

Research Agenda of the Oncology Nursing Society: 2019–2022

The Oncology Nursing Society (ONS) is committed to promoting excellence in oncology nursing and quality cancer care. In keeping with this mission, since 2001, ONS has prepared and disseminated a national Research Agenda. The ONS Research Agenda serves to identify gaps in the knowledge base needed to deliver quality cancer nursing care to patients and families, articulate priorities for research, and delineate critical areas for funding consideration by funding agencies. A multimethod, iterative, consensus-building process that consisted of expert opinion, literature review, surveys, focus groups, town halls, and review of research priorities from other professional organizations and funding agencies was used to identify contemporary research priorities and to update the Research Agenda.

Overview of Topics

Three overarching priority areas were identified where new scientific knowledge is needed: (a) symptom science, (b) health disparities, and (c) palliative and psychosocial care in oncology. Four cross-cutting themes to provide context for these priorities emerged: aging, survivorship, healthcare delivery implications, and advanced research methods. A description of each of these areas is presented in this executive summary.

Symptom Science

Two areas of importance for future research emerged as priority topics related to symptom science: evolving use of immunotherapies (IO), which include immune checkpoint inhibitors (ICPI) and chimeric antigen receptor (CAR) T-cell therapies, and precision health/biosignatures.

Symptom science related to evolving IO treatments: (a) Develop, test, and refine reliable, valid, and

sensitive patient-reported outcome tools to capture treatment experiences in patients receiving IO, and link those measures to clinical decision support and treatment pathways to improve clinical outcomes; (b) characterize variability in presentation, trajectory, and management of immune-related adverse events (irAEs) across various patient populations; (c) examine factors (age, gender, diet, weight, exercise, stress, and sleep patterns) that may influence patient responses to ICPI therapy and irAE development; and (d) conduct randomized trials to test the efficacy of supportive care interventions to alleviate irAEs.

Symptom science related to precision health and biosignatures: (a) Harmonize assessment measures and strengthen the use of common data elements; (b) identify the optimal approaches to characterize patients' and survivors' symptom profiles and their associated genotypes and phenotypes; (c) comparatively evaluate approaches to examine the mechanisms underlying variation in patients' and survivors' symptom experiences; (d) determine optimal methodologic approaches to predict patients and survivors at greatest risk for symptom burden; (e) establish the biosignatures (i.e., phenotypic and molecular characteristics) of common individual symptoms and symptom clusters in patients and survivors; and (f) develop and test interventions to manage single symptoms and symptom clusters.

Health Disparities

The National Institutes of Health has designated health disparity populations in the United States as Blacks/African Americans, Hispanics/Latinos, American Indians/Alaska Natives, Asian Americans, and Native Hawaiians and other Pacific Islanders; socioeconomically disadvantaged populations, including underserved rural populations; and sexual and gender minorities.

Relevant research directions to advance equity:

(a) Develop and test interventions to increase minority and vulnerable population participation in cancer clinical trials; (b) examine the effects on cancer outcomes of social determinants of health (i.e.,

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physical, social, and economic factors); (c) develop and test interventions to address health disparities related to behavioral factors such as obesity, physical inactivity, diet, tobacco use, and immunizations that can prevent malignancies associated with human papillomavirus and hepatitis B; (d) evaluate interventions to address financial toxicity associated with cancer treatment; and (e) examine the role of technology, including telehealth strategies, to improve access to care, particularly among rural populations.

Palliative and Psychosocial Care in Oncology

The National Consensus Project of Quality Palliative Care developed guidelines for quality care, which were endorsed by 80 organizations, including ONS. Palliative care has been integral to oncology care because cancer is recognized as an illness with significant burden for patients and family caregivers.

Relevant research directions to further enhance quality care: (a) Develop and test interventions for culturally sensitive palliative and psychosocial oncology care; (b) examine the effects of telehealth on improving patient and caregiver symptoms and health outcomes; (c) determine the most effective interventions to improve patient and caregiver health-related quality of life (HRQOL), satisfaction with care, and use of healthcare resources; (d) determine the effects of early or integrated palliative care intervention on patient and family caregiver outcomes (e.g., symptoms, HRQOL, psychological health, rehospitalizations); and (e) understand the impact of single or multiple symptoms on function, disease outcomes, HRQOL, and treatment decision making in seriously ill older adults with cancer, particularly those with multiple comorbidities.

Cross-Cutting Themes

Aging: From 2010 to 2030, cancer incidence is expected to rise 67% in those aged 65 years or older, compared to a rise in incidence of only 11% for those younger than age 65 years. The National Cancer Institute (2019) estimates that, by 2040, 73% of cancer survivors in the United States will be aged 65 years or older. In addition, older adults typically have other medical conditions that need to be considered when choosing cancer treatment. Research is needed to identify the most effective models for delivering services to older adults with cancer, and to test, tailor, and target supportive care and rehabilitative interventions that can preserve and enhance HRQOL and function.

Survivorship: The number of cancer survivors is projected to increase from 16.9 million in 2019 to 21.7

million by 2029, and survivors are living longer. In addition, many survivors, even among those who are cancer-free, must cope with the late and long-term effects of treatment, as well as psychosocial concerns such as fear of recurrence and being at high risk for developing other malignancies.

Healthcare delivery system implications: Innovative models of care delivery and reimbursement are needed to deliver high-quality, cost-effective care, and to position nurses as leaders in transforming cancer care.

Advanced research methods: Biobehavioral science, population science, and data science are advancing at a rapid rate, and developments in these offer oncology nurse scientists new tools, technologies, and methods related to research design, measurement, and data analysis. At the same time, the receipt of research funding from federal and other sources is highly competitive. For oncology nurse scientists to be successful, innovative advanced research methods that have the potential to offer robust new insights and speed the translation of science into real-world settings need to be incorporated into research training programs and grant applications.

Conclusion

The ONS Research Agenda (Von Ah et al., 2019) synthesizes the state of the science in key areas in cancer care, identifies gaps, and proposes directions for continued future research to address contemporary challenges in oncology nursing and to drive improvements in health outcomes, care quality, and access for patients across the cancer control continuum. The ONS Research Agenda identifies three priority areas where new knowledge is urgently needed: symptom science, health disparities, and palliative and psychosocial care in oncology. Considerations to enhance the significance, rigor, and relevance of oncology nursing science include a focus on priority populations (older adults and cancer survivors), innovative care delivery models, and advanced research methods and data analytics. This focused set of priorities serves to concentrate the professional efforts of scientists and clinicians and to direct resources for scientific training, career development, and research funding opportunities.

The ONS Research Agenda can be used to align initiatives and resources across the ONS enterprise, to guide specification of research questions and study designs to advance oncology nursing science, and to provide direction for evidence-based practice and healthcare policy to support the delivery of quality cancer care.

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