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The 2014–2018 Oncology Nursing Society Research Agenda

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The Oncology Nursing Society (ONS) developed its first Research Agenda in 2001 and has updated the agenda every four years. The dual purpose of the ONS Research Agenda is to determine priority topics for research consistent with the ONS mission to promote excellence in oncology nursing and quality cancer care and to provide the ONS Foundation with the data needed to support the decision-making process for funding oncology nursing research. ONS identified content leaders and experts from the membership for the 2014–2018 Research Agenda Project Team. This team used a multimethod consensus-building approach that was informed by the results of the 2013 ONS Research Priorities Survey (LoBiondo-Wood et al., 2014), a comprehensive literature review, and a review of the national priorities for cancer and nursing research (see Figure 1). Since 2001, the ONS research priorities have reflected the disciplinary perspective of nursing and the mission of ONS. Management of physical and psychological symptoms, health promotion, patient and caregiver issues, end-of-life care, survivorship, and healthcare delivery systems have consistently shaped the Research Agenda. Dynamic progress in understanding the biology of cancer and identification of targets for therapeutic interventions have resulted in the widespread concept of personalized medicine to treat cancer. An understanding of both inter-patient variability and biologic mechanisms are equally important to interpretation of patient responses and to the development and testing of interventions. The increasing national emphasis on evidence-based practice and patient-centered care, as

Purpose/Objectives: To identify priority areas of research for the Oncology Nursing Society (ONS) Research Agenda for 2014–2018, consistent with ONS's mission to promote excellence in oncology nursing and quality cancer care.

Data Sources: Review of the literature, 2013 ONS Research Priorities Survey, National Institute of Nursing Research, and the National Cancer Institute research foci.

Data Synthesis: Multimethod consensus-building approach by content leaders and content experts of the ONS Research Agenda Project Team.

Conclusions: The 2014–2018 Research Agenda Project Team identified eight high-priority research areas: symptoms, late effects of cancer treatment and survivorship care, palliative and end-of-life care, self-management, aging, family and caregivers, improving healthcare systems, and risk reduction. In addition, four cross-cutting themes were identified: biomarkers, bioinformatics, comparative effectiveness research, and dissemination and implementation science.

Implications for Nursing: The Research Agenda is a synthesis of the state of the science in cancer and identifies gaps and directions for the conduct and dissemination of research. Oncology nurses can use the agenda to inform clinical practice, develop research proposals, inform policy makers, support interdisciplinary research efforts, and promote scientist and clinician collaborations in targeted patient-centered research.

Key Words: oncology; nursing; research

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identified by Institute of Medicine reports related to cancer care and the Patient-Centered Outcomes Research Institute, further support the research areas and cross-cutting themes. The 2014–2018 Research Agenda

Project Team identified eight high-priority research areas: symptoms, late effects of cancer treatment and survivorship care, palliative and end-of-life care, self-management, aging, family and caregivers, improving the healthcare systems, and risk reduction, as well as four cross-cutting themes: biomarkers, bioinformatics, comparative effectiveness research, and dissemination and implementation science.

The data supporting these research areas were summarized in the form of a draft agenda and posted on the ONS website in the fall of 2014 for public comment. Comments from the members were reviewed by the content leaders and content experts of the Research Agenda Project Team and revised for a final Research Agenda draft that was forwarded to the ONS Board of Directors. The Research Agenda was approved by the ONS Board of Directors in October 2014 and is available on the ONS website as a complete report (ONS, 2015a), and an Executive Summary (ONS, 2015b). The purpose of this article is to disseminate the findings from the Executive Summary to inform the ONS membership and the larger interdisciplinary oncology community.

The Oncology Nursing Society's 2014–2018 Research Priority Areas

A. Symptoms

- Evaluate interventions that integrate symptom management into systems of care and their efficacy on outcomes of care, which includes symptom control, quality of life, and costs of care.
- Examine the underlying biobehavioral mechanisms for individual and co-occurring symptoms and test mechanistic hypotheses within the context of intervention research.
- Determine factors associated with racial or ethnic disparities in symptom severity and develop and evaluate interventions that address these disparities.

1. Fatigue

- Explore motivational factors and barriers to increase the uptake of interventions.
- Disseminate exercise interventions in community settings.
- Gain a better understanding of the underlying biologic mechanisms associated with fatigue.
- Examine whether combining nonpharmacologic and pharmacologic approaches enhances the effects of individual treatments.

2. Pain

- Implement systems-level interventions that promote uptake of evidence-based pain management.
- Understand factors associated with racial disparities and the undertreatment of pain and evaluate interventions that address disparities.

3. Sleep disturbances

- Focus on other homogeneous groups of patients other than women with breast cancer (e.g., men, older adults).
- Determine optimal dose, frequency, and duration of interventions.
- Compare various treatments to determine the most effective approaches to decrease sleep disturbances.

4. Symptom clusters

- Develop a taxonomy of symptom clusters that can guide future intervention studies.
- Understand the underlying biobehavioral mechanisms associated with symptom clusters.
- Include more racially diverse samples of patients to test interventions.

5. Cancer- and cancer treatment-related cognitive impairment

- Identify sensitive and clinically useful cognitive assessment measures.

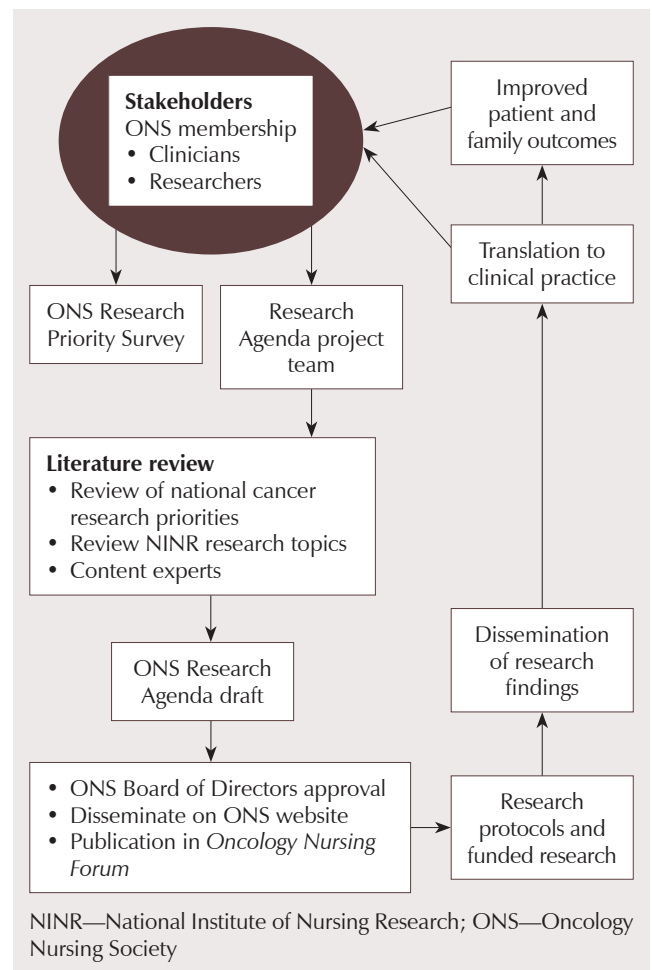


Figure 1. The ONS Research Agenda

Note. From *Oncology Nursing Society Research Agenda 2003–2005*, by D.L. Berry (Ed.), 2003, Pittsburgh, PA: Oncology Nursing Society. Copyright 2003 by the Oncology Nursing Society. Adapted with permission.

- Identify risk factors (e.g., demographic, treatment, genetic factors) of post-treatment cognitive decline because only a subset of patients experience long-term cognitive changes.
 - Develop longitudinal studies that examine cognitive changes in context to age-related decline to thoroughly understand their implications.
 - Develop translational evidence-based interventions to address cognitive performance and enhance coping with cognitive changes.
6. Chemotherapy-induced peripheral neuropathy (CIPN)
- Identify well-validated, reliable, and clinically useful assessment measures of CIPN, including physiological markers.
 - Identify risk factors for patients with severe and/or irreversible CIPN symptoms.
 - Develop evidence-based pharmacologic and non-pharmacologic treatment options.
7. Psychological distress
- Identify predictors of distress for cancer survivors and their families.
 - Develop translational research to foster successful implementation of distress screening in clinical practice.
 - Develop large-scale, well-designed trials establishing evidence of the effect of nonpharmacologic interventions and psychosocial support that are feasible to deliver and cost effective.

B. Late Effects of Cancer Treatment and Survivorship Care

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.
 - 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.
 - Design healthy lifestyle behavior interventions to maintain a healthy weight; improve physical, functional, and psychological outcomes; decrease recurrence; and improve survival.
 - Conduct interventions that address social and work reintegration issues during and after therapy.
 - Evaluate outcomes of survivorship intervention research on healthcare use.
2. Explore factors associated with the delivery of quality cancer care to survivors.
 - Develop and test the effects and efficiency of models of care to support the Institute of Medicine's recommendations for survivorship care (e.g., treatment summaries, surveillance, health promo-

tion recommendations). Inherent in this effort is attention to unique needs of specific populations.

- Explore approaches that address system barriers to implementation of IOM recommendations.
- Participate in health informatics initiatives to enhance cancer survivorship care delivery.
- Explore effective ways to care for the growing number of survivors, with attention to older survivors and minority populations.
- Explore challenges facing oncology care and the oncology nursing workforce related to survivorship.

C. Palliative and End-of-Life Care

1. Research to enhance communication and shared decision making
 - Explore models for training providers to effectively communicate with patients in palliative care and end-of-life phases of care.
 - Evaluate team-based approach models of communication on patient and family outcomes.
 - Explore and test interventions to improve shared decision making in palliative care and end-of-life phases of care.
 - Explore preferences for decision making and care in the palliative and end-of-life phases of care among the growing and diverse U.S. population.
2. Focus on palliative care for children.
 - Evaluate symptom management intersections for children at end of life.
 - Examine effects of advanced care planning on pediatric patients with cancer and family outcomes.
 - Explore models of palliative and end-of-life care from hospital to community for pediatric patients with cancer and their families.
3. Explore and test models of palliative care delivery, including but not limited to the interdisciplinary team, cost-benefit of services, timeliness of referrals, continuity of care and care coordination, and use of technology.
4. Explore the use of electronic health records to identify unmet palliative care needs.
5. Research how to best support and evaluate professional education and development models for improving palliative and end-of-life care.

D. Self-Management

1. Develop and test measures of self-management outcomes across the cancer care continuum.
 - Develop and test new and established self-management measures for multiple populations, including various minority groups, ethnicities, and those with coexisting comorbidities.
 - Develop and test new and established measures to access self-management outcomes across the cancer care continuum.

2. Develop and test models of care in self-management across the cancer care continuum.
 - Identify the needs of patients and family caregivers regarding self-management during periods of transition from treatment to survivorship.
 - Develop and test new and established models of care in self-management for multiple populations, including various minority groups, ethnicities, and those with coexisting comorbidities.
 - Develop and test models of care to improve coordinated care across disciplines or specialties to improve self-management at all phases of the cancer care continuum.
 3. Develop and test self-management interventions directed at the individual and/or the family caregivers that address health-related outcomes across the cancer care continuum.
 - Develop strategies that promote self-management in children, adults, and family caregivers across cultures and ethnicities.
 - Conduct intervention studies to improve patient engagement in self-management activities.
 - Develop and test interventions to improve care coordination and address the changing self-management needs of individuals with cancer and their family caregivers over time.
 - Develop and test self-management interventions to assist patients in managing their cancer and other preexisting chronic conditions.
 4. Develop and test interventions to improve adherence with prescribed and/or recommended plans of care.
 - Develop and test strategies for improving adherence with prescribed treatment regimens.
 - Develop and test strategies for improving adherence with self-management recommendations prescribed in cancer care plans across the care continuum.
- Test interventions that promote engaged treatment decision making based on risks assessed through a comprehensive geriatric assessment (CGA). Determine which components of the CGA predict treatment outcomes (e.g., functional status, health-related quality of life).
 - Determine how to adapt symptom management interventions, to decrease risk and enhance protective factors, and to promote positive outcomes in older adult patients.
 - Test interventions for palliative, supportive, and end-of-life care for older adults who are unable to tolerate active curative treatment.
 - Test interventions to improve outcomes in family caregivers with chronic medical conditions who are caring for an older adult with cancer.
 - Test interventions to improve patient-clinician communication and self-management for the patient.
 - Identify those older adult patients with cancer at higher risk of poorer outcomes, and target interventions to maintain or improve outcomes.
3. Evaluate factors associated with the delivery of cancer care.
 - Evaluate how multiple comorbidities (e.g., diabetes, obesity, heart failure, arthritis) affect the symptom burden and treatment responses of older adults with cancer.
 - Evaluate factors that influence the delivery of quality and safety of care, as well as healthcare use among older adults with cancer.
 - Evaluate the efficacy of using technology to improve outcomes in older adults undergoing cancer treatment.
 - Investigate patient outcomes (at levels of frailty and function) beyond progression and survival (e.g., impact of disease and treatment on health-related quality of life, function, cognition, independence).

E. Aging

1. Carry out descriptive work to obtain information needed to fill the knowledge gap.
 - Describe how lifestyle factors, such as nutrition, exercise, smoking, and alcohol intake, affect the symptom burden and treatment responses of older adult patients.
 - Explore the impact of age, cancer, and biased decisions related to stigma on older adult patient outcomes.
 - Evaluate the relationship between predictive factors (e.g., performance status, age, physical and psychological comorbidities, polypharmacy) of chemotherapy toxicity and symptom burden across geriatric age groups from the youngest old to the oldest old.
2. Develop, test, and implement interventions to improve the care of older adult patients.

F. Family and Caregivers

1. Identify the impact of caregiver outcomes on patient outcomes.
 - Conduct studies that examine the influence of the caregiver on the quality of patient care delivered.
 - Conduct studies that determine the extent to which caregiver distress influences patient and system resource use, such as symptom severity, emergency department visits, patient distress, and adherence to treatment.
 - Conduct intervention trials focused on the dyad or family to improve patient outcomes across the care continuum.
2. Determine the impact of the stress of providing care on the caregiver's physiologic health.

- Conduct studies that examine cellular response to providing care to identify key biomarkers for future work.
 - Examine longitudinal cohort studies to determine whether changes at the cellular level translate into meaningful changes in caregivers' comorbid conditions.
 - Conduct intervention trials focused on psychosocial and physiological strategies to improve overall health.
3. Explore, define, and determine the extent of economic burden and its impact on families of patients with cancer.
 - Explore the impact of economic burden on caregiver and patient outcomes, including quality-of-life outcomes as well as outcomes related to the use of supportive medication and adherence to treatment regimens.
 - Describe ways in which caregivers and families of patients with cancer make short- and long-term lifestyle changes to afford cancer care.
 - Implement interventions that provide strategies to ameliorate employment and economic burden.

G. Improving Healthcare Systems

1. Expand the knowledge of patient-centered cancer nursing care.
 - Evaluate best practices for oncology nurse-led care coordination.
 - Examine interventions for improving nurse-patient communication and their effect on patient outcomes.
 - Design and test cost-efficient patient care models for improving patient outcomes across the cancer care continuum.
2. Evaluate the effect of nursing care on promoting and maintaining treatment quality and safety.
 - Understand predictors (risk models), cost settings, side effects, educational approaches, population health literacy, and cognitive changes associated with adherence to self-care.
 - Evaluate the influence of various care providers and cost effectiveness on quality and safety.
 - Evaluate strategies for the identification and prevention of adverse events related to quality and safety.
 - Develop and test interventions that support delivery of quality care indicators.

H. Risk Reduction

1. Develop and/or test interventions to sustain cancer screening behavior beyond completion of one-time screening.
 - Develop and/or test interventions to increase first-time and interval cancer screening for underserved and understudied populations (e.g., ethnic

minorities, urban poor, rural residents, older adults, sexual minorities).

- Develop or test culturally responsive interventions, including those that enhance healthcare providers' cultural competence.
 - Apply findings from other areas with more extensive research (e.g., breast cancer screening) to increase screening for other cancers.
 - Conduct comparative effectiveness trials to apply evidence-based intervention strategies in cancer screening to clinical and community practice settings.
2. Develop and/or test innovative and cost-effective interventions to change multiple health behaviors in a population that can reduce or prevent cancer (e.g., obesity, tobacco cessation).
 - Develop and test interventions to adopt or maintain health behaviors that prevent or reduce the risk for cancer (e.g., reductions in tobacco use and alcohol abuse, dietary change, physical activity, weight management, reductions in exposure to ultraviolet light).
 - Develop and/or test innovative and cost-effective interventions for health behavior change.
 - Develop and/or test culturally appropriate health behavior interventions for minority and underserved groups.
 3. Develop and/or test dissemination and implementation of evidence-based interventions in screening.
 - Adapt and test efficacious interventions for implementation in clinic or community settings.
 - Implement and evaluate dissemination and implementation models for translating evidence-based interventions to practice.
 - Develop and test academic-practice partnerships to accelerate dissemination and implementation models.
 - Collaborate with healthcare systems and practices to test models of dissemination and implementation of efficacious interventions to enhance sustainability.

I. Cross-Cutting Themes

Four innovative cross-cutting themes were identified: bioinformatics, biomarkers, comparative effectiveness research, and dissemination and implementation science.

1. Bioinformatics
 - Use large data sets to explain patient outcomes and increase understanding of the complexity of disease, treatment, and patient responses.
 - Create predictive models.
2. Biomarkers
 - Identify underlying mechanisms for a particular condition or symptom.
 - Identify patients at high risk for poorer outcomes.

- Develop interventions that are tailored to address inter-individual variability.
 - Test interventions to improve patient outcomes.
3. Comparative effectiveness research
- Compare benefits and harms of a specific treatment or intervention.
 - Evaluate applicability of evidence generated through randomized, controlled trials to practice.
 - Investigate effects of treatments on morbidity, quality of life, and survival outcomes.
4. Dissemination and implementation science
- Studies of strategies (e.g., audit and feedback, clinician reminders or alerts, decision support, practice facilitation) that promote the adoption of cost-effective interventions
 - Studies that examine the extent to which research-tested interventions (e.g., exercise for fatigue, cognitive-behavioral therapy for sleep, cancer screening) can be tailored to a wide variety of service delivery models while, at the same time, maintaining efficacy
 - Evaluate research-practice partnerships that increase the likelihood that cost-effective interventions can be embedded within care delivery processes.
 - Studies to enhance the usability, acceptability, and integration into workflow of informatics and other technologies that support the delivery of patient-centered, guideline-concordant care
 - Test system-wide efforts to routinely achieve evidence-based care, including the development, implementation, and evaluation of point-of-care information collection using patient-reported outcomes and sensor devices, as well as point-of-care testing coupled with clinical decision support.

Conclusion

The Research Agenda is a synthesis of the state of the science in cancer and identifies gaps and directions for the conduct and dissemination of research. Oncology nurses can use the agenda to inform clinical practice, develop research proposals, inform policy makers, support interdisciplinary research efforts, and promote scientist and clinician collaborations in targeted patient-centered research.

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