The 2009–2013 Research Agenda for Oncology Nursing

The 2009–2013 Oncology Nursing Society Research Agenda Team

The Oncology Nursing Society (ONS) Foundation’s mission is to improve cancer care and the lives of people with cancer by funding oncology nursing research, scholarships, awards, and educational programs. The ONS Research Agenda has provided important direction for funding oncology nursing research since 2001. The purpose of the agenda is to identify priorities for oncology nursing research that contribute directly to the generation and application of new knowledge, thereby addressing ONS’s overall mission to promote excellence in oncology nursing and quality cancer care.

A multimethod, stakeholder-driven, consensus-building process is used to develop the agenda, which is revised every two years in response to rapid advances in oncology nursing practice and emerging research.

The ONS Research Agenda was revised in 2009 by a team of content leaders, content experts, advanced practice nurses (APNs), ONS research team members, and a consumer representative. Prior to the meeting, the individuals reviewed many documents, including the 2008 ONS Research Priorities Survey results (Doorenbos, Berger, Brohard-Holbert, Eaton, et al., 2008; Doorenbos, Berger, Brohard-Holbert, Kozachik, et al., 2008), the 2007 ONS Research Agenda (ONS, 2007), and ONS Foundation reports summarizing awards for research during recent funding cycles (ONS Foundation Research Funding, 2009). Results informed the Research Agenda Team as they synthesized the research literature and determined the state of the science, including recent advances and ongoing gaps in the evidence base for oncology nursing practice and emerging research.

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The ONS Board of Directors approved the 2009–2013 ONS Research Agenda in May 2009, and it has been made available in three formats: the complete Research Agenda (ONS 2009a), an executive summary (ONS, 2009b), and talking points (ONS, 2009c).

Three additions were made to the process of developing the ONS Research Agenda in 2009. A seventh content area (end of life [EOL]) was added, a draft agenda was posted on the ONS Web site for public comments that were examined when finalizing the document, and a plan was approved to publish an article based on the executive summary in the Oncology Nursing Forum to increase access and provide a reference for the agenda.

The 2009 ONS Research Agenda team members identified many critical themes that cross all priority topics and subtopics proposed in the revised agenda. These cross-cutting themes were grouped into three categories listed in Table 1: individual or population issues, design or methods issues, and systems issues.

The Research Agenda is used to inform ONS and the ONS Foundation during planning for their research initiatives as well as to advise external individuals and groups regarding scientific priorities. High-priority topics and subtopics are specified for each of seven content areas: health promotion, cancer symptoms and side effects, late effects of cancer treatment and long-term survivorship issues, EOL issues, psychological and family issues, nursing-sensitive patient outcomes (NSPOs), and translation science. The order in which the priorities are listed does not imply a preference for a particular area.

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Research Priorities in Oncology Nursing, 2009–2013

A. Health Promotion

Since 2003, when research in health promotion was first identified as an ONS priority topic, only one health promotion study has been conducted using ONS Foundation funding. Oncology nursing research on health promotion has primarily addressed health behaviors in cancer survivors and screening. In lieu of a cure, cancer risk reduction in healthy populations is a critical area for research. Few health behavior theories have been adequately tested (Bowen et al., 2009), and achieving effective, long-lasting lifestyle changes—such as tobacco control, physical activity, healthful eating, and weight control—is an ongoing challenge (Heath & Andrews, 2006; World Cancer Research Fund/American Institute for Cancer Research, 2009). Intriguing new research suggests that a simultaneous approach to multiple behavior changes may be superior to changing single behaviors sequentially (Hyman, Pavlik, Taylor, Goodrich, & Moye, 2007).

As a health promotion strategy, cancer screening has been shown to decrease mortality from cancer (Cokkinides, Bandi, Siegel, Ward, & Thun, 2007). However, research focused on screening for other cancers pales in comparison to breast cancer screening studies. The extensive knowledge gained from research on screening for specific cancers has been extended only minimally to research on other cancer screenings or to interventions that promote cancer screening (Meissner et al., 2004). The continued unequal burden of cancer on poor, minority, older, and other underserved populations underscores the need for more research on screening for other cancers in these populations, which often experience access and healthcare disparities (Smith, Cokkinides, & Brawley, 2009).

Summary and Recommendations

A.1 Develop or test interventions to adopt or maintain health behaviors (e.g., tobacco control, physical activity, dietary change, stress management) that reduce risk factors for or prevent cancer.

A.1.1 Test the applicability of findings from other areas (e.g., diabetes), focusing more specifically on the underserved (e.g., ethnic minorities, urban poor, rural residents, older adults, sexual minorities).

A.1.2 Develop or test early interventions for risk reduction (e.g., with youth, on attitudes and beliefs, to enhance access and referral to human papillomavirus vaccine, with those at higher risk for hereditary cancers).

A.1.3 Develop or test innovative and cost-effective interventions targeting multiple health behaviors.

A.2 Develop or test interventions to increase first-time and interval cancer screening, with an emphasis on underserved and understudied populations (e.g., ethnic minorities, urban poor, rural residents, older adults, sexual minorities) and those at higher risk for hereditary cancers.
A.2.1 Develop or test culturally sensitive interventions, including those that enhance healthcare providers’ cultural competence.

A.2.2 Apply findings from other areas with more extensive research (e.g., breast cancer screening) to increase screening for other cancers.

A.2.3 Develop or test cost-effective and accessible multicomponent and technology-based interventions.

B. Cancer Symptoms and Side Effects

Understanding the nature and management of individual and multiple symptoms related to cancer or its treatment has long been a research priority in oncology nursing. Because of the complexity of symptoms, most research has focused on understanding individual cancer symptoms—fatigue, sleep-wake disturbances, depression, pain, hot flashes, and changes in cognitive function—and interventions to manage these symptoms (Berger, Sankaranarayanan, & Watanabe-Galloway, 2007; Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005). For some symptoms, research has been sufficient to recommend incorporating specific interventions into clinical practice based on the ONS Putting Evidence Into Practice (PEP) resources and National Comprehensive Cancer Network (NCCN) supportive care guidelines (Fulcher et al., 2008; Mitchell, Beck, Hood, Moore, & Tanner, 2007; NCCN, 2009; Page & Berger, 2009).

An increased focus on multiple co-occurring symptoms (symptom clusters) in oncology populations (Barsevick, Whitmer, Nail, Beck, & Dudley, 2006) has occurred. However, clarity is lacking regarding how to operationally define a symptom cluster with regard to the number of symptoms and the nature of the relationship between or among them. In addition, more research is needed to explicate the causal mechanisms underlying particular symptom clusters (Miaskowski & Aouizerat, 2007). Future research on symptom clusters, therefore, should examine biologic pathways that could influence multiple symptoms and whether assessment and management of symptom clusters have positive effects on patient outcomes.

Summary and Recommendations

B.1 Develop an in-depth understanding of cancer-related symptoms and side effects in children and adults across cultures and ethnicities.

B.1.1 Develop scientific knowledge of individual or multiple symptoms and side effects to
• Determine causal pathways.
• Identify short- and long-term outcomes.
• Develop measures (subjective, objective).
• Develop and evaluate nursing interventions to prevent or ameliorate symptoms.

B.1.2 Develop and evaluate systems of care that integrate scientific knowledge of symptoms and side effects into oncology clinical practice.

C. Late Effects of Cancer Treatment and Long-Term Survivorship Issues

Since 2004, cancer survivorship has received tremendous emphasis and increased awareness. There are more than 12 million cancer survivors in the United States (Winer, Gralow, Diller, Karlan, & Loehrer, 2009). Cancer survivors report poorer health than the general population, lower quality of life (QOL), more health limitations, and lost productivity. Chronic comorbid conditions, such as hypertension and heart disease, are prevalent among survivors, and many have more than one comorbid condition. An Institute of Medicine (2006) report described the state of the science and identified eight domains of cancer survivorship research: descriptive and analytical (e.g., physiologic and psychological effects) intervention research (e.g., to prevent or reduce adverse physiologic or psychological effects), examination of survivorship sequelae in understudied cancer sites, follow-up care, surveillance, economic sequelae, health disparities, family and caregiver issues, and instrument development.

Since 2004, the small-grants program supported by the ONS Foundation has awarded several small grants on long-term or late effects. In addition, several ONS members are conducting survivorship research that is funded by the National Cancer Institute. Preliminary data from several studies with survivors of breast and colorectal cancer suggest that routine physical activity may decrease the risk of recurrence and improve survival. The number of survivorship programs is limited, and even in institutions where they exist, they provide care to only a select population of cancer survivors. System issues, financial considerations, and provider issues that support or impair the ability to provide high-quality survivorship care should be explored.

Summary and Recommendations

C.1 Develop or test interventions to minimize adverse outcomes related to long-term or late effects and risks associated with the development of comorbid illnesses. Long-term effects are any side effects or complications from therapy that continue beyond the end of treatment. Late effects occur months to years after treatment is completed (Aziz, 2007).

C.1.1 Conduct intervention trials to reduce risks of long-term and late effects of treatment and the risk of chronic illness.

C.1.2 Design physical activity and healthful eating interventions for survivors to improve physical, functional, and psychological outcomes,
as well as decrease recurrence and increase survival.
C.2 Explore factors associated with the delivery of quality cancer care to survivors.
C.2.1 Identify models of care to support the Institute of Medicine’s recommendations for survivorship care (e.g., treatment summaries, surveillance recommendations) and develop interventions to address system barriers in implementing them.
C.2.2 Explore effective ways to manage the growing number of survivors and the challenges of the oncology and nursing workforce shortages.

D. End-of-Life Issues

Although no exact definition of EOL exists, it is a period of time marked by disability or disease that is progressively worse until death (National Institutes of Health, 2004). Limited symptom research has been conducted with patients with cancer near the EOL, prompting the addition of this priority area to the 2009–2013 Research Agenda. Most therapy given near the EOL is palliative (focused on symptom management) rather than curative. Most studies have focused on describing the patient’s symptom experience and a few have tested an intervention for symptoms in patients with cancer near the EOL. Information about differences in cultural and ethnic groups in the United States and worldwide is largely missing from these studies, as are symptom measures that have been validated on groups with varying ethnic backgrounds. Research is needed that tests interventions for patients with cancer near the EOL and for symptom measures that have been validated on culturally diverse groups. This research is fundamental to achieving the international goal for palliative or EOL care, which is to enhance QOL for patients and family members (Ferrell et al., 2007).

Summary and Recommendations

D.1 Develop knowledge of mechanisms and management of symptoms for patients with cancer near the EOL.
D.1.1 Develop or test efficacious, feasible, cost-effective, culturally sensitive interventions for patients with cancer near the EOL.
D.1.2 Validate culturally sensitive symptom measures for assessing symptoms in patients with cancer near the EOL.

Oncology nursing research about QOL with populations near the EOL is fundamental to understanding this multidimensional, dynamic concept (Jocham, Dassen, Widdershoven, & Halfens, 2006) and to enhancing QOL for patients and family members (Ferrell et al., 2007).

Literature on QOL near the EOL has focused primarily on patients, but the QOL of caregivers and families is equally important (Cohen, 2001). A review of QOL research with populations near the EOL found limited research in this critical area (Jocham et al.), and it was concluded that continued conceptual development of QOL near the EOL was needed.

Also needed are valid and reliable QOL measures to use near the EOL that have demonstrated evidence of validity and sensitivity in this population. For example, existential issues are an important domain of QOL at the EOL (Melin-Johansson, Odling, Axelsson, & Danielson, 2008; Sherman et al., 2005) but are not often included in QOL measures (Cohen, Mount, Tomas, & Mount, 1996). Selection of the most meaningful aspects of physical function when measuring QOL at the EOL requires conceptual and empiric clarification (Jordhoy et al., 2007). QOL measures at the EOL also should be validated with different cultural and age groups (Duggleby & Raudonis, 2006). Systematic programs of research in the area of QOL near the EOL are critical to achieving the goal of high-quality EOL care.

D.2 Develop knowledge that promotes QOL for patients with cancer near the EOL and their families.
D.2.1 Conceptualize, develop, and validate specific measures of QOL for diverse groups.
D.2.2 Develop or test efficacious, feasible, cost-effective, and culturally sensitive interventions for supporting QOL in patients with cancer near the EOL and families.

E. Psychological and Family Issues

Only a few intervention studies have been conducted that included partners or other family caregivers despite documentation of the stressful effects of cancer on family caregivers (Cochrane & Lewis, 2005; Kim & Given, 2008). Intervention studies have lagged far behind descriptive research, and the quality of the intervention research that exists is limited (Cochrane & Lewis). Research is beginning to identify patients and family members at higher risk of distress or inferior outcomes. Interventions are needed that target at-risk caregivers and identify those who are burdened or depressed (Given, Sherwood, & Given, 2009). Comprehensive screening tools are needed that identify patients at high risk and family members who may be experiencing a range of psychosocial stressors that interfere with patients’ and caregivers’ abilities to manage the illness and maintain QOL. In a time of limited resources, the cost and potential cost savings associated with interventions must be examined.

Progress in genetic testing is occurring at a rapid rate and continues to raise a number of psychosocial and ethical questions because of its widespread availability (Meiser, 2005). More exploratory research is needed.
about family communication and family functioning in regard to disclosing test results, perceived conflict and regret about one’s decision to pursue genetic testing, and family genetics among minority families.

Summary and Recommendations

E.1 Design or test interventions to reduce negative outcomes (e.g., depression, burden, symptom distress) and improve positive outcomes (e.g., coping, benefits of illness, QOL) in patients with cancer and their family caregivers.
E.1.1 Evaluate patient and family models that encompass risk and protective factors and their relationship to outcomes.
E.1.2 Design or test interventions that identify patients and caregivers at higher risk of poorer outcomes and target interventions to meet their needs; these studies should address cancer-related cost and resource use issues for patients and families.

E.2 Examine the impact of having a high risk for cancer, including a family history of cancer, on individuals and families.
E.2.1 Explore family communication and family functioning in disclosing test results, conflict, and regret about pursuing genetic testing, role of significant others in decisions to pursue testing, and genetic testing in minority families.
E.2.2 Develop or test interventions using decision aids, risk communication strategies, and educational support for probands and families considering genetic testing.

F. Nursing-Sensitive Patient Outcomes

The growing number of anticancer agents delivered orally and the shift of responsibility from inpatient to outpatient settings underscore the continuing importance of treatment adherence as a patient outcome sensitive to oncology nursing intervention. Several studies and review articles have examined adherence issues in cancer care (Daley, Crank, Mutrie, Saxton, & Coleman, 2007; Fahey et al., 2008; Greer, Pirl, Park, Lynch, & Temel, 2008; Kelly & Agius, 2006; Lette & Lette, 2008; Malbasa, Kodish, & Santacroce, 2007; Miaskowski, Shockney, & Chlebowski, 2008; Valeberg et al., 2008).

Research related to adherence must address key aspects of care, including clinical trials participation, medication, diet, exercise, and self-management. Studies also are needed to examine adherence to interventions targeting a variety of nursing-sensitive outcomes, including those identified as recommended for practice or likely to be beneficial by the ONS PEP summaries.

A need exists to examine adherence in culturally and ethnically diverse populations across the care trajectory from screening through survivorship and EOL care. Models that consider variables that influence adherence (e.g., self-efficacy, health literacy, side effects, care provider relationships) must be developed and tested. These predictive models provide a basis for mechanism-targeted intervention studies that encompass individual and group interventions and exploit novel approaches, such as community-based patient navigators and emerging technologies for health education and service delivery.

Summary and Recommendations

F.1 Evaluate the effect of nursing care on promoting and maintaining treatment adherence.
F.1.1 Understand the predictors (risk model), costs, settings, side effects, educational approaches, population, health literacy, and cognitive changes associated with adherence to oral chemotherapeutic agents.
F.1.2 Evaluate the influence of various care providers and cost effectiveness regarding adherence to care issues.
F.1.3 Explicate the issues of adherence in all aspects of a plan of care, including clinical trial participation, medications such as oral chemotherapeutic agents, diet, and self-care strategies.
F.1.4 Evaluate strategies for the identification and prevention of adverse events related to treatment, such as vascular devices.
F.1.5 Develop or test interventions that support adherence to care.

F.2 Expand knowledge regarding the relationship between physical function and nursing-sensitive patient outcomes.

Functional ability has been defined as the capacity to perform normally expected activities and tasks in the fulfillment of life roles (ONS, 2004). The concept of physical function includes biologic, psychological, and social perspectives and is a key determinant in patient perceptions of health-related QOL. As combined-modality treatment regimens and an older age threshold for active treatment become more common, limitations in physical function with consequent adverse events (e.g., falls) may become more prevalent (Amemiya et al., 2007; Bylow et al., 2008; Given, Given, Sikorskii, & Hadar, 2007; Goodwin, 2007; Snyder et al., 2008). Perhaps because of the variety of factors that contribute to physical function, it has had limited empirical study during and following cancer treatment. A gap is identified in the conceptualization of physical function, and measurement of physical function in this context should be developed.
The results of randomized trials suggest that modest improvements in physical function may result from nursing interventions (Christman & Cain, 2004; Demark-Wahnefried et al., 2006; Doorenbos, Given, Given, & Verbitsky, 2006). Studies, primarily from the gerontologic literature, have explicitly linked changes in physical function with injurious falls. This is an important area for study in patients with cancer. The policy decision to deny hospital reimbursements in cases where injurious falls have occurred may provide an impetus for care provider and researcher partnerships to address this area (Neergaard, 2008). Impaired physical function also may affect other clinical outcomes, including pressure ulcers, hospital length of stay, and cost of care. The impact of these clinical and health use outcomes requires additional analysis in patients with cancer. Based on descriptive studies, interventions will need to be developed and tested.

Summary and Recommendations

F.3 Expand knowledge regarding relationships between physical function and nursing-sensitive outcomes.

F.3.1 Explicate the relationship between nursing interventions and physical functioning in patients with cancer.

F.3.2 Evaluate the relationship between physical function and falls with injury in patients with cancer.

G. Translation Science

The evidence base for cost-effective oncology nursing practice continues to expand; however, a gap exists between available evidence and current practice. If oncology nursing interventions with known efficacy and cost-effectiveness are not used by providers, consumers, and service systems, the impact of our science will be modest. Evidence-based guidelines have been developed within the ONS PEP model, and an opportunity exists to test the impact of these resources to improve clinical outcomes (Doorenbos, Berger, Brohard-Holbert, Eaton, et al., 2008).

The continuum of translational research encompasses basic science exploring mechanisms, studies of intervention efficacy and effectiveness, and research that builds new knowledge about how to achieve adoption of best practices in the community (Brekke, Ell, & Palinkas, 2007). Implementation science refers to studies designed to evaluate the effectiveness of an intervention in a population or evaluate a process of transferring to a target audience the knowledge, skill, and systems support needed to deliver an intervention. Therefore, this priority encompasses strategies such as audit and feedback, clinician reminder systems, and capacity building that promote clinician adoption of cost-effective interventions; tailoring tested interventions to ensure compatibility with a variety of service delivery models while preserving efficacy; encouraging research-practice partnerships; and the development, implementation, and evaluation of point-of-care information collection and clinical decision support (Doran et al., 2007; Dulko, 2007; Glasgow & Emmons, 2007; Rabin, Brownson, Kerner, & Glasgow, 2006; Sussman, Valente, Rohrbach, Skara, & Pentz, 2006; Titler, Everett, & Adams, 2007; van Achterberg, Schoonhoven, & Grol, 2008).

Summary and Recommendations

G.1 Develop implementation science methods and techniques to improve the capacity of clinicians to screen, assess, and deliver effective interventions and optimize oncology nursing care quality and outcomes.

G.1.1 Investigate methods to exploit technology and system redesign to link screening, assessment, interventions, and outcomes.

G.1.2 Promote research-practice partnerships to integrate efficacious, cost-effective interventions into clinical care.

Accumulating evidence supports the effectiveness of strategies to improve clinical outcomes such as pain, fatigue, mood, and sleep disturbances (Barsewick, Dudley, & Beck, 2006; Berger et al., 2009; Doorenbos et al., 2005; McCorkle et al., 2009; Northouse et al., 2007). Studies also suggest that interventions effective for one symptom (e.g., cognitive behavioral therapy, exercise) also may be effective for other co-occurring symptoms (or symptom clusters). However, research examining the simultaneous effects of symptom management interventions on these outcomes is sparse, and there have been few efforts to translate these evidence-based interventions into programs that can be adopted and delivered by staff nurses.

The development, dissemination, and testing in naturalistic settings of interventions that target multiple symptoms and that have been packaged for delivery by clinical oncology nurses would accelerate the adoption of effective interventions into clinical practice, promote greater system efficiency by simultaneously addressing multiple symptoms, and lead to improved outcomes (Proctor et al., 2009). These interventions also must be linked with screening measures that identify patients in need of intervention and with real-time clinical monitoring and outcomes evaluation. Approaches might capitalize on efforts such as the Patient-Reported Outcomes Measurement Information System (www.nih promis.org) designed to strengthen and streamline the evaluation and interpretation of symptoms, functional status, and other health outcomes (Garcia et al., 2007).
Summary and Recommendations

G.2 Identify cognitive-behavioral, psychoeducational, rehabilitative, and self-management interventions (individual and multilevel) with demonstrated effectiveness in targeted populations, and refine, manualize, and evaluate those interventions for use by clinicians to address multiple outcomes. Based on feedback from a survey of ONS members, pain, sleep, fatigue, and mood disturbance interventions should be prioritized for funding.

G.2.1 Conduct exploratory analyses and test resultant hypotheses in experimental designs to develop new knowledge that allows interventions to be effectively targeted (i.e., develop knowledge that contributes to identifying what interventions work best for whom, under what conditions or contexts, at what cost, and to achieve what outcomes).

G.2.2 Modify interventions for use by clinicians to target multiple outcomes simultaneously (e.g., symptom distress, functional status) and examine implementation, service, and client outcomes.

How to Use the Research Agenda—What It Means for You

The 2009–2013 ONS Research Agenda is a synthesis of selected oncology nursing literature in content areas identified as priorities for future oncology nursing research. The current state of the science and gaps in our evidence base are highlighted to stimulate continued knowledge generation and to promote translation of evidence into oncology nursing practice. A more complete and detailed Research Agenda is provided on the ONS Web site (ONS, 2009a). Figure 1 outlines possible ways in which the agenda can shape professional endeavors. The agenda has relevance for many different stakeholders, including researchers, clinicians, educators, students, administrators, funding agencies, professional organizations, and policymakers. It is the research team’s hope that this agenda will inspire and empower oncology nurses to become engaged in research, support quality improvement, and advocate for resources to address these priorities and improve the lives of patients with cancer.

Summary

This document can be used as a framework to achieve the following strategic objectives of ONS and the ONS Foundation.

- Increase the knowledge base for oncology nursing practice through identifying leading-edge or critical priority areas of oncology nursing research.
- Develop future oncology nurse researchers who will be prepared to implement ongoing programs of research and to seek support from major sponsors.
- Prepare clinical nurses as critical consumers of research findings that can be applied to practice.

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