents/pdfs/Kit.pdf. What is not completely clear is if, or how, these tools contribute to the cancer risk assessment process. Regardless of whether these tools present an accurate profile of risk factors and influences, risk-reduction behaviors remain to be seen.

Future research directions

Tobacco control

- Describe patterns of tobacco use and exposure to secondhand smoke among people diagnosed with cancer, people undergoing treatment for cancer, and survivors of cancer.
- Describe the relationship of continued smoking among patients diagnosed with cancer and treatment side effects and symptom distress.
- Describe the biologic and physiologic interactions of nicotine dependence, treatment side effects, and symptom distress.
- Describe variables influencing smoking cessation and continued smoking after a cancer diagnosis.
- Investigate the impact of pharmacotherapy for tobacco cessation and the relationship with symptoms, well-being, and other outcomes for people with cancer.
- Explore the range of issues involved in smoking in the face of end-stage disease, including symptom distress and risk of fire-related injury.
- Describe the role of biochemical verification of tobacco use among people with cancer.
- Explore the stigma and blame experienced by patients with a tobacco-induced malignancy and the impact on quality of care.

Prevention: Evidence-based interventions are needed to enhance the role of oncology nurses in tobacco prevention.

- Examine the efficacy and cost effectiveness of nursing interventions in tobacco prevention programs.
- Integrate tobacco use prevention into care and follow-up of survivors of childhood cancer.
- Evaluate methods to increase knowledge, enhance attitudes, and remove barriers to facilitate nursing involvement in tobacco prevention.
- Investigate the role of oncology nurses in affecting policy to reduce the role of the tobacco industry in promotion and advertisement of tobacco use, mass media, government regulations of tobacco products, smoke-free environments, tobacco excise tax, and coverage for cessation services and pharmacotherapy.

- Investigate the role of the oncology nurse in community-based tobacco control interventions to impact cultural norms, family use, school-based programs, community and workplace policies, income, insurance coverage, and mass media.

Cessation: Intervention studies are needed to evaluate the effectiveness of evidence-based tobacco cessation interventions in oncology nursing practice.

- Evaluate recommended cessation strategies (social support, skills training, and pharmacotherapies) for use in different cancer care settings and with different populations.
- Validate existing theories for tobacco cessation (e.g., transtheoretical model) in the cancer population.
- Identify variables associated with continued smoking after a cancer diagnosis, and tailor interventions appropriately.
- Determine the efficacy and cost effectiveness of delivery of tobacco cessation interventions by oncology nurses.
- Test the use of new interventions for cessation, such as telephone quit lines and Web-based support in the cancer population.
- Describe the use of existing cessation services by patients with cancer.
- Explore the differential contributions of age, gender, education and literacy, socioeconomic status, concurrent addictions (e.g., alcohol), and history of use (age at initiation of tobacco use) to the efficacy of tobacco cessation interventions in people with cancer.
- Test family-focused smoking cessation strategies.
- Evaluate methods to increase nursing involvement in tobacco cessation intervention.
- Test methods to assist nursing professionals with their own smoking cessation.

Exposure to secondhand smoke: Interventions are needed to decrease and eliminate exposure to secondhand smoke.

- Evaluate strategies to reduce and eliminate exposure to secondhand smoke among people at risk for or with cancer.
- Explore the role of oncology nurses in supporting policies to reduce exposure to secondhand smoke in public environments.

Outcomes

1. Inclusion of tobacco history and current use in sample descriptions in oncology nursing research
2. Prevention of tobacco uptake
3. Increased quit attempts and long-term cessation among patients with cancer, people at risk for cancer, and family members
4. Increased knowledge and skills of oncology nurses about tobacco prevention and cessation and decreased exposure to secondhand smoke
5. Implementation of tobacco assessment and delivery of cessation interventions, including referral to resources such as the national quit line, in oncology nursing practice
6. Prevention of exposure to secondhand smoke
7. Enhanced tobacco control policies to support a smoke-free society

Breast cancer and colorectal cancer screening: Now that descriptive work to increase breast and colorectal cancer screening has been completed, we need research in evidence-based

interventions to address

- Developing interventions that are tailored to individual and cultural variables
- Targeting interventions to those at greatest risk, including African American men and women and an older population
- Directing interventions toward multiple levels including individuals, healthcare providers, and communities
- Examining the cost-effectiveness of all screening interventions
- Translating interventions into the healthcare system
- Identifying interventions to track abnormal screening
- Using technology to deliver interventions
- Developing decision aids to help patients and care providers select appropriate screening recommendations
- Developing interventions to simultaneously promote appropriate risk based screening for breast and colorectal cancer
- Understanding the barriers to screening at individual, system, and policy levels
- Developing interventions to address continued interval screening as opposed to one-time screening.

Outcomes

1. Increase adherence to risk-based screening guidelines for breast and colorectal cancer.
2. Translate efficacious interventions into healthcare practice.
3. Increase adherence of risk-based screening guidelines in at-risk populations.
4. Increase appropriate resolution of abnormal screenings.

Cancer risk assessment: Cancer risk assessment that includes heredity, environment, and biomarkers should be included in primary and secondary prevention.

- Descriptive studies to (a) develop and/or test new or existing models of risk assessment processes and (b) develop or adapt measures of risk assessment that capture the meaning of risk to individuals or families.
- Interventions to build the evidence base for risk assessment strategies. Intervention studies should be conducted in (a) populations that historically have been studied in a descriptive fashion (e.g., breast, ovarian, colorectal, lung, and prostate cancers) and (b) understudied groups such as people at risk for melanoma and nonmelanoma skin cancers and cancers of the uterus and pancreas. Examples of specific interventions are risk assessment methods (e.g., in-person counseling, Internet-based strategies, print communications), delivery of risk communications (e.g., delivery by nurse, physician, media, “target” family member), and interventions to enhance risk-reduction behaviors.
- Development of criteria for clinically significant change in (a) the quality of risk assessment by nurses and (b) the quality of cancer risk communications by healthcare providers.
- Important predictor and outcome variables.
- Examples of predictor variables are family history of cancer and precancerous conditions; perceived risk of cancer; family communications of risk, risk perception, and risk-reduction behaviors; healthcare provider communications of risk and risk-reduction behaviors; cancer worry; access to health care; and cancer status (e.g., history of cancer, no cancer but strong risk factors).

- Examples of outcome variables are positive use of risk-reduction or risk-modification behaviors, decreased cancer worry, healthy family communications about cancer risk processes, appropriate healthcare provider communications of risk and risk-reduction behaviors, and early detection of cancer.

Specific resources for this priority

- Focused funding
- Development of collaborative network of ONS researchers interested in this area
- Increased visibility of primary and secondary prevention within ONS
- Increased nursing involvement in multidisciplinary research in primary and secondary prevention

4. Research that considers the late effects of cancer treatment and long-term survivorship issues for patients and their families

Priority topics

- 4.1 Describe the range of potential late effects for cancer survivors.
- 4.2 Identify modifiable behaviors that can be targeted to minimize late effects of cancer treatment.

Rationale and background

One in three individuals in the United States will be affected by cancer either through their own diagnoses or those of loved ones. Today, an estimated 9.6 million individuals are living in the United States following a cancer diagnosis, representing approximately 3% of the population. Improvements in prevention, early detection, and treatment strategies, including surgery, chemotherapy, and radiotherapy, have led to dramatic improvements in survival and cure rates for many adult as well as pediatric patients with cancer. Because of these gains, now approximately 14% of our country's nearly 10 million cancer survivors were diagnosed more than 20 years ago, creating a large number of cancer survivors with significant health-related issues that must be addressed (Reis et al., 2003). A large portion of these survivors are adults who already have been shown to experience a greater risk for certain health problems, such as osteoporosis and certain cardiovascular complications. In fact, 61% of cancer survivors today are aged 65 or older, and older adults often experience other physical and psychological comorbidities that may compound the effects of cancer on their health. The potential scope of late effects from cancer and its treatment has yet to be well described, leaving a void of knowledge that not only impairs clinicians' abilities to optimally care for cancer survivors as they live beyond their diagnosis and treatment but also has begun to create a significant threat to our country's public health as numbers of cancer survivors continue to grow.

In response to these challenges, the CDC and Lance Armstrong Foundation (LAF) conducted a workshop in June 2003, called Building Partnerships to Advance Cancer Survivorship and Public Health, and developed a national action plan to outline how public health can address critical cancer survivorship issues. This action plan was developed by expert participants who addressed each of the following public health areas in the context of cancer survivorship.

- Surveillance and research
- Communication, education, and training
- Programs, policies, and infrastructure
- Access to quality care and services

- Evaluation and quality improvement

With respect to research, the national action plan articulated the specific objective of establishing a knowledge base regarding the “ongoing physical, psychological, social, spiritual, and economic issues facing cancer survivors” (CDC & LAF, 2004, p. 14) and acknowledged the need for an infrastructure to support a cancer survivor database. As described in the national action plan, three stages of cancer survivorship exist: acute, extended, and permanent. The acute stage encompasses the initial stage of diagnosis and acute treatment. The extended stage begins when acute treatment ends and the focus becomes adaptation to chronic late effects of treatment, as well as surveillance for cancer recurrence and late effects of treatment. The national plan makes a distinction between the extended and permanent stages in that the permanent phase is a time when the likelihood of disease recurrence is sufficiently small.

NCI also has recently validated the urgent need to address the unique issues of cancer survivors. Survivorship has been identified as a new priority for NCI, and an action plan was outlined for fiscal year 2004 focusing on survivorship and public health in an agenda quite similar to that outlined by the CDC and LAF (Jacobs & Giarelli, 2004). In fact, NCI clearly identifies that cancer survivorship research is to address the health and life of an individual with cancer beyond the acute diagnosis and treatment phase, corresponding to the extended and permanent stages of survivorship. According to NCI, cancer survivorship research encompasses the physical, psychosocial, and economic sequelae of a cancer diagnosis and its treatment in pediatric and adult cancer survivors. It also includes issues related to care delivery, access, and follow-up as they relate to survivors. Survivorship research focuses on the health and life of a person with a history of cancer beyond the diagnosis and treatment phase. It seeks to prevent and control adverse cancer outcomes such as late effects of treatment, including second cancers and poorer quality of life, provide a knowledge base regarding optimal follow-up care and surveillance, and optimize health after cancer treatment (<http://survivorship.cancer.gov>). Clearly, major policy and research funding organizations recognize the importance of generating a body of knowledge specific to the needs of cancer survivors beyond the acute diagnosis and treatment phase of cancer as well as acknowledge the far-reaching impact that these long-term survivorship issues have on the public health of our nation.

Although long-term survivorship issues have gained attention for adult cancer survivors only recently, the identification of late effects and the subsequent need for specialized, risk-based care for survivors began more than 20 years ago for childhood cancer survivors (Schwartz, Constine, & Hobbie, 1994). Given the small amount of research on adult survivorship, little data exist on which to base surveillance guidelines for adult cancer survivors. Most of what we know about these issues today has come from studies about survivors of childhood cancer. The field of adult cancer survivorship must integrate the knowledge learned from pediatric cancer survivorship while earnestly working to expand the knowledge base regarding unique issues for adult cancer survivors. ONS has a critical role to play in joining forces with other national organizations such as NCI, LAF, and CDC, in advancing this critical research agenda to improve the health of millions. Consistent with NCI’s description of cancer survivorship research and the stages of cancer survivorship outlined in its national action plan, cancer survivorship research priorities outlined in this document will pertain to issues in cancer survivors in the extended and permanent stages, which occur beyond the acute diagnosis and treatment of cancer. In these stages, the predominant focus no longer is on eradication of known or subclinical disease but rather on surveillance for recurrent disease and late effects of treatment, with the overall goal of

promoting long-term health. For the purpose of this document, late effects are defined as sequelae of treatment that either begin after or persist beyond acute diagnosis and treatment.

Future research

- Prospective, longitudinal, descriptive case-control studies to identify and characterize the full range of specific late effects of cancer treatment
- Prospective, longitudinal, descriptive case-control studies that identify, characterize, and link specific late effects to specific treatments
- Development of valid, sensitive, and specific instruments that can index the late effects experienced by cancer survivors and capture intervention outcomes
- Design, implementation, and testing of theory-driven interventions that aim to minimize adverse late effects of cancer diagnosis and treatment through prevention, early detection, and treatment of these late effects
- Translation of research into evidence-based practice guidelines and implementation of consistent use of these guidelines
- Determination of key predictor and outcome variables
 - a. Age (at treatment exposure and current age) and effects related to the aging process
 - b. Gender
 - c. Family medical and occupational history associated with heightened risks
 - d. Ethnicity and race
 - e. Genetic endowment
 - f. Socioeconomic status (e.g., marital status, level of education, type of employment, income, availability of insurance, access to specialty care)
 - g. Menopausal status (in female survivors)
 - h. Cancer diagnosis
 - i. Treatment exposures (e.g., nature, intensity, delivery mode of treatment agents, treatment co-exposures, site of exposure [radiation therapy], factors such as gender, age at treatment)
 - j. Time lapsed since completion of cancer treatment
 - k. Evidence of late effects
 - l. Comorbidities
 - m. Functional status
 - n. Quality of life (both cancer related and general)
 - o. Health behaviors (e.g., diet, exercise, participation in recommended screening, tobacco and alcohol use)

Specific resources for this priority

- A multi-site centralized database of cancer survivors summarizing treatment information and subsequent late effects of treatment
- Creative partnerships with pharmaceutical industry and other funding sources to develop funding for survivorship research
- Education of survivors as well as their primary care and specialty care providers regarding prevention, early detection, and management of potential late effects
- Linkages with national cooperative clinical trials group databases to prospectively capture late effects in individuals enrolled in cancer clinical trials
- A network of institution-based late effects teams to support multisite clinical trials of descriptive, interventional, and translational research
- Evidence-based late effects surveillance guidelines for adult cancer survivors
- Algorithms for evaluating late effects (including risk factors)

5. Research in nursing-sensitive patient outcomes (NSPOs)

Priority topics

- 5.1 The effectiveness and quality of nursing care on NSPOs within the context of the healthcare system to prevent adverse events
 - 5.1.1 Infection
 - 5.1.2 Prevention of adverse events related to cancer treatment modalities
 - 5.1.3 Work force issues that promote or threaten quality care
- 5.2 The effectiveness and quality of nursing care on NSPOs within the context of health management for individuals
 - 5.2.1 Maintain or promote physical function, functional status, or functional ability of individuals who receive cancer treatment
 - 5.2.2 Nursing interventions to prevent or decrease fatigue in individuals with cancer

Rationale and background

NSPOs within the context of the healthcare system: The quality of health care in our nation has become a priority not only for nurses but also for many groups and organizations. Specific efforts have been taking place through the Institute of Medicine (IOM), the American Nurses Association, and the National Quality Forum quality indicators and outcomes. As such, we need to develop the science on nursing interventions, which can impact these outcomes. Specific IOM documents have examined the quality of cancer care and have focused on evaluating cancer care in general, end-of life care, palliative care, children with cancer, breast cancer, and survivorship. Concern for outcome indicators has been central to these documents. Although the shortage of nurses adds to the threat of quality of care for individuals with cancer and the shortage of nurses and the workforce must be addressed, the demand for professional accountability regarding outcomes dictates that nurses be able to identify and document outcomes that are attributed to nursing care. This requires that nurses use their evidence base to develop the science around NSPOs to enable us to describe the specific contributions of nursing care to and outcomes for patients with cancer, notably in preventing the adverse events of infection and safe administration of cancer treatment.

Patients with cancer receiving chemotherapy have high levels of infection. The absence of granulocytes; disruption of integument, mucosal, and mucoallary barriers; and inherent microbial flora shifts predispose neutropenic patients to infection (National Comprehensive Cancer Center [NCCN], 2004). Roughly 10%–20% of patients with neutrophil counts less than 100/mm³ will develop an infection. Primary sites of infection are alimentary tract, sinuses, lungs, and skin. The NCCN guidelines recommended that risk assessments for neutropenia be determined at the initial evaluation. Neutropenia and febrile neutropenia can result in cessation of treatment, dose reductions, and dose delays of chemotherapy. Neutropenia adds to complexity of management and to the signs and symptoms that patients experience. This complication and side effects are life threatening. Nurses can perform definable activities to reduce the risk of infection in patients with cancer. These activities cluster in five domains: hygiene, IV therapy, nutrition and gastrointestinal management, environment, and chemoprevention. Evidence for these activities is not at a high level. Evidence-based guidelines for prevention of infection are available from national and international panels of experts but rarely are focused specifically on patients with cancer. Risk factors are available for episodes of neutropenia. Risk assessments for neutropenia are not applied readily in practice settings. Measurement tools, specifically with

regard to timing of measures based on location of care, are underdeveloped and unavailable for nurses to use.

Oncology nursing experts recognized that these interventions may vary depending on clinical population and urban or rural setting. Several interventions identified by oncology nursing experts were reported in the literature, namely systematic assessment and rapid intervention based on aberrant findings and nurse-led patient education on such topics of symptom assessment, reportable conditions, and precautionary measures. These interventions warrant future research and attention to authors as they develop systematic literature reviews.

Gaps in current evidence

- *Reporting errors:* Although a mechanism exists for reporting chemotherapy medication errors, the United States Pharmacopeia Medication Errors Reporting Program, the incidence of reporting to this program is not optimal. The reasons for the lack of reporting to this program are not clear.
- *Reporting extravasation:* The reporting of extravasations to this program is not optimal, and the reasons for the lack of reporting to this program are not clear.
- *Evaluating education:* ONS offers a standardized Chemotherapy and Biotherapy Course to nurses, but evidence is lacking regarding whether taking this course affects the incidence and severity of chemotherapy medication errors.
- *Measuring safety:* Evidence is lacking regarding the most effective way to measure the level of safety in a healthcare system.
- *Computerized order entry:* Information system use has been found to assist in preventing medication errors by identifying incorrect doses and frequencies, allergies, and potentially harmful drug interactions. However, a large number of computerized order entry systems do not adapt well for chemotherapy and biotherapy ordering. The impact that this has on the rate of chemotherapy and biotherapy medication errors is unclear.
- *Prevalence and patterns:* Although the CDC conducts extensive prevalence studies in hospital-acquired infections, the prevalence of infection in the outpatient setting is not well known. Further, whereas infection incidence is reported in the cancer literature, data seldom are aggregated to understand a more complete picture of the true “risk” for the population of patients with cancer.
- *Assessment/measurement:* The CDC advocates for infection control standards and standardized infection reports. Some authors have attempted to standardize culture techniques in patients with cancer, but these initiatives are largely restricted to blood culture. The optimal schedules for assessing patients for infection or the frequency of obtaining cultures are not known.
- *Mechanisms/etiology:* Surveillance activities to ascertain the source of infection are advocated strongly by the CDC. What is less clear is how the receipt of surveillance data changes clinical practice and ultimately, patient outcomes.
- *Correlates:* Systematic reviews have yet to incorporate emerging concepts of risk assessment for infection in patients with cancer; this area should be a high priority target for future reviews. Further, the impact of advanced cancer stage on infection prevention activities has been understudied.
- *Management/nursing interventions:* Little is known about how specific nursing activities alter the risk of infection in patients with cancer. For example, understanding whether systematic nursing assessments performed at regular intervals or nurse-led patient teaching would be useful in identifying early stage and precursors to infection.

- *Diverse populations:* None of the literature reviewed addressed cultural or ethnic diversity of the patient sample. Expert reviews of this summary suggested that an important area for further research is the differences in patient needs based on geographic location. Infection control in older adults has less specificity in cancer. Although reviews and studies often take special exception to the neutropenia of hematopoietic stem cell populations, less attention is paid to specific tumor types or patients receiving specific modalities.
- *NSPOs within the context of health management for individuals:* Functional ability is defined as the actual or potential capacity to perform the activities and tasks normally expected of individuals; it is individuals' performance of activities and tasks associated with life roles. Physical function integrates biologic, psychological, and social domains and affects how patients describe their quality of life. Patients with cancer often experience loss of functional status because of treatments such as chemotherapy, surgery, or symptoms. Symptoms such as pain and fatigue or symptom severity add to the loss of function for some patients. Functional status may change during patients' cancer experiences—diagnosis and treatment across the cancer trajectory. Nurses' goal is to consider how they can help patients maintain quality of life by sustaining maximum physical function.

Research has demonstrated a reduction in physical function as a result of cancer itself, surgery, and chemotherapy. Chirikos, Russel-Jacobs, and Jacobson (2002) found that statistically significant differences existed between an age- and work-matched group of 105 women with and 105 without cancer. Women with breast cancer were more likely than controls to be functionally impaired at five years. Impaired women, in turn, were more likely to reduce work effort and to experience downturns in market earnings. Baker, Haffer, and Denniston (2003) explored a Health Care Financing Administration data set of 167,097 respondents, of whom 22,747 had cancer. Patients with cancer were significantly different on physical function and role functioning. Patients receiving cancer treatment had lower functioning than those not receiving treatment, and patients with lung cancer receiving treatment had the lowest levels of function. Functioning also was lower for patients with cancer than those with no cancer. Patients had poorer quality of life and physical function with advanced lung cancer and poorer functioning with increasing fatigue.

Functional status decline threatens patients diagnosed with cancer, especially older adults. Regular exercise was found to be associated with higher levels of physical findings among older cancer survivors. Kurtz, Kurtz, Stommel, Given, and Given (2001) and Kurtz et al. (1999) identified in a group of older adults with cancer that higher levels of symptom severity and physical functioning deficits predicted higher levels of depression symptomatology, which adds to the cancer morbidity. Given, Given, Azzouz, and Stommel (2001) found that compared to national norms, patients with more intensive cancer treatment reported greater difficulty in functioning. Pain, fatigue, and insomnia had a significant effect on losses in function unrelated to patients' treatment or comorbid conditions. This was supported by other work by this team (Given, Given, Azzouz, Stommel, & Kozachik, 2000; Kurtz, Kurtz, Given, & Given, 1993).

Hewitt, Rowland, and Yancik (2003) compared 4,878 cancer survivors and those without a history of cancer (N = 90,737) examine general health, limitations in activities of daily living, physical function, and health-related ability to work. Cancer survivors were significantly more likely than others to report being in fair or poor health (29.8% versus

10.5%), to have three or more other chronic medical conditions (3.2% versus 0.9%), one or more limitations of activities of daily living (ADL) or instrumental ADL (IADL) (11.3% versus 3.2%), one or more functional limitations (58.1% versus 28.5%), and, among those younger than 65, to be unable to work because of their health status (16.8% versus 5.0%).

Significantly higher levels of self-reported poor health status and functional disability were observed in each of the three age groups assessed (18–44, 45–64, and 65 and older). One-third (33.9%) of the individuals with a history of cancer reporting ADL or IADL or certain functional limitations mentioned cancer as a cause of their limitations. Cancer survivors, as compared to those without cancer or other chronic illness, were significantly more likely to report being in fair or poor health (OR = 2.97 and 10.03, respectively, for those with only cancer and those with cancer in addition to other chronic illness), to have disabling psychological problems (OR = 2.18 and 5.91, respectively), one or more limitations in ADL or IADL (OR = 2.22 and 6.20, respectively), and one or more functional limitation (OR = 1.74 and 5.06, respectively). Those aged 65 and younger were unable to work because of their health (OR 3.22 and 11.80, respectively).

Men with cancers other than skin or prostate cancer were more likely to report inability to work because of their physical health status. Higher educational attainment generally was associated with better health and lower levels of functional disability.

An increased number of comorbid conditions consistently were associated with poorer health and higher levels of functional disability. When a cancer history is coupled with the occurrence of another chronic illness, the likelihood of poor health and disability is approximately 5–10 times higher than would be expected. The excess morbidity may reflect persistence of late effects of cancer and its treatment and the consequences of underlying risk factors for cancer.

The use of physical and occupational therapy was significantly greater among cancer survivors than among those without a history of cancer (12.8% versus 6.7%). Use of these services was even greater among cancer survivors reporting functional limitations (18.2%). Among cancer survivors unable to work because of their health, 19.5% had received Supplemental Security Income disability benefits from the Social Security Administration. A medical history of cancer at least doubles an individual's likelihood of poor health and disability. Disability among cancer survivors appears to be most pronounced in the area of physical functioning. Nearly one in six (16.8%) working-age cancer survivors reported an inability to work, and another 7.4% were limited in their ability to work. Clinicians should consider the appropriateness of rehabilitative services, and overall concern for functional status of patients with cancer should be raised.

Fatigue is a common, persistent, and subjective sense of tiredness, related to cancer or treatment for cancer, that interferes with usual functioning. Fatigue is one of the most prevalent and distressing cancer symptoms and is a common side effect of many of the treatments available for the management of malignant disease. Little is known about the cause and mechanisms of fatigue, and research into methods of alleviating the condition has focused on treatment for anemia and behavioral interventions, such as exercise, both of which are effective in reducing fatigue. Although research into the condition has increased considerably in the past decade, important gaps in knowledge remain (Ahlberg, Ekman, Gaston-Johansson, & Mock, 2003).

In women with breast cancer receiving adjuvant therapy, the intensity of fatigue seems to be stable throughout the treatment cycles, despite the common perception that more chemotherapy treatments lead to greater fatigue. The first two days after a chemotherapy treatment seem to be the worst period. The influence of factors such as pain, impaired quality of sleep, and depression are highly consistent across several studies, although it often is not clear whether the symptoms cause the fatigue or vice versa (De Jong, Courtens, Abu-Saad, & Schouten, 2002).

The physiologic basis of fatigue remains poorly understood, and many proposed interventions have not been studied systematically (Stasi, Abriani, Beccaglia, Terzoli, & Amadori, 2003). Two tested interventions show consistent positive effects: treatment of chemotherapy-induced anemia and aerobic exercise (Nail, 2002). One multisite study indicated that energy conservation has a modest but significant effect (Barsevick et al., 2004). Other frequently suggested interventions, such as adequate nutrition, psychostimulants, antidepressants, and increased sleep and rest, either have not been tested or studies under way are not yet completed. Current practice guidelines are based on a combination of research and expert clinical judgment.

A recent summary (Beck, Erickson, & Shun, 2004) of current evidence indicated that

- Aerobic exercise has been shown to reduce fatigue in adult patients receiving a variety of treatments. The most consistent evidence is in women with breast cancer receiving chemotherapy. Limited evidence exists in patients undergoing autologous stem cell transplantation and those receiving interferon. Information is limited about the effectiveness and acceptability of an exercise program designed for patients who already have high levels of fatigue.
- Recombinant human epoetin alpha has been shown to increase hemoglobin level, decrease transfusion requirements, and improve self-reported energy and activity in adult patients with anemia secondary to myelosuppressive cancer chemotherapy for nonmyeloid malignancies.
- Initial but limited evidence indicates that a nurse-delivered energy conservation and activity management program can produce a modest decrease in fatigue in patients undergoing cancer treatment.
- Initial but limited evidence indicates that structured education and support interventions may reduce fatigue.
- Evidence is inadequate to support the use of megestrol acetate, prednisone, amifostine, and methylphenidate.
- Evidence regarding treatment of fatigue for children and adolescents, older adults, individuals with cognitive impairment, and individuals from different racial and ethnic groups is insufficient.

Future research recommendations

Infection

- Are comprehensive nursing assessments of risk of infection effective for the actual prevention of infection in patients with cancer? Early detection?
- What specific nursing activities are helpful to mediate the severity and duration of infection once abnormal assessment findings are found?
- Development of systematic measures for infections and their prevention for patients with cancer across the care continuum is vital. (Consider the major cancers, age, comorbidity,

and stages of disease and treatments.) What are early signs of infection, and, once detected, what actions influence outcomes?

- What is the optimal frequency for measurement of this outcome across the cancer care continuum? Across the treatment phase?
- What is the effectiveness of nurse-led patient educational interventions with patients and families surrounding the prevention of infection in patients with cancer? (early detection, severity of episode)
- How should nursing activities be altered or tailored: based on age, comorbidity, cultural or geographic differences?
- Multicenter, experimental, or quasi-experimental designed studies are necessary to consider the interventions that possess theoretical support but lack empirical support.
- Compare the characteristics and factors that describe those who do and those who do not develop infections during a cancer treatment episode.
- Develop descriptive studies of nursing interventions over and above pharmacologic strategies to affect symptom control (value added).
- Examine associated and subsequent symptoms, function, mental health, and resource utilization of various infection scenarios based on nursing.

Chemotherapy and biotherapy safety

- Basic descriptive and correlational studies are needed to begin to define the problem of safety related to chemotherapy and biotherapy medication errors.
- What effect does a standardized approach to chemotherapy and biotherapy orders have on incidents related to medication errors?
- What effect does a computerized order entry and verification have in preventing medication errors?
- What effect does attending and successfully completing the ONS Chemotherapy and Biotherapy course have on the incidence of medication errors related to chemotherapy and biotherapy?
- What effect does attending and successfully completing the ONS Chemotherapy and Biotherapy course have on the type of chemotherapy and biotherapy medication errors that occur?
- What effect does a standardized clinical practicum (after successfully passing the ONS Chemotherapy and Biotherapy course) have on the type and incidence of chemotherapy and biotherapy medication errors?
- Do comprehensive cancer centers and certified community cancer centers have fewer chemotherapy and biotherapy medication errors compared to other institutions?
- Measurement of “core processes” related to chemotherapy and biotherapy administration to determine whether variation can exist in carrying them out, such as percentage of chemotherapy orders that do not comply with standardized prescribing guidelines (e.g., mg/m² dose included with calculated dose, single daily doses, not course dose, protocol provided to the RN regarding “nonstandardized” orders).
- Measurement of structures within organizations to assess the culture, values, and leadership regarding safety within an organization.
- Measurement of adverse drug events in settings that administer chemotherapy and biotherapy.
- In institutions where incident reporting is now anonymous, has this practice increased the number of reported incidents regarding chemotherapy and biotherapy?

Usual function

- Clarify the concept of functional status and create a definition of function for NSPOs.
- Distinguish physical function from other dimensions of quality of life, symptom management, and self-care.
- Explore mechanisms of physical function and patient expectations.
- Define an outcome within the scope of nursing practice that at the same time avoids placing limits on what patients with cancer can achieve for functional status.
- Studies are needed to describe impact and the pattern over time for major cancers and in various phases of the cancer care trajectory and with various cancer treatments.
- Tools to measure functional status should be identified. How do measurements vary by stage, phase of treatment, and diagnosis? Core measures should be selected.
- Evaluate the types of nursing interventions that influence outcomes in targeting function in patients with cancer.
- Function is an important area in the quality of life of patients with cancer and needs to be examined from the perspective of nurse intervention impact.
- Research has identified that function is related to symptom management, but few studies describe the pattern of functional status during the cancer trajectory with variation of symptom control.
- No meta-analyses or integrative reviews of cancer nursing interventions to promote physical function were identified.
- No single studies of cancer nursing interventions designed to influence the functional status of patients with cancer were identified.

Fatigue

- Develop instruments and interventions to meet the needs of diverse populations.
- Research is needed on the definition, occurrence, assessment, and treatment of fatigue through adequately funded prospective studies.
- Consider patient characteristics such as age, ethnicity, geographical distance from providers, and coexisting conditions in studies of fatigue.
- Improve basic descriptive epidemiology of fatigue. Conduct prospective studies with sufficient sample sizes to provide more accurate estimates of incidence and prevalence of fatigue.
- Conduct studies comparing the experience of patients with cancer to that of healthy normal subjects.
- Develop conceptual models to direct systematic research.
- Explore whether symptoms differ quantitatively and qualitatively between cancer and noncancer populations.
- Develop mechanisms-based classifications of fatigue.
- Reach consensus on a definition and use consistent measures that are reliable and valid.
- Evaluate accommodation to symptoms and response shift over time. Include measures of the impact of fatigue on daily functioning.
- Develop and test new treatments to address fatigue, including the mechanisms by which such treatments are effective. Repeat interventional studies to increase the evidence in varying samples of patients.
- Investigate the relationship between fatigue management and adherence to cancer treatment.
- Conduct longitudinal studies that include measures prior to surgery.
- Conduct research with adequate sample sizes.

Infection

- Initiate leadership in ONS in selecting assessment measures for monitoring and determination of those at risk for infection.
- Develop indicators of infection for nurses.
- Work with ONS and NINR, Agency for Healthcare Research and Quality (AHRQ), ACS, and NCI on targeting and promoting this priority area as nursing intervention, not merely give colony-stimulating factors.
- Develop a database on nature of problems.
- ONS Foundation should fund multi-site studies to examine what nursing actions make a difference on duration, severity, and resolution of infection.

Chemotherapy and biotherapy safety

- A central location for medication reporting is the USP Medication Errors Reporting Program (800-23-ERROR) that members of ONS could use in collecting data.
- ONS has a computerized list of all individuals who have successfully completed the ONS Chemotherapy and Biotherapy course.
- All Joint Commission on Accreditation of Healthcare Organizations accredited institutions must maintain data regarding medication safety and incident reporting.
- Establish funding for multicenter, descriptive, and correlational studies to look at the issues related to chemotherapy and biotherapy safety.
- Develop a research partnership with the USP Medication Errors Reporting Program.

Fatigue

- Clinical research scholar in fatigue
- ONS multi-site outcomes study related to fatigue in advanced practice nurse outpatient practices
- Small grants mechanism to pilot test innovative approaches
- Establish a symptom management cooperative group.

Physical function

- Develop a research practice partnership to explore and define to better reflect the contributions that nurses can make to physical function of patients with cancer.
- Work with NCI, ACS, AHRQ, and NINR to target and promote funding physical functioning as a priority for patients with cancer.
- ONS should take leadership to encourage clinical and practice settings to consider physical function as central to nursing care.
- Launch an educational campaign for practicing nurses on physical function.
- Develop multisite centralized database summarizing effect of treatment on functional status.
- Link with national cooperative clinical trial groups to examine patterns of functional status by cancer site and treatment regimen.

Resources needed

- ONS funding for descriptive studies as explained previously for each issue
- Continue ONS Steering Council work of collaborative group to come up with set of interventions, risk assessments, tools, and measures.

6. Translational research to develop, test and evaluate strategies designed to determine which system- and clinician-related factors affect the clinical application of already created evidence-based guidelines; in situations where it is possible, to determine whether patient outcomes are improved as a result of the clinical use of the guidelines.

Priority topics

6.1 Identify barriers and facilitators in the clinical practice setting for translational research.

6.2 Create and implement methods to translate the research into the practice setting.

6.3 Compare implementation methods in a variety of practice settings.

Definition

Translational research is the implementation and evaluation of research and/or other forms of evidence-based practice change in clinical settings designed to improve care outcomes, care quality, effectiveness, efficacy, or overall care costs. Also of relevance is the sustainability of the evidence-based practice change. Sustained evidence-based practice means that more individuals with cancer are likely to receive highest quality and best possible care outcomes (Bartelink et al., 2000; Forrest, Simpson, & Clancy, 1997; Lerman, 1997).

Rationale and background: Since the mid 1980s, ONS has supported the development of new knowledge for oncology nursing practice. We have witnessed that the investment of dollars spent on research endeavors has increased the number of completed studies and the number of publications in scientific journals. By necessity, more attention has been given primarily to the generation of new knowledge than to the translation and use of the new knowledge. The lag time between the generation of new knowledge and the translation of that knowledge into evidence-based practice guidelines must be kept to a minimum. Findings of the most rigorous and well-conducted study will have insufficient impact unless used to advance patient care.

New methodologies to successfully translate clinical findings into practice are needed. Coalition building will be essential to ensure the acceptance of changes in practice. Training programs will need to be a component of translating findings into practice. Processes to include the decision makers in the practice setting in the translational process also will be essential. Consumers of oncology health care will need to be well informed of the new knowledge and the importance of the new knowledge to care quality and care outcomes.

This ONS priority of translational research extends past ONS research priority areas by providing a mechanism to move the credible research findings from those priority areas directly into clinical practice. The careful translation of those findings into practice will improve patient care and care outcomes. Clinical practice guidelines of certain well-studied symptoms now are available, such as fatigue, nausea and vomiting, pain, chronic insomnia, and fever and neutropenia (NCCN, 2004a, 2004b; National Guideline Clearinghouse, 2005). Evidence-based summaries for measuring oncology nursing-sensitive patient outcomes on pain, dyspnea, fatigue, mucositis, nausea and vomiting, sleep-wake disturbances, peripheral neuropathy, nutritional status, return to usual functioning, prevention of infection, and depression are available on the ONS website (<http://onsopcontent.ons.org/toolkits/evidence/Clinical/summaries.shtml>). These may become the first target topics for translational research in oncology nursing. Different types of methods and designs will be necessary to translate evidence-based practice guidelines into clinical care settings because different care settings and the strength of the guidelines themselves will require such diverse approaches. ONS Foundation has supported research that has contributed to these well-studied areas through the PRISM and FIRE[®] initiatives. These

successful projects involved a two-phase process, with several one-year pilot or development grants awarded during the development phase, followed by a large, multisite study in the research phase. Because of this success, ONS has identified the current priority areas related to symptom management in understudied areas: hormonal imbalances, sleep disturbances and insomnia, and peripheral neuropathy. At the same time, ONS recommended that continued work be supported for pain, fatigue, dyspnea, cognitive impairment, anorexia, and neutropenia. This priority builds nicely on the evidence currently available to oncology nursing care and interfaces with the symptom management research priority. Therefore, we recommend that symptom management be the first focus area for this translational research priority.

Future research directions

Although translational research processes include the identification and weighing of all available evidence, we do not recommend that this be a part of the ONS Research Translation priority. Instead, we recommend that a two-phase process, similar to that used in the past ONS research initiatives, be used for translation research efforts.

Phase 1: Develop multiple awards made for developing and assessing methods for implementing evidence-based practice guidelines into clinical practice, including a focus on the system-related factors that influence the clinical integration efforts, especially the knowledge uptake and use of the guidelines by direct care oncology nurses.

Phase 2: Fund large, three-year grants for studies to test the translational models identified in phase 1. We recommend that these be applied to any cancer population, including palliative care approaches.

Resources and mechanisms needed

We recommend that a state-of-the-science conference be convened and include scientists from Canada, the United Kingdom, and the United States who have theoretical and empirical experiences essential to translational research. The conference would include a diverse group of approximately 30 theorists, scientists, methodologists, and clinicians who will share their experience with conceptualizing translational findings, implementing translational research, and analyzing the resulting data.

V. FUNDING MECHANISMS

The RFA mechanism is a process through which ONS and the ONS Foundation issues a request for applications to study a given problem or topic. ONS also is open to ideas about the specific topic, and the responding individuals or groups will initiate their own research questions and methodology. Thus, “researcher-initiated proposal” development in the identified priority area is the preferred method. In addition, the major research grants should consider the areas of science in the following list. The driving force for funding will be based on scientific criteria and, through this approach, a range of models, including human and animal, will be considered. We expect that the majority of funding will support investigator-initiated research in the priority areas, areas of science, and populations. Content areas of science and priority populations should be appropriately integrated in the calls for applications for each priority area.

ONS’s strategies and priorities for funding (small and major grants) should be the stepping stone for ONS researchers to use as pilot work in preliminary and exploratory scientific inquiry. Clinicians should be involved in dissemination, translation, and application to care and work in partnership with the researchers for the development and translation of research. Various mechanisms are

needed for funding studies ranging from basic research to clinical intervention studies. We encourage ONS to fund research studies and projects using this full set of mechanisms when funds are available. The following types of funding mechanisms are proposed to advance the development of new knowledge and to facilitate the development of new researchers and research partnerships.

A. Partnership funding mechanisms

Funding Type	Funding Amount	Funding Period
Clinician-researcher project	\$15,000–\$20,000	One year
APN-researcher partnership	\$50,000	Two years
Dissertation	\$15,000	One year
Postdoctoral training grant	\$20,000, including \$2,000 designated for the sponsor	One year
Senior-junior research award	Maximum of \$100,000	One to two years

All proposals submitted in this category must include the role and support of the clinician and researcher, mentor and fellow, or faculty and student.

1. Clinician-researcher project (\$15,000–\$20,000)

Applicant must be a beginning researcher who will work with a senior researcher in conducting a research project. The senior researcher will receive \$2,000 for support.

2. APN-researcher partnership (\$50,000)

A partnership between the APN and researchers will apply for funds for APN release time (20% salary, up to \$13,000 per year), researcher honoraria (\$10,000), travel for partnership meetings (\$4,000), and project funds (\$10,000). A clinical research proposal will be developed and completed by this partnership within the two-year funding period.

3. Dissertation (\$15,000)

Applicant must be at dissertation stage (eligible to submit a proposal) in his or her doctoral program and have a letter of support from the chair of the dissertation committee (faculty). The chair must document the availability of staff, research support, and facilities to assist the applicant. The chair should be an active researcher who presents evidence of documented skill in one of the areas of the proposed research and will directly supervise the applicant’s research.

4. Postdoctoral training grant (\$20,000, including \$2,000 designated for the sponsor)

A specific application form needs to be completed for this training grant. Before submitting, the applicant must identify a sponsoring institution and individual who will serve as a sponsor to supervise the training and research experience. The sponsor should be an active investigator who presents evidence of documented skill in one of the areas of the proposed research-training program and will directly supervise the applicant’s research. The sponsor must document the availability of staff, research support, and facilities to assist the applicant. Applicants must demonstrate how this grant will support new training experiences designed to broaden their scientific background and what significance this training will have in the area of oncology nursing research.

5. **Senior/junior research award** (maximum of \$100,000 for junior researcher with a senior researcher; the senior researcher’s salary can be included up to 15%)

The purpose of this award is to support the career development of investigators who have made a commitment to focus their research on specific issues of oncology nursing practice. Applicants must identify a mentor with extensive research experience who is willing to spend up to 15% effort facilitating the research career development and clinical research project for the applicant. The application should reflect the collaborative preplanning that has taken place between the applicant and the proposed mentor. The mentor must document the level of planned involvement and the availability of resources to allow for the success of the project.

B. Individual funding mechanisms

Funding Type	Funding Amount	Funding Period
Pilot work funding	\$20,000 - \$50,000	One year
New investigator	Maximum of \$25,000	One year
Supplemental	Maximum of \$100,000 per year	Two years
Established researcher	Maximum of \$100,000 per year	Two years
Integrated reviews of research (synthesis)	\$5,000	One year
Evidence-based practice change projects	\$10,000 - \$50,000	Two years

1. **Pilot work funding** (\$20,000–\$50,000) for a one-time, one-year project
The applicant may be a new investigator, junior or senior researcher
2. **New investigator** (maximum of \$25,000) for a one-year project
The principal investigator for this award should have a completed doctorate and no previous NIH funding.
3. **Supplemental** (maximum of \$100,000 per year for up to two years)
The applicant will submit a supplemental study focused on a specific issue or topic. The supplemental study will be attached to a major currently funded project already in progress with at least one year remaining in the original funding. The originally funded project does not need to be focused on a population or issue where the supplemental study focus is feasible, valid, and with scientific merit. It must be clear how the two studies will interface and that the supplemental grant will add to the original grant, not duplicate the objectives or aims of the original grant.
4. **Established researcher** (maximum of \$100,000 per year for two years)
5. **Integrated reviews of research** (\$5,000 for one year)
The synthesis of research literature regarding a specific topic area is very time consuming (up to 200 hours). Funding to support this time with the outcomes of a publication, presentation, and/or online resource is essential. A funding amount of \$5,000 is recommended for this mechanism.

6. Evidence-based practice change projects (\$10,000 – 50,000 for two years)

Evidence-based practice change projects are an essential component of achieving the goal of preparing clinical nurses as consumers and implementers of research-based practice changes. A funding amount of \$10,000 - \$50,000 per project is recommended to provide support for clinician time, meetings, supplies, resource materials, evaluation, etc.

VI. RESOURCES NEEDED FOR ALL PRIORITY AREAS

- A.** At least \$500,000 per year is needed to fund fully across all funding mechanisms for **each** priority area. (See funding mechanisms. If these are used, new investigators and established researchers can be funded for each mechanism).
- B.** Recommendations should be made by expert panels (usually by conference call) when funding becomes available as to the focus of the call for proposals. The expert panel will review the current state of the science in the priority area, gaps in research, areas of science, populations, and specific funding mechanisms. The ONS research director will write and disseminate the calls for proposals.
- C.** Resources also will be needed to support the ongoing review, evaluation, and revision of the ONS Research Agenda every two years at the National Conference on Cancer Nursing Research and to support the Research Priorities Survey every four years.

VII. TIMELINE

Activity	Date
Acceptance of plan by ONS Foundation Board	Summer 2005
Fundraising by ONS Foundation Board for priority areas	10/05–12/07
Expert panels convened, calls for proposals, funding (as funding is received)	11/05–12/07
2008 ONS Research Priorities Survey conducted	Spring 2008
Review, evaluation, and revision of priority areas (meeting during 2/07 at research conference)	6/06–3/07
Review of revised priority areas/agenda by ONS Foundation Board	3/07
Fundraising by Board	5/07–12/08
Review, evaluation, and revision of priority areas (meeting during 2/09 at research conference; unfunded at this time)	1/09–3/09

VIII. BUDGET

- A.** \$500,000 for each priority
- B.** Project start-up costs: Solicit funds for first one or two priority areas.
- C.** Funding options
 - Pharmaceutical funds
 - Federal funding, ACS, or ONS Foundation funding
 - Contracts with funding agencies

IX. BENEFITS AND EVALUATION OF PROJECT

A. Benefits of funding through the ONS Foundation

The benefits of funding research through the ONS Foundation include

1. The process of identifying knowledge gaps and practice needs through the use of ONS expert panels facilitates the funding of relevant, cutting-edge cancer care issues.
2. Calls for proposals are disseminated to a wide variety of potential researchers.
3. Proposals are reviewed thoroughly by expert oncology nursing researchers in the area of the call.
4. Mechanisms are in place to monitor the progress of the grants.
5. The ONS structure provides several mechanisms to rapidly and efficiently disseminate the findings of funded research through education programs, online resources, publications, and the media.
6. Funding research through the ONS Foundation eliminates the perception of conflict of interest.
7. The ONS Foundation's relationship to the ONS membership provides a resource for dissemination studies that taps into the vast majority of cancer care settings across the country.

B. Expected outcomes

1. Increased knowledge base for oncology nursing practice
2. Evidence-based oncology nursing care in cancer care institutions
3. Improved quality of cancer care
4. Forge ongoing partnerships between nurse clinicians and researchers
5. ONS funds used as "seed" and "stepping-stone" grants to facilitate researchers who will obtain federal dollars for larger amounts
6. Increased number of junior cancer nurse researchers
7. Contribution to the body of nurse researchers with knowledge, expertise, and funding history to serve on NIH and NCI grant review teams

C. Monitoring of grant recipients

1. Expectations clearly communicated through Research Award Recipient Agreement
2. Annual progress reports required
3. Final reports required
4. Grant outcomes evaluated: presentations, publications, and other funding
5. Summary reports of completed funded studies on ONS Website (www.ons.org)
6. Grant Outcomes Follow-up Reports at one, three, and five years after study completion

X. IMPACT OUTCOME

A. Organization

The ONS Research Agenda will have a major impact on the organization because it will enable ONS and the ONS Foundation to approach possible donors with priority areas based on the current state of the science in oncology nursing. ONS members will benefit directly from this through the availability of research funding to support the building of a scientific base for oncology nursing practice. The people cared for by ONS members will benefit through the application of new knowledge throughout the cancer care trajectory. These goals are related directly to the mission and strategic goals of ONS.

B. Financial

The Research Agenda will enable the ONS Foundation to seek funding in priority areas needing research to improve the care of people with cancer. Thus, the financial impact can be great as new sources of funding become available.

C. Professional practice

The new knowledge produced is the basis of what is needed to transform this knowledge to clinical practice for improved patient care and outcomes. The partnership and involvement of clinicians in the research helps to ensure that the focus of the research is on key issues pertinent in practice. Knowledge gained also will transform the practice of all those involved as they gain new insights into clinical realities (for researchers) and into research realities (for clinicians).

D. Consumer

The most important outcome of the ONS Foundation funding of oncology nursing research is the improvement of cancer care. The consumer will benefit from the improved care and the resulting improved outcomes of care that are based on the new discoveries made by the nursing research funded and by the nurse researchers whose career development is enhanced by this funding.

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