



**ONCOLOGY NURSING SOCIETY
2009–2013 RESEARCH AGENDA**

Prepared and Submitted by

Ann M. Berger, PhD, APRN, AOCN[®], FAAN
ONS Research Agenda Team Leader

Meeting Content Leaders

Andrea Barsevick, PhD, RN, AOCN[®], FAAN
Ann M. Berger, PhD, APRN, AOCN[®], FAAN
Barbara Cochrane, PhD, RN, FAAN
Wendy D. Duggleby, PhD, RN, AOCN[®]
M. Tish Knobf, PhD, RN, AOCN[®], FAAN
Laurel L. Northouse, PhD, RN, FAAN
Geri LoBiondo-Wood, PhD, RN, FAAN

Meeting Content Experts

Debra L. Barton, RN, PhD, AOCN[®], FAAN
Patricia H. Berry, PhD, APRN, BC-PCM
Christopher R. Friese, PhD, RN, AOCN[®]
Maria Katapodi, PhD, RN
Deborah K. Mayer, PhD, RN, AOCN[®], FAAN
Usha Menon, PhD, RN
Sandra A. Mitchell, PhD, CRNP, AOCN[®]

Advanced Practice Nurses

Margaret Rosenzweig, PhD, FNP-BC, AOCNP[®] (NP SIG Coordinator)
Catherine Jansen, PhD, RN, OCN[®] (CNS SIG Representative)

Consumer Representative

Beverly Turner

ONS Research Team Members

Gail Mallory, PhD, RN, NEA-BC
Jennifer Brown

I. EXECUTIVE SUMMARY

A. Project background

The purpose of the Oncology Nursing Society (ONS) Research Agenda is to provide guidance for research initiatives to meet ONS's mission to promote excellence in oncology nursing and quality cancer care. The 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 Foundation Endowment provided support for the ONS 2009–2013 Research Agenda meeting. The ONS Research Agenda process has been a multi-method, stakeholder-driven, consensus-building effort since its initial development in 2001. The agenda has been revised every two years in response to rapid advances in oncology practice.

The 2011 meeting content leaders, content experts, and advanced practice nurses (APNs) carefully reviewed many documents in preparing the 2011 update. This document is not intended to set priorities for ONS for any other initiatives, such as education or policy. Our goal is that the research agenda can inform research initiatives of ONS and the ONS Foundation. High-priority topics are specified for each of the seven content areas, which are ordered in a logical fashion with no preference for any particular area.

B. How to use this document

This document can be used to inform ONS' and the ONS Foundation's planning for their research initiatives as well as external individuals and groups regarding scientific priorities. This document can be used as a framework to achieve the missions of ONS and the ONS Foundation:

- (1) To increase the knowledge base for oncology nursing practice through identifying leading edge/critical priority areas of oncology nursing research
- (2) To develop future oncology nurse researchers who will be prepared to implement ongoing programs of research and to seek support from major sponsors
- (3) To prepare clinical nurses as critical consumers of research findings that can be applied to practice

C. Cross-cutting themes

As you read this research agenda, you will note themes that apply to more than one content area. The themes identified by content leaders and experts fall into three broad categories and include:

(1) Individual/Population Issues

- **Cultural** sensitivity or cultural competence
- **Health disparities** (race or ethnicity, gender, income, education, sexual orientation, culture, geography, access, health literacy, medically underserved)
- **Lifespan orientation:** special needs at phases
- **Family as the care recipient**
- **Global health issues**

- **Ethics**
- **Personalized medicine**
- (2) Design/Methods Issues**
 - **Models** outside oncology nursing
 - **Mechanisms** (biological, psychological, behavioral, socio-cultural) underlying responses to cancer and treatment
 - **Longitudinal, multi-site or multi-level designs** (when appropriate to the question)
 - **Intervention work** that builds on adequate descriptive work
 - **Targeted interventions** for specific groups/populations (what works, for whom, and in what context, and for which outcomes)
 - **Behavioral change** as an overarching theme underlying several intervention approaches
 - **Informatics** or technologic innovations
 - **Outcomes evaluation** using a multi-dimensional approach: *implementation outcomes* (feasibility, fidelity, penetration, sustainability, uptake and costs), *service outcomes* (efficiency, effectiveness, patient-centeredness), and *client outcomes* (satisfaction, function, symptoms)
 - **Measurement science strengthening**
- (3) System Issues**
 - **Interdisciplinary teams**
 - **Mentored** grants to optimize capacity building simultaneously with knowledge generation
 - **Partnerships and team building** with other professional organizations (e.g., American Society of Clinical Oncology, Association of Pediatric Oncology Nurses)
 - **Partnerships among researchers, clinicians, and regulators**
 - **Workforce issues** of medical oncologists and oncology-certified APN or Nurse Practitioners
 - **Cost** and cost-effectiveness measures embedded
 - **Partnerships** joining researchers and service organizations to promote implementation
 - **Health policy** implications of projects
 - **Healthcare reform**

D. Relationship to ONS Strategic Plan: The 2009–2013 ONS Research Agenda, revised in 2011, represents the core work of ONS, “establishing priorities for oncology nursing research,” and contributes directly to the knowledge strategy, “generation and application of research.” The ONS Research Agenda provides important and timely direction for the research, evidence-based practice, and quality components of the ONS mission to promote excellence in oncology nursing and quality cancer care.

II. CONTENT AREAS AND PRIORITY TOPICS FOR RESEARCH 2009–2013

A. *Health Promotion*

A.1. Develop or test interventions to adopt or maintain health behaviors (e.g., tobacco control, physical activity, dietary change, weight management, 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 papilloma virus vaccine, with those at higher risk for hereditary cancers, to prevent tobacco use or overweight/obesity).

A.1.3. Develop or test innovative and cost-effective interventions targeting multiple health behaviors that can address key risk factors (e.g., overweight/obesity) and mechanisms of effects (e.g., biomarkers).

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 **responsive** interventions, including those that enhance healthcare providers' cultural competence.

A.2.1. Apply findings from other areas with more extensive research (e.g., breast cancer screening) to increase screening for other cancers.

A.2.2. Develop or test cost-effective and accessible multi-component and/or technology-based interventions.

A.2.3. Conduct comparative effectiveness trials to apply evidence-based intervention strategies in cancer screening to clinical and community practice settings.

B. *Cancer Symptoms and Side Effects*

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

B.1.1. Determine causal pathways, including physiological and psychological mechanisms and genetic susceptibility.

B.1.2. Identify short- and long-term outcomes that are sensitive to symptom intervention.

B.1.3. Establish norms, cut-off scores, and minimally important clinical differences for symptom measures and harmonize different scales through co-calibration.

B.1.4. Develop and evaluate symptom interventions with a clear understanding of active components.

B.2. Develop and evaluate systems of care that integrate scientific knowledge of symptoms and side effects into oncology clinical practice.

B.2.1. Develop and evaluate symptom screening and assessment methods with the potential to improve care in the clinical setting.

B.2.2. Adapt symptom interventions with proven effectiveness and evaluate their feasibility in the clinical setting and effect on patient outcomes.

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

***Definitions:** 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, N. (2007). Late effects of cancer treatment. In P.A. Ganz (Ed.), *Cancer survivorship*. New York, NY: Springer.

C.1. Develop or test and implement interventions to prevent or minimize adverse outcomes related to long term* or late effects* and risks associated with the development of comorbid illnesses.

C1.1. Conduct intervention trials to reduce long-term risks from cancer therapy with special attention to high-risk populations, specifically childhood cancer survivors and adults at risk for cardiovascular toxicity and bone loss.

C 1.2. Design healthy lifestyle behavior interventions to maintain a healthy weight; improve physical, functional, and psychological outcomes; minimize risk of recurrence; and prolong survival.

C 1.3. Conduct interventions that address social and work reintegration issues during and after cancer therapy.

C 1.4. Evaluate outcomes of survivorship intervention research on healthcare use.

C.2. Explore factors associated with the delivery of quality cancer care to survivors.

C.2.1. Develop and test the effects and efficiency of models of care to support the Institute of Medicine's (IOM's) recommendation for survivorship care (e.g., treatment summaries, surveillance and health promotion recommendations). Inherent in this effort is attention to unique needs of specific cancer populations.

C.2.2. Explore approaches that address system barriers to implementation of IOM recommendations.

C.2.3. Participate in health informatics initiatives to enhance cancer survivorship care delivery.

C.2.4. Explore effective ways to care for the growing number of survivors, with attention placed on older adult survivors and minority populations.

C.2.5. Explore challenges facing oncology and the oncology nursing workforce related to survivorship.

D. End-of-Life (EOL) 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). *National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care*. Retrieved from <http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm>)

D.1. Develop knowledge of mechanisms and management of symptoms for patients with cancer near EOL and their families.

D.1.1. Develop or evaluate efficacious, feasible, cost-effective, culturally sensitive interventions for patients with cancer near EOL and their families.

D.1.2. Validate culturally sensitive symptom measures for assessing symptoms for patients with cancer near EOL and their families.

D.2. Develop knowledge that promotes quality of life (QOL) for patients with cancer near EOL and their families.

D.2.1. Conceptualize, develop, and validate specific measures of QOL for diverse groups.

D.2.2. Develop and/or evaluate efficacious, feasible, cost-effective, culturally sensitive interventions and systems of care for supporting QOL in patients with cancer near EOL and their families.

D.2.3. Develop and/or evaluate interventions for implementation early in the cancer trajectory to promote anticipation, discussion, and/or preparation for EOL issues with patients with cancer and their families to enhance QOL near EOL.

E. Psychosocial and Family Issues

E.1. Well-designed intervention studies to reduce negative outcomes and improve positive outcomes in patients with cancer and their family caregivers

E.1.1. Research to test patient and family models that encompass both risk factors and protective factors and their relationship to outcomes

E.1.2. Intervention studies that identify patients and caregivers at higher risk of poorer outcomes and target interventions to meet their needs. These studies need to address cancer-related cost and resource use issues for patients and families.

E.2. Research focused on the impact of high risk for cancer, including a family history of cancer, on individuals and families

E.2.1. Exploratory research in areas pertaining to 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. Testing of interventions using decision aids, risk communication strategies, and educational support for probands and their families

F. Nursing-Sensitive Patient Outcomes (NSPOs)

F.1. Evaluate the effect of nursing care on promoting and maintaining treatment adherence.

F.1.1. Understand 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 strategies for various innovative models of care (e.g., APN-led teams, patient-centered medical home, chronic care models) and the cost effectiveness related to adherence of 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 relationships between physical function and NSPO.

F.2.1. Explicate the relationship between nursing interventions and physical functioning for patients with cancer.

F.2.2. Evaluate the relationship between physical function and falls with injury for patients with cancer.

G. *Translation Science*

G.1. Identify and test implementation science methods and techniques designed 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.

G.2. Identify cognitive-behavioral, psychoeducational, rehabilitative, and self-management interventions (individual and multi-level) 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, interventions that address pain, sleep, fatigue, and mood disturbances 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 (that is, develop knowledge that contributes to identifying what interventions work best for whom and under which conditions/contexts, at what costs, and to achieve which outcomes).

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