ONCOLOGY NURSING SOCIETY
2014–2018 RESEARCH AGENDA

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I. EXECUTIVE SUMMARY

A. Project background
The Oncology Nursing Society (ONS) Research Agenda’s purpose is to provide guidance for research initiatives to meet the ONS 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. Since its initial development in 2001, the ONS Research Agenda process has been a multi-method, stakeholder-driven, consensus-building effort. The development of the 2014-2018 ONS Research Agenda was supported by the ONS Foundation.

The ONS Research Agenda provides important and timely direction for research and evidence-based practice. The Research Agenda Team identified eight priority content areas (symptoms, survivorship, palliative and end-of-life care, self-management, aging, family and caregivers, improving health systems, and risk reduction) and four cross-cutting themes (bioinformatics, biomarkers, comparative effectiveness research, and dissemination and implementation science).

II. CONTENT AREAS AND PRIORITY TOPICS

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 bio-behavioral 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 undertreatment of pain, and evaluate interventions that address disparities.

3. Sleep Disturbances
• Focus on homogenous 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 bio-behavioral 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.
• Identify risk factors (e.g., demographic, treatment, genetic factors) of post-treatment cognitive decline as only a subset of patients have long-term cognitive changes.
• Develop longitudinal studies that examine cognitive changes in context to age-related decline to thoroughly understand the 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, including physiologic markers.
• Identify risk factors for patients with severe and/or irreversible CIPN symptoms.
• Develop evidence-based pharmacologic and nonpharmacologic treatment options.

7. Psychological Distress
• Identify predictors of distress for cancer survivors and their families.
• Translate research to foster successful implementation of distress screening in clinical practice.
• Conduct large-scale, well-designed trials, establishing evidence of the effect of nonpharmacologic interventions and psychosocial support that are feasible to deliver as well as 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 cancer therapy.
   • Evaluate outcomes of survivorship intervention research on healthcare utilization.

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 (IOM's) recommendation for survivorship care (e.g., treatment summaries, surveillance and health promotion recommendations). Inherent in this effort is attention to the unique needs of specific cancer 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 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 increasingly diverse U.S. population.

2. Focus on palliative care for children, including
   - Evaluate symptom management intersections for children at end of life.
   - Examine the effects of advanced care planning on outcomes for pediatric patients with cancer and their families.
   - Explore models of palliative and end-of-life care from hospital to community for pediatric patients with cancer and their families.

3. Diversity in palliative or end-of-life care
   - Explore issues such as advanced care planning and barriers in access to palliative or end-of-life care in diverse populations.
   - Explore models of care delivery to facilitate access in diverse communities.

4. Explore and test models of palliative care delivery, including but not limited to the interdisciplinary team, development of criteria for referrals, cost and benefit of services, timeliness of referrals to hospice, strategies to facilitate early and appropriate referrals, continuity of care or care coordination, and use of technology.

5. Explore the use of electronic health records to identify unmet palliative care needs.

6. 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 assess 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 caregiver(s) 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 cancer care continuum.

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 use of alcohol intake affect the symptom burden and treatment responses of older patients.
   • Explore the impact of age, cancer, and stigmas related to biased decisions on the outcomes of older patients.
   • Evaluate the relationship between predictive factors (e.g., performance status, age, physical and psychological comorbidities, poly-pharmacy) 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 patients.
   • 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, decrease risk and enhance protective factors, and promote positive outcomes in older 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 older patients with cancer at higher risk for poorer outcomes and target interventions to maintain or improve those outcomes.

3. Evaluate factors associated with the delivery of 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 utilization among older adults with cancer.
- Evaluate the efficacy of using technology to improve outcomes in older adults undergoing cancer treatment.
- Investigate patient outcomes (at all 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).

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 room visits, patient distress, and adherence to treatment.
- Conduct intervention trials focused on the dyad or family to improve patient outcomes across the care trajectory.

2. Determine the impact of stress on caregivers’ physiologic health related to providing care.

- Conduct studies that examine the 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 physiologic strategies to improve overall health.

3. Explore 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 such as 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 the 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 that can reduce or prevent cancer in a population (e.g., obesity and 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.
   - Develop and/or test interventions to change multiple health behaviors that can reduce or prevent cancer in a population (e.g., obesity and tobacco cessation).

3. Develop and/or test dissemination and implementation of evidence-based interventions in cancer 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.

III. 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 higher 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 clinical trials to practice.
• Investigate effects of treatments on morbidity, quality of life, and survival outcomes.

4. Dissemination and Implementation Science
• Conduct studies of strategies (e.g., audit and feedback, clinician reminders or alerts, decision support, practice facilitation) that promote the adoption of cost-effective interventions.
• Conduct 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 maintaining efficacy.
• Evaluate research-practice partnerships that increase the likelihood that cost-effective interventions can be embedded within care delivery processes.
• Conduct 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 and point-of-care testing, coupled with clinical decision support.