



ONCOLOGY NURSING SOCIETY 2009–2013 RESEARCH AGENDA

Prepared and Submitted by

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I. EXECUTIVE SUMMARY

A. Project background

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 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 ONS Research Agenda's purpose is to provide guidance for research initiatives to meet ONS's mission to promote excellence in oncology nursing and quality cancer care. The agenda has been revised every two years in response to rapid advances in oncology practice.

The 2009 meeting content leaders, content experts, and advanced practice nurses (APNs) carefully reviewed many documents, including the 2008 ONS Research Priorities Survey results, to revise the 2007 ONS Research Agenda. Three additions were made in 2009: a) a seventh content area was added (end of life); b) the draft agenda was posted on the ONS website for public comments for two weeks; and c) the Executive Summary will be adapted and published in the *Oncology Nursing Forum* in late 2009. 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 other works 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**

(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)

(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, etc.)
- **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

D. Relationship to ONS Strategic Plan: The 2009-2013 ONS Research Agenda 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 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, 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 multi-component and/or technology-based interventions

B. *Cancer Symptoms and Side Effects*

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 and 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*

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 has been completed.

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

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

C.1.2 Design physical activity and healthy eating interventions for survivors to improve physical, functional, and psychological outcomes, recurrence, and 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 recommendation 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 (EOL) Issues*

Although there is no exact definition of EOL, it is a period of time marked by disability or disease that is progressively worse until death. The National Institutes of Health issued a state-of-the-science conference statement on improving EOL care. This priority area was added in 2009 due to limited research to date in this increasingly important area.

D1. Develop knowledge of mechanisms and management of symptoms for patients with cancer near EOL

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

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

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 or test efficacious, feasible, cost-effective, culturally sensitive interventions for supporting QOL in patients with cancer near EOL and their families

E. Psychosocial and Family Issues

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 factors 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 need to address cancer-related cost and resource utilization issues for patients and families

E.2. Examine the impact of 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 (persons who chose to be tested) and families considering genetic testing

F. Nursing-Sensitive Patient Outcomes (NSPOs)

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 relationships between physical function and nursing-sensitive patient outcomes

- F.2.1. Explicate the relationship between nursing interventions and physical functioning in patients with cancer
- F.2.2. Evaluate the relationship between physical function and falls with injury in patients with cancer

G. *Translation Science*

G.1. Develop 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 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, 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 (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 and functional status) and examine implementation, service, and client outcomes