



**ONCOLOGY NURSING SOCIETY
2014–2018 RESEARCH AGENDA**

M. Tish Knobf, PhD, RN, AOCN[®], FAAN
ONS Research Agenda Team Leader

Content Leaders

Mary E. Cooley, PhD, RN, FAAN
Sonia Duffy, PhD, RN, FAAN
Ardith Doorenbos, PhD, RN, FAAN
Linda Eaton, PhD, RN, AOCN[®]
Barbara Given, PhD, RN, FAAN
Deborah Mayer, PhD, APRN, AOCN[®], FAAN
Ruth McCorkle, PhD, RN, FAAN
Christine Miaskowski, PhD, RN, FAAN
Sandra Mitchell, PhD, CRNP, AOCN[®]
Paula Sherwood, PhD, CNRN, FAAN

Content Experts

Catherine Bender, PhD, RN, FAAN
Janine Cataldo, PhD, RN
Denise Hershey, PhD, FNP
Maria Katapodi, PhD, RN
Geri LoBiondo-Wood, PhD, RN, FAAN
Usha Menon, PhD, RN, FAAN
Christine Miaskowski, PhD, RN, FAAN
Karen Schumacher, PhD, RN
Virginia Sun, PhD, RN
Diane Von Ah, PhD, RN, FAAN

ONS Research Team Members

Gail Mallory, PhD, RN, NEA-BC
Jennifer Brown
Kerri Moriarty, MLS

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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 under-treatment 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 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

- 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.

Complete 2014 – 2018 ONS Research Agenda

I. INTRODUCTION

The 2014–2018 ONS Research Agenda represents the core work of ONS, “establishing priorities for oncology nursing research,” and contributes directly to knowledge development and utilization through the “generation and application of research.” 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, self-management, risk reduction, family and caregivers, palliative and end-of-life care, improving health systems, and aging) and four cross-cutting themes (biomarkers, bioinformatics, comparative effectiveness research, and dissemination and implementation science).

II. CONTENT AREAS

A. *Symptoms*

Significance and Background

Symptoms are defined as subjective experiences that reflect changes in biopsychosocial functioning, sensations, or cognitions. Unrelieved symptoms are associated with decreased function, quality of life, and survival. Symptom research has been a priority for oncology nurses since the inception of ONS and the Research Agenda. Oncology nurses have led multidisciplinary teams that defined common metrics for patient-reported symptoms (Reeve et al., 2014). Moreover, oncology nurses have made significant strides in the development and testing of technology-based interventions that seek to integrate symptom management into systems of care (Berry et al., 2014; Cooley et al., 2014; Mooney, Beck, Friedman, Farzanfar, & Wong, 2014). Berry et al. (2014) reduced symptom distress in ambulatory patients with cancer using an electronic self-report symptom and quality-of-life assessment and self-care program. Future research needs to (a) further evaluate interventions that integrate symptom management into systems of care and their efficacy on outcomes of care such as symptom control, quality of life, healthcare utilization, and costs of care and (b) understand the differential effects of symptom management interventions (Given, Bradley, You, Sikorskii, & Given, 2010; Sikorskii et al., 2014).

Fatigue

Cancer-related fatigue (CRF) is defined as a persistent and subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activities and interferes with usual functioning. CRF is one of the top three symptoms that are the most difficult to manage and most distressing to patients in ONS research surveys since 2004.

Inflammatory processes, dysfunction of the hypothalamic-pituitary-adrenal (HPA) axis, disruption of circadian rhythms, and disturbance of the monoamine pathways that regulate serotonin, dopamine, and norepinephrine have been examined and are

implicated as mechanisms underlying CRF (Barsevick et al., 2013). A recent study by Dhruva et al. (2014) examined differences in cytokine genes among participants with morning and evening patterns of fatigue and whether participant characteristics differed between these groups. They found that different inflammatory genes were associated with high or low levels of fatigue and participant characteristics differed by group, suggesting that morning and evening fatigue may be distinct but related symptoms.

The efficacy of exercise is firmly established as a treatment for CRF (Brown et al., 2011). In a meta-analysis, Brown, Hueda-Medina, et al. (2011) found that CRF levels were reduced by a greater degree in interventions using a theory-driven approach and those with more intense resistance exercise. Psychoeducational interventions, management of concurrent symptoms, and complementary and alternative medicine (CAM) treatments are some approaches that are likely to be effective but need further confirmation (Barton et al., 2013; de Raaf et al., 2013). Additional research is needed to (a) explore motivational factors and barriers to increasing the uptake of interventions, (b) disseminate exercise interventions in community settings, (c) gain a better understanding of the underlying biologic mechanisms associated with CRF, and (d) examine whether combining nonpharmacologic and pharmacologic approaches enhance the effects of individual treatments.

Pain

Pain is defined as an unpleasant, multidimensional, sensory and emotional experience associated with actual or potential tissue damage. Cancer-related pain is the most feared and debilitating symptom associated with cancer and cancer treatment. Although 95% of pain can be effectively treated, undertreatment remains a widespread problem that has not changed over the last two decades (Fisch et al., 2012). Moreover, racial disparities in pain treatment exist (Anderson, Green, & Payne, 2009). Fisch et al. (2012) found that the inadequate prescription of analgesia was twice as high for minority patients compared to Caucasian patients.

Factors associated with undertreatment of pain are complex and involve the healthcare system, clinicians, and patients. In addition, bias, stereotyping, and prejudice contribute to pain treatment disparities. Schumacher et al. (2014a, 2014b) examined patient experiences of self-management of pain and found that complex skills are involved in the acquisition and administration of medications in the home setting, and navigating the array of healthcare providers in healthcare systems is difficult at best.

Self-care management and psychosocial interventions are important components of pharmacologic management (Koller, Miaskowski, De Geest, Opitz, & Spichiger, 2012; Sheinfeld Gorin et al., 2012). Koller et al. (2012) evaluated the content, structure, and efficacy of self-care interventions and found clinically meaningful differences in their ability to decrease pain intensity. However, no single component was found to be most efficacious. Drwecki, Moore, Ward, and Prkachin (2011) conducted laboratory experiments examining the role of empathy and perspective-taking in reducing racial disparities in pain treatment. The results suggested that an empathy-inducing, perspective-based intervention reduced racial bias by as much as 55% and improved

pain treatment for African American patients. Additional research is needed to (a) implement systems-level interventions that promote the uptake of evidence-based pain management and (b) understand factors associated with racial disparities and the undertreatment of pain and evaluate interventions that address these disparities.

Sleep Disturbance

Sleep disturbances are defined as difficulty falling or staying asleep, waking up too early, or poor sleep quality. Sleep disturbances are more common in patients with cancer compared to the general population. Insomnia is the most common sleep disorder, and the majority of research has focused on this type of disorder.

Although a surge in sleep research in patients with cancer has occurred, the underlying mechanisms for sleep disturbances are complex and poorly understood (Langford, Lee, & Miaskowski, 2012). Multiple factors are related to sleep disturbances, including co-occurring symptoms and disruptions in circadian rhythms, HPA-axis regulation, and epigenetic processes. Proinflammatory cytokines are hypothesized to be possible mediators associated with sleep-wake disturbances (Miaskowski et al., 2010).

The majority of sleep interventions used nonpharmacologic approaches and focused on women with breast cancer. CAM treatments have been studied most often (because of the diversity of interventions that fall within this category) followed by cognitive-behavioral therapy (CBT) and then exercise. CBT has been the most rigorously studied intervention, and it was found to have moderate treatment effects in a meta-analysis conducted by Langford et al. (2012). CAM and exercise were found to be efficacious. Despite the frequency of insomnia in ambulatory patients with cancer, clinicians attended to self-reports of insomnia from patients only about half of the time; however, they provided management strategies likely to be effective (Siefert, Hong, Valcarce, & Berry, 2014). Future studies need to (a) focus on other homogenous groups of patients other than women with breast cancer, (b) determine optimal dose, frequency, and duration of interventions, and (c) compare various treatments to determine the most effective approach for sleep disturbances.

Symptom Clusters

A symptom cluster is defined as a group of symptoms that occur together and are interrelated (Kim, Barsevick, Fang, & Miaskowski, 2012). Controversy exists regarding whether a minimum of two or three symptoms need to be present to be considered a cluster. Current evidence suggests that as few as two paired symptoms are related to patient outcomes, providing a rationale that those symptoms can be considered a cluster. Studies have examined the nature of symptom clusters and found evidence for a core set of symptoms that remain stable over time (Skerman, Yates, & Battistutta, 2012). The presence of a sentinel or “indicator” symptom marks the presence of a cluster (i.e., pain) (Brown, Cooley, Chernecky, & Sarna, 2011), and some symptoms seem to occur in a cascade pattern in which one symptom (i.e., insomnia) contributes to the development of other symptoms (i.e., fatigue and then depression) (Jim et al., 2013).

Extensive evidence exists for the presence of a psychoneurologic symptom cluster, which consists of fatigue, depression, sleep disturbance, pain, and cognitive impairment (Kim et al., 2012). Common biologic mechanisms underlying this cluster have been proposed, including alterations in proinflammatory cytokines, HPA axis regulation, alterations in adenosine triphosphate metabolism, glucocorticoid signaling, and monoamine neurotransmitter system dysregulation.

The understanding of statistical techniques used for the analysis of symptom clusters has advanced in the past several years (Xiao, Bruner, Jennings, & Hanlon, 2014). Interventions focused on symptom clusters have increased, especially fatigue, depression, anxiety, and insomnia in early-stage patients with cancer (Berger, Yennu, & Million, 2013). CBT, CAM, psychoeducation, and exercise interventions were found to have efficacy. Future research is needed to (a) develop a taxonomy of symptom clusters that can guide future interventions, (b) understand the underlying biobehavioral mechanisms associated with symptom clusters, and (c) include more racially diverse samples of patients to test interventions.

Cancer Treatment-Related Cognitive Impairment

Cognitive impairment is defined as cognitive changes that negatively affect higher-order mental processes. Deficits in attention, memory, speed of processing, language, and executive functioning (problem solving) appear to be the most common manifestations (Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005). Neuroimaging studies documented structural and functional alterations following cancer and chemotherapy (Holohan, Von Ah, McDonald, & Saykin, 2013). Although cognitive deficits may be subtle, they have a significant impact on quality of life in cancer survivors (Myers, 2013). The exact etiology of cognitive impairment is not fully understood. Potential pathophysiologic mechanisms include neurotoxic injury in the brain, microvascular injury, secondary central or systemic inflammatory processes, and dysregulation of the HPA axis resulting in changes in endogenous hormones (estrogen). Cancer treatment may accelerate cognitive aging by influencing aging at a cellular level, including inflammation, DNA damage, oxidative stress, telomere length, and cell senescence (Ahles, Root, & Ryan, 2012). Individual differences in age, educational level, intelligence, menopausal status, comorbid conditions, medication use, and genetics may contribute to cognitive deficits in cancer survivors (Bender & Thelen, 2013). Cognitive deficits may be compounded by other related symptoms, including fatigue, depression, anxiety, pain, and sleep disorders (Bender & Thelen, 2013).

The complexity associated with cognitive changes after cancer and cancer treatment contributes to the difficulty of assessing and effectively treating this symptom (Bender & Thelen, 2013). The International Cognition and Cancer Task Force recommended a set of neuropsychological assessments for research purposes (Wefel, Vardy, Ahles, & Schagen, 2011), and the National Institutes of Health-supported Patient Reported Outcomes Measurement and Information System (www.nihpromis.org) recommended assessing perceived cognitive concerns and cognitive abilities (Lai, Wagner, Jacobsen, & Cella, 2014) although no definitive cognitive function assessment standards exist

(Jansen, 2013). Researchers have explored pharmacologic (e.g., methylphenidate, memantine, modafinil, donepezil) and nonpharmacologic interventions (e.g., cognitive training, exercise, CBT) (Von Ah, Jansen, Allen, Schiavone, & Wulff, 2011). To date, only cognitive training is designated as likely to be effective in improving cognitive performance (Von Ah et al., 2012).

Future research should address (a) the identification of sensitive and clinically useful cognitive assessment measures, (b) the identification of risk factors (e.g., demographic, treatment, genetic) of post-treatment cognitive decline as only a subset of patients have long-term cognitive changes, (c) the development of longitudinal studies that examine cognitive changes in context to age-related decline to thoroughly understand its implications, and (d) the development of translational, evidence-based interventions to address cognitive performance and enhance coping with cognitive changes.

Chemotherapy-Induced Peripheral Neuropathy

Chemotherapy-induced peripheral neuropathy (CIPN) is a common and distressing problem for patients with cancer receiving neurotoxic chemotherapeutic agents such as taxanes, epothilones, bortezomib, thalidomide, or vinca alkaloids (Lobiondo-Wood et al., 2014; Smith et al., 2013). Although they are effective in treating cancer, these agents damage the nerve cell axon, myelin sheath, and cell body in the dorsal root ganglion (Han & Smith, 2013). However, the exact pathophysiology of the processes that result in CIPN is unknown. Diagnostic features that distinguish CIPN include symmetrical, distal, length-dependent, “glove-and-stockings” distribution; predominately sensory symptoms, including pain, numbness, and tingling; and onset following chemotherapy that may be rapid, progressive, and irreversible (Stubblefield et al., 2009). Other symptoms may include muscle weakness that can impair functioning and mobility (Miltenburg & Boogerd, 2014) and result in falls and other injuries (Toftagen, Visovsky, & Berry, 2012). For some patients, CIPN symptoms may result in chemotherapy dose reductions, treatment delays, and even discontinuation of treatment (Stubblefield et al., 2009). The frequency and severity of CIPN symptoms vary based on the treatment regimen, dose administered, cumulative dosage, and duration as well as demographic, genetic, and comorbid factors (Stubblefield et al., 2009).

Research has been limited by the lack of approved, validated assessments that include sensory and functional elements (Smith, 2013). To date, no known agents are available to prevent CIPN (Hershman et al., 2014). In terms of treatment, randomized clinical trials identified duloxetine as moderately effective in reducing pain associated with CIPN (Hershman et al., 2014; Smith et al., 2013). Treatments used for neuropathic pain in other populations such as gabapentin, tricyclic antidepressants, and a compounded topical gel of baclofen, amitriptyline HCL, and ketamine need additional research but may provide pain relief (Hershman et al., 2014).

Additional research is needed to address (a) the identification of well-validated, reliable, clinically useful assessment measures, including physiologic markers, (b) the identification of risk factors for patients with severe or irreversible CIPN symptoms, and (c) evidence-based pharmacologic and nonpharmacologic treatment options.

Psychological Distress

Psychological distress was identified as the sixth vital sign, and it affects a subgroup of survivors. In fact, researchers have found that 20%–40% of the 28.8 million cancer survivors worldwide experience psychological distress (National Comprehensive Cancer Network [NCCN], 2013). Psychological distress occurs on a continuum from normal feelings of sadness and fear to overwhelming and potentially disabling symptoms such as depression and anxiety. Practice guidelines mandate screening for psychological distress (Holland, Watson, & Dunn, 2011; Jacobsen & Wagner, 2012; NCCN, 2013). However, researchers found that screening remains limited with only 70% of member institutions in compliance (Donovan & Jacobsen, 2013). In addition, evidence is mixed as to whether screening is cost-effective and leads to improved quality of life (Jacobsen & Wagner, 2012). Most recently, a joint interdisciplinary task force included ONS-identified strategies for the successful implementation of distress screening (Pirl et al., 2014). The Patient Health Questionnaire-4 and the Distress Thermometer were identified as acceptable, reliable, and valid instruments to assess psychological distress (Donovan, Grassi, McGinty, & Jacobsen, 2014; Pirl et al., 2014).

One recent, large, epidemiologic study identified worsening health over time as a significant predictor of psychological distress (Brinkman et al., 2013); however, more research is needed to identify predictors of distress for cancer survivors and their families. Other priorities include (a) translational research to foster successful implementation of distress screening in clinical practice and (b) large-scale, well-designed trials establishing evidence of the effects of nonpharmacologic interventions and psychosocial support that are feasible to deliver and cost-effective.

B. Long-Term/Late Effects of Cancer Treatment and Survivorship Care

Definitions

Late effects are defined as health problems that occur months or years after a disease is diagnosed or after treatment has ended. Late effects may be caused by cancer or cancer treatment. They may include physical, mental, and social problems and second cancers (National Cancer Institute [NCI], n.d.a.).

Long-term effects are residual problems caused by a disease or its treatment that may continue for months or years after treatment ends. Long-term effects of cancer treatment include, but are not limited to, heart, lung, kidney, or gastrointestinal tract problems; pain, numbness, tingling, loss of feeling, or heat or cold sensitivity in the hands or feet; fatigue; hearing loss; cataracts; and dry eyes or dry mouth (NCI, n.d.b.).

Survivorship care includes survivorship care plans, information on persistent and late effects of therapy, follow-up and surveillance (i.e., recurrence of primary cancer, risk of second cancer), and access to care (NCI, n.d.c.).

Significance and Background

In 2014, approximately 14.5 million survivors with a history of cancer were living in the United States, representing 5% of the population (this number excludes in situ cancers and nonmelanoma skin cancers). This number is estimated to grow to almost 19 million survivors by 2024. Currently, 64% of survivors were diagnosed five or more years earlier and 46% are 70 years of age or older (American Cancer Society, 2014). Cancer survivors may face long-term effects and late effects, which may occur months to years after treatment is completed (Aziz, 2007; Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010; Shi et al., 2011; Wu & Harden, 2014; Zucca, Boyes, Linden, & Girgis, 2012). Comorbid illnesses contribute to the issues facing survivors (Hewitt, Rowland, & Yancik, 2003; Snyder et al., 2013; Yabroff, Lawrence, Clauser, Davis, & Brown, 2004). These comorbidities result in a poorer quality of life because of physical and emotional problems (Weaver et al., 2012).

Healthcare delivery issues addressing cancer survivorship include evaluating different models of care (e.g., who delivers the survivorship care) (Halpern et al., 2014; Hoekstra, Heins, & Korevaar, 2014; Nekhlyudov & Wenger, 2014; Oeffinger & McCabe, 2006) and aspects of that care (e.g., survivorship care plans, self-management programs) (Mayer, Birken, Check, & Chen, 2014; McCorkle et al., 2011).

Future research needs to (a) 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 late effects, (b) design healthy lifestyle behavior interventions to maintain healthy weights, minimize risk of recurrence, prolong survival, and improve physical, functional, social, and psychological outcomes, (c) conduct intervention trials that address social and work reintegration and growth during and after cancer therapy, (d) evaluate the outcomes of survivorship intervention research on economic burden and health care utilization, (e) explore factors associated with the delivery of quality cancer care to survivors, (f) develop and test the effects and efficiency of models of care to support the Institute of Medicine's (IOM's) recommendation for survivorship and psychosocial care (inherent in this effort is attention to the unique needs of specific cancer populations), (g) explore approaches that address system barriers to the implementation of IOM recommendations, (h) participate in health informatics initiatives to enhance cancer survivorship care delivery, (i) explore effective ways to care for the growing number of survivors with attention to older adult survivors and minority populations, (j) conduct intervention trials that mitigate disparities in care in survivors who are members of populations that experience these disparities, and (k) explore challenges facing oncology and the oncology nursing workforce related to delivering survivorship care.

C. Palliative and End-of-Life Care

Definition of the Topic

The World Health Organization ([WHO], 2014) definition of palliative care states that palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification, impeccable

assessment, and the treatment of pain and other physical, psychosocial, and spiritual issues. Palliative care

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help family members cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families including bereavement counseling, if indicated
- Enhances quality of life and may positively influence the course of illness
- Is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes investigations needed to better understand and manage distressing clinical complications.

Palliative care may begin early in the course of treatment and can be delivered concurrently with disease-directed therapies. It can be delivered in a number of ways across the continuum of healthcare settings (in the home, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics). Palliative care encompasses hospice and specialty care (provided by certified interdisciplinary teams) or basic (provided by noncertified professionals) palliative care. End-of-life care refers generally to the processes of addressing the medical, social, emotional, and spiritual needs of people who are nearing the end of life (Institute of Medicine [IOM], 2014). It may include a range of services, including palliative and hospice care. Palliative care is an essential part of cancer care.

Significance and Background

By 2030, 20% of the U.S. population will be older than age 65. One in four adults will develop a cancer with which they will live for years before death. These years are characterized by physical and psychological symptom distress, progressive functional dependence and frailty (Smith, Walter, Miao, Boscardin, & Covinsky, 2013), and high family caregiver support needs. Specific factors, such as the aging population in the United States, structural barriers in access to care, and a fragmented healthcare system, continue to present challenges for the provision of person-centered, family-focused palliative and end-of-life care (IOM, 2014).

Related in part to the aging population, attention to the field of palliative care has dramatically increased over the past 20 years. This increase is particularly notable in the development of palliative care clinical programs. Over a three-year period from 2001–2003, the number of hospital-based palliative care programs nationwide grew by more than 60% and the proportion of hospitals with a palliative care program grew from 15% to 25%. By 2011, this proportion increased to 85% (Morrison, Augustin, Souvanna, & Meier, 2011). Palliative care is rapidly becoming a routine part of health care, spurring the development of evidence-based research on the effectiveness of palliative care interventions (Walling, Lorenz, & Dy, 2008).

Since the IOM report, *Approaching Death: Improving Care at the End of Life*, (Field & Cassel, 2001) as well as *Improving Palliative Care for Cancer* (Foley & Gelband, 2001) many new programs, policies, and systems of care were introduced to improve the quality of palliative and end-of-life care. National clinical practice guidelines, such as those created through the National Consensus Project (Dahlin, 2013), are available to guide the implementation of quality palliative and end-of-life care.

Although palliative and end-of-life care has become increasingly mainstream, challenges remain in its provision and widespread integration.

The science of palliative care is relatively new and is evolving. Funded research in this important field has failed to keep pace with the need to expand the efficient delivery of effective, evidence-based care to patients and their families (Gelfman, Du, & Morrison, 2013). Patient care often is characterized by inadequately treated physical distress, strains on family caregiver and support systems, fragmented care systems, and poor communication among healthcare teams, patients, and families.

For recommendations on research regarding symptoms, aging families, and caregivers, please review these sections.

Communication and Decision-Making

Communication is a central component of palliative care and an area in need of research. The overall quality of communication between healthcare providers and patients with advanced illnesses is poor, particularly in topics such as prognosis and goals of care (Epstein & Street, 2007). There also is a lack of evidence-based models for training nurses to effectively communicate with patients and families in palliative and end-of-life care settings (Fletcher & Panke, 2012). A team-based approach to communication in palliative and end-of-life care may serve as a potential model because this approach is currently suggested (Epstein & Street, 2007).

Technical advancements and a lack of accurate prognostication have created additional challenges in decision-making during the cancer journey (Gwilliam et al., 2011; Krishnan et al., 2013; Zier, Sottile, Hong, Weissfeld, & White, 2012). As clinical success in saving lives increases, the risk of more-frequent use of these advancements in potentially inappropriate clinical situations simultaneously rises, leading to difficult decisions for patients, families, staff members, and healthcare systems. More research is needed regarding nursing roles and strategies to understand decision-control preferences and to support shared decision-making (Adams, Bailey, Anderson, & Docherty, 2011; Yennurajalingam et al., 2013). Often at the end of life, patients are no longer able to make decisions for themselves; therefore, additional research is needed on how to improve surrogate decision making (Wendler & Rid, 2011; White et al., 2012). Future research needs to (a) explore models for training providers to effectively communicate with patients in palliative and end-of-life phases of care, (b) evaluate the effects of team-based approach models of communication on patient and family outcomes, (c) explore and test interventions to improve shared decision-making in

palliative and end-of-life phases of care, and (d) explore preferences for decision-making and care in the palliative and end of-life-phases of care in the growing, diverse population in the United States.

Palliative Care for Children

Palliative care for children represents a special, albeit closely related, field that is separate from adult palliative care. Palliative care for children consists of active, total care of the child's body, mind, and spirit, and involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease.

Pediatric-related research needs may be especially pressing. A need exists for research in symptom management (Pritchard et al., 2010; Wolfe et al., 2000); bereavement support; studies examining the effects of advanced care planning and palliative care on outcomes and on the patient experience (Lotz, Jox, Borasio, & Führer, 2013); and studies on how best to staff, manage, and finance hospital-based pediatric palliative and community-based pediatric hospice services (Bona, Bates, & Wolfe, 2011; Doorenbos et al., 2013; Feudtner et al., 2013). Future research needs to (a) evaluate symptom management intersections for children at the end of life, (b) examine the effects of advanced care planning on pediatric patient and family outcomes, and (c) explore models of palliative and end-of-life care from the hospital to the community for pediatric patients and their families.

Diversity in Palliative and End-of-Life Care

In the next two decades, the increase in the number of older adults with minority backgrounds will substantially outpace that of non-Hispanic whites. The population of older non-Hispanic whites is expected to increase by only 59% compared to 160% for minorities (Administration on Aging, 2011). The United States is an increasingly diverse society, and culturally mediated beliefs and values can affect access to palliative and end-of-life care, advanced care planning, communication about prognosis, and pain and symptom management (Carr, 2012; Johnson, 2013; Mack, Paulk, Viswanath, & Prigerson, 2010; Waite et al., 2013). Geographic and socioeconomic factors also may impact access to care (National Institute of Nursing Research, 2013).

Understanding and reversing health disparities is an important priority, and health disparities are well-documented yet poorly understood in palliative care. Importantly, preferences for care (particularly care received at the end of life) vary by race, ethnicity, and culture, but not all of these differences represent disparities (Johnson, 2013). An important challenge in palliative care research is to develop an understanding of which differences represent the informed values and preferences of patients and their families and which represent disparities in how care is discussed or delivered. Differences based on the values and preferences of patients and their families must be supported; differences based on disparities in health or health care must be eliminated. These profound and complicated differences create an imperative in palliative care research. Research is needed to explore issues such as advanced care planning and barriers to accessing palliative and end-of-life care in diverse populations.

Palliative Care Delivery

Based on the results of recent research, a call was made to integrate palliative care into the trajectory of future cancer care (Bruera & Hui, 2010). Temel et al. (2010) randomly assigned patients diagnosed with stage IV lung cancer to either early palliative care plus standard, disease-directed therapies or standard disease-directed therapies alone. Patients in the early palliative care plus standard treatment group reported better quality of life and fewer depressive symptoms compared to patients in the standard treatment group. Patients in the early palliative care plus standard care group received less aggressive end-of-life care (defined as chemotherapy within the last 14 days of life, no hospice care, or hospice admission three days or less before death). However, they had longer survival rates compared to patients in the standard treatment group (11.6 months versus 8.9 months, $p = 0.02$). Bakitas et al. (2009) conducted a randomized, controlled trial to test the effects of a nurse-led palliative care intervention (Project ENABLE) on quality of life, symptom intensity, mood, and resource use in 322 patients with advanced cancer (gastrointestinal, lung, genitourinary, and breast). Quality of life and mood were higher in the intervention group. Based on this evidence, the American Society of Clinical Oncology issued a provisional clinical opinion stating that all seriously ill patients with cancer be given concurrent palliative and oncology care (Smith et al., 2012).

Based on the current evidence, early, integrated palliative care is a model with enormous potential; however, more research is needed to (a) identify models of care delivery to facilitate access in diverse communities and (b) explore and test models of palliative care delivery, including but not limited to interdisciplinary teams, the development of criteria for referrals, the cost-to-benefit ratio of services, timeliness of referrals to hospice, strategies to facilitate early and appropriate referrals, continuity of care and care coordination, and use of technology. In addition, more research is needed to test the effectiveness of innovative palliative care models in specific settings (Cheng, King, Alesi, & Smith, 2013; Murphy, Siebert, Owens, & Doorenbos, 2013).

Biomedical and Health Informatics

A number of key opportunities exist in palliative care research to explore informatics, a diverse field using information and informatics to improve health and health care. An example of informatics is exploring how telehealth technologies can be used to train or support clinicians in rural areas or areas poorly served by palliative care (Haozous et al., 2012). Research using technology such as videophones and web interfaces may offer opportunities to increase access to hospice and cancer care in the home for patients and their families (Carpenter, Stoner, Schmitz, McGregor, & Doorenbos, 2014; Demiris et al., 2012) and may assist in healthcare decisions (Vollandes et al., 2013). Finally, research using the electronic health records offers opportunities to identify patients with unmet palliative care needs and implement quality metrics for palliative care.

Professional Education and Development

Hospice and palliative medicine is an established medical specialty, and professional nursing organizations such as Hospice and the Palliative Nurses Association are providing certifications for nurses who specialize in palliative and end-of-life care. Although substantial improvements are realized in the education of health professionals

who provide palliative and end-of-life care, serious problems remain. This includes the lack of evidence for the transfer of knowledge to most clinicians and nurses caring for patients and families in single-profession education silos. These silos serve as barriers to knowledge and skills regarding the delivery of palliative and end-of-life care in an interdisciplinary, team-based approach. Although many palliative care-focused courses such as the End-of-Life Nursing Education Consortium have developed and established core curriculums to educate nurses in the delivery of quality palliative and end-of-life care, whether these curricula translate to improved patient care is yet to be determined (Curtis et al., 2013). Models of professional education such as interprofessional education should be tested to determine its effectiveness in improving care (Aziz, Grady, & Curtis, 2013). Models of interprofessional education also should be developed and tested to prepare students in nursing and other health professions in the delivery of team-based palliative and end-of-life care (Head et al., 2014, Youngwerth & Twaddle, 2011).

D. Self-Management

Definition

Self-management is a dynamic process in which patients monitor and manage their own chronic health conditions in collaboration with their family caregivers and healthcare providers. Self-management includes the ability to focus on illness needs (i.e., learning, taking ownership, performing health promotion activities), activating resources (i.e., health care, psychological, spiritual, social, community), and living with a chronic illness (i.e., processing emotions, adjusting, integrating illness into daily life, meaning making) (McCorkle et al., 2011; Schulman-Green et al., 2012).

Significance and Background

The importance of self-management was initially recognized as it related to diabetes and arthritis. In the 1980s, care for individuals with a chronic illness started to transition to the home, and the urgent need for interventions to support self-management was recognized (Corbin & Strauss, 1985). As cancer care shifted from the inpatient to the outpatient arena and was recognized as a chronic condition, new challenges and opportunities for self-management research in individuals with cancer were created. Cancer self-management interventions can improve health-related outcomes and quality of life across the cancer trajectory from prevention to survivorship (McCorkle et al., 2011; Salvatore, Ahn, Jiang, Lorig, & Ory, 2015; Wagner & McCorkle, 2010).

Self-management is one of the essential components of chronic disease management (Institute of Medicine [IOM], 2012). Core self-management skills include problem-solving, decision-making, resource utilization, forming partnerships with healthcare providers, and taking action as well as goal setting and building or enhancing self-efficacy (IOM, 2012; McCorkle et al., 2011). The Chronic Care Model (Wagner, 1998) identifies these essential components as well as the areas that need to be further addressed through research. Areas of deficiency include (a) the inadequacy of patients' preparation to manage their illnesses, (b) the lack of standardized approaches by providers, partly because of the increased demands of high patient volumes, (c) the lack

of care coordination, and (d) the lack of active follow-up to ensure the best patient and provider outcomes (Improving Chronic Illness Care, 2014). Each of these areas of deficiency are explored in the context of the individual with cancer in the following sections.

Inadequately Prepared Patients

As cancer care transitions from the inpatient to the outpatient arena, patients are required to take more responsibility for their own care. The complexity of cancer treatments and the presence of comorbidities complicate patients' abilities to assume that responsibility quickly. The majority of patients do not have the necessary skills to self-manage their cancer and treatment effects along with coexisting comorbidities simultaneously. Over the past decade, the study of self-management in patients with cancer has primarily focused on the management of symptoms (Given et al., 2002, 2004; Koller, Hasemann, Jaroslowski, De Geest, & Becker, 2014; Koller, Miaskowski, De Geest, Opitz, & Spichiger, 2013a; Miaskowski et al., 2004; Rustøen et al., 2014; Sherwood et al., 2005). Interventions are needed to assist in improving adherence to treatment regimens and to empower patients to be active self-managers who work collaboratively with their healthcare providers.

To date, interventions related to improving empowerment in patients with cancer have primarily used an educational approach delivered individually or in a group setting (Fee-Schroeder et al., 2013; Jerofke, Weiss, & Yakusheva, 2014; Stang & Mittelmark, 2010). Studies of this approach used a qualitative approach to analysis, and none addressed the sustainability of the interventions over time. With the shift toward oral chemotherapeutic agents, studies addressing adherence to these agents surfaced (Banning, 2012; Bassan et al., 2014; Bender et al., 2014; Sarradon-Eck et al., 2012; Spoelstra et al., 2013). These studies address either adherence rates (Banning, 2012; Bassan et al., 2014), factors that influence adherence (Bender et al., 2014), strategies used by individuals to improve adherence (Sarradon-Eck et al., 2012), or interventions to improve adherence (Spoelstra et al., 2013). Studies that explore patient adherence to the self-management regimens prescribed in cancer care plans are missing in the literature. Interventions targeted at assisting patients and their family caregivers in successful self-management strategies are needed. Self-management interventions need to be adapted to the patient needs and changes in health status over time. Future research needs to (a) develop and test new and established self-management measures for multiple populations, including various minority groups, ethnicities, and those with coexisting comorbidities, and (b) develop and test new and established measures to assess self-management outcomes across the cancer care continuum.

Lack of Standardized Approaches

Guidelines commonly are used to assist providers in standardizing approaches to manage individuals with chronic conditions. Many of these guidelines include recommendations for self-management. Another strategy includes ONS's Putting Evidence Into Practice content, which provides an evidence-based approach to symptom self-management. Symptom self-management is the most widely studied phenomenon. Some studies incorporated or tested guidelines for the management of

specific symptoms (Hammelef, Friese, Breslin, Riba, & Schneider, 2014; Lovell et al., 2013; Stevinson, Lydon, & Amir, 2014) whereas others contributed knowledge to the development of guidelines for the management of symptoms (Koller et al., 2013b; Rustøen et al., 2014; Sherwood et al., 2005). Very little research has been conducted on the use of guidelines to promote and improve self-management outcomes in patients with cancer. Additional research is needed to (a) identify the needs of patients and caregivers regarding self-management during periods of transition from treatment to survivorship, (b) 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, and (c) develop and test models of care to improve coordinated care across disciplines and specialties to improve self-management at all phases of the cancer care continuum.

Lack of Care Coordination

Care coordination is an essential component of chronic disease management. A lack of care coordination can lead to confusion for individuals regarding self-management. Patients may be left to determine how to self-manage all components of their health care. They may prioritize their care in a way that can have a negative impact on how they self-manage their cancer and other coexisting chronic conditions (Hershey, Tipton, Given, & Davis, 2012). Schulman-Green et al. (2012) noted that coordinating self-management activities across disciplines could facilitate and improve self-management. McCorkle et al. (2011) suggested that the development of collaborative care plans coordinated across disciplines should serve as a guide for self-management interventions across the cancer continuum. Studies have suggested care coordination as a strategy for improving self-management in individuals with cancer (Lovell et al., 2013; McConigley et al., 2011; Regan, Mills, & Ristevski, 2012), although research related to the use of strategies to improve care coordination is lacking. Future research needs to (a) develop strategies that promote self-management in children, adults, and family caregivers across cultures and ethnicities, (b) conduct intervention studies to improve patient engagement in self-management activities, (c) develop and test interventions to improve care coordination and address the changing self-management needs of individuals with cancer and their family caregiver's overtime, and (d) develop and test self-management interventions to assist patients in managing their cancer and other pre-existing chronic conditions.

Lack of Follow-Up

With more individuals not only being diagnosed with cancer but also transitioning to survivorship, there is a need for active follow-up regarding self-management. Assessments of self-management need to occur over time, and self-management care plans need to be modified, adapted, and personalized as the patient moves through the cancer treatment continuum (Ozdilli, Wilkinson, & Frew, 2013; Palmer, Bartholomew, McCurdy, Basen-Engquist, & Naik, 2013; Schulman-Green et al., 2011; Sheppard, 2007). Failure to address the changing self-management needs of patients with cancer over time could potentially result in patients (a) not interpreting or recognizing symptoms related to recurrence and treatment effects, (b) not taking appropriate action regarding the management of symptoms, (c) not meeting their health goals, and (d) not improving

their quality of life and psychosocial outcomes (Dingley & Roux, 2014; Martin, Turner, Bourne, & Batehup, 2013; Palmer et al., 2013; Sheppard, 2007). Research regarding interventions to improve self-management that addresses the frequency and type of follow-up needed in individuals with cancer over time is missing from the literature. Research is needed to (a) develop and test strategies for improving adherence to prescribed treatment regimens and (b) develop and test strategies for improving adherence to self-management recommendations prescribed in cancer care plans across the cancer care continuum.

E. Aging

Definition of the Topic

The paucity of research on the impact of cancer and its treatment on older adults is problematic. Most types of cancer are diagnosed in older age groups, and the number of people diagnosed with cancer continues to rise. The absolute number of cases will rise from about 1.7 million today to about 2.5 million by 2040 (Rowland & Bellizzi, 2014). Most of these new cases will occur in older adults. The majority of new cancer cases already occur in three older groups: 65-74, 75-84, and 85 or older.

As the geriatric population grows and the ability to treat cancer improves, the number of older adults who are survivors of cancer will increase. More than 13 million cancer survivors are currently living in the United States. This number is expected to rise to about 18 million by 2020. Greater than half of these people are older than 65 years (Rowland & Bellizzi, 2014), and this percentage will increase. The lack of research focused on older adults with cancer makes it difficult to generalize findings and make treatment decisions. There is a lack of high-quality data to guide patient care. The Institute of Medicine made several recommendations to improve the evidence base for older adults (Levit, Balogh, Nass, & Ganz, 2013). For example, it is important to understand the efficacy of and side effects associated with targeted therapies in this patient population. There is a need for both elderly specific trials and for increased participation in general trials.

Many older individuals will require significant, ongoing care across the continuum of the treatment (Lichtman, Hurria, & Jacobsen, 2014). Oncology care relies on the delivery of interdisciplinary care. This approach requires collaboration across settings, including primary care, surgery, radiation oncology, medical oncology, palliative care, and end-of-life care. To provide optimal oncology care to older adults, geriatricians and advanced practice nurses who are trained in geriatrics will need to be added to the team and research on models of care are needed.

Significance and Background

The special vulnerabilities of older individuals, such as coexisting medical conditions (referred to as co- or multimorbidities), can shorten life independently from the effects of cancer and can complicate the delivery of cancer therapies. The median age at onset of most of the common cancers ranges from 60-72. The number of people older than the ages of 65, 75, and 85 will increase markedly over the next three decades, almost

doubling those older than 65 years and almost tripling those older than 85 years. Age must be considered as a major risk factor for cancer; more than half of all cancers are diagnosed in people older than the age of 65 (Rowland & Bellizzi, 2014).

Older patients with cancer who are otherwise in good health will likely receive surgery, radiotherapy, or drug therapy. Older patients with cancer appear to experience fewer symptoms with less frequency and less distress than their younger counterparts. In addition, older patients are capable of withstanding cancer treatments because of improvements in symptom management and control of adverse effects (e.g., pain, nausea, bone marrow suppression). Comorbidities, however, have to be considered.

The social and psychological aspects of the care of older patients deserve increased attention, as do finances, location of residence, and the heavy burden placed on family caregivers. There is a lack of information on the safety and efficacy of cancer treatment for older patients with cancer.

As the demands for care of the aging population continue to grow, workforce shortages, payment cuts, and the consolidation of oncology practices add to the limitation of access to specialty care.

The literature reports that age-related differences in treatment patterns persist, with older adults often receiving less aggressive therapy. Standard trial end points do not capture a key concept in geriatric medicine, which is the maintenance of active life expectancy (i.e., years one lives independently without significant disability). The effects of cancer therapies on physical or cognitive function are important.

Managing older patients with cancer requires assessment and monitoring (Wildiers et al., 2014). In addition to traditional, cancer-related outcomes such as survival and disease response, other outcomes include quality of life and performance status. Supportive care is essential. Febrile neutropenia, pain, nausea and vomiting, anemia, depression, fatigue, and insomnia are important areas of focus because they affect not only patients' quality of life but also can interfere with treatment in addition to adding complexity to an older patient with multiple comorbid conditions. The best management of these issues is their recognition and prevention (Naeim, Aapro, Subbarao, & Balducci, 2014).

Because family caregivers play an integral part in cancer survivors' care, particularly for older survivors who often have more healthcare-related needs to begin with, it is important to include them in the survivorship care planning process (Rowland & Bellizzi, 2014).

There are gaps in the knowledge about cancer care for older adults. Research is clearly needed to (a) describe how lifestyle factors such as nutrition, exercise, smoking, and alcohol intake affect the symptom burden and treatment responses of older patients, (b) explore the effects of age, cancer, and biased decision-related stigma on older patient outcomes, (c) 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, (d) test interventions that promote engaged treatment decision-making based on risks assessed through a comprehensive geriatric assessment (CGA) and determine which components of the CGA predict treatment outcomes (e.g., function status, health-related quality of life), (e) determine how to adapt symptom management interventions to decrease risk and enhance protective factors and to promote positive outcomes in older patients, (f) test interventions for palliative, supportive, and end-of-life care for older adults who are unable to tolerate active curative treatment, (g) test interventions to improve outcomes in family caregivers with chronic medical conditions who are caring for an older adult with cancer, (h) test interventions to improve patient-clinician communication and self-management for the patient, (i) identify older patients with cancer at a higher risk of poor outcomes and target interventions to maintain or improve these outcomes, (j) evaluate how multiple comorbidities (e.g., diabetes, obesity, heart failure, arthritis) affect the symptom burden and treatment responses of older adults with cancer, (k) evaluate factors that influence the delivery of quality, safe care and healthcare utilization in older adults with cancer, (l) evaluate the efficacy of using technology to improve outcomes in older adults undergoing cancer treatment, and (m) 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).

F. Family and Caregivers

Definition of the Topic

Successive ONS research agendas have recognized that a cancer diagnosis impacts more than the patient. It affects family members and friends in a multitude of ways. The content area termed “psychosocial and family issues” in the 2009–2013 ONS Research Agenda transitioned to a focus on “family and caregivers” for the current agenda. The definition of this content area for the 2014–2018 Research Agenda goes beyond the historic focus on negative emotional outcomes for family members and caregivers, emphasizing the biologic, behavioral, and socioeconomic dimensions of family caregiving. The range of relationships that comprise “family” (i.e., dyads, nuclear, extended, and nontraditional configurations) is acknowledged and, therefore, family is defined as an experience rather than a formal relationship. Family caregivers are further defined as valued partners who play a vital role in cancer treatment and supportive care in a number of ways, including providing direct care, assistance with instrumental activities of daily living, and emotional support.

Significance and Background

An estimated 34 million people in the United States provide unpaid care to family members (Houser & Gibson, 2008). Family caregivers assist with a multitude of activities, ranging from personal care and household tasks to symptom management and medical and nursing procedures in the home. Caregivers play an essential role in access to treatment, as cancer treatment is provided primarily on an outpatient basis with frequent visits needed for the administration of treatment and the surveillance of patient response. Family caregivers are the primary providers of care in the home,

where most care is provided. Extended periods of treatment and testing, plus interactions with numerous, highly specialized health professionals, cause caregivers to be involved with much more than transportation to multiple medical appointments. They serve as informal case managers, coordinating care and communication among multiple health professionals over extended periods of time. They truly are partners with health professionals in the quest to achieve optimal treatment outcomes and patient quality of life. Research to date has underscored the negative psychological and physical consequences on family members of people with cancer, including anxiety, depressive symptoms, burden, altered immune function, poor overall health, and increased overall mortality (Northouse, Katapodi, Schafenacker, & Weiss, 2012; Williams & McCorkle, 2011). However, despite considerable research on family caregiving over the last 25 years, major knowledge gaps persist. These knowledge gaps preclude the implementation of comprehensive, family-centered services that support families over the long haul of cancer treatment, survivorship, and end-of-life care. Given the key role played by family caregivers across the entire cancer trajectory, comprehensive, family-centered services are needed to achieve optimal patient outcomes as well as to support the long-term health and well-being of caregivers.

Status/Progress of Research Since Last Agenda (2009–2013)

Using multiple databases (including PubMed, CINAHL, and PsycINFO), a review of published research from 2009–2014 was conducted for two purposes. The first was to assess the extent to which the 2009–2013 ONS research priorities were addressed. The second was to gain a broader overview of the state of the science of family caregiving research in oncology. Searches using the key words “cancer” and “caregiver” or “family” in the title or abstract field generated more than 500 articles published across a wide variety of scientific journals. Only those articles that focused primarily on caregiver outcomes were reviewed for this paper.

Progress in ONS Research Priorities

The overall 2008 ONS research priority for oncology caregiving was to conduct well-designed intervention studies to reduce negative outcomes and improve positive outcomes in patients with cancer and their family caregivers. More specific subgoals pertained to model-testing and targeted interventions.

The first subgoal was to “research to test patient and family models that encompass both risk factors and protective factors and their relationship to outcomes.” The literature review revealed the predominance of studies focused on psychosocial risk in relation to quality-of-life outcomes (e.g., depressive symptoms, caregiver burden, anxiety). Most were small, single-institution, cross-sectional, descriptive studies. Many articles reported on particular stressors and their relationships to caregivers’ depressive symptoms, burden, and anxiety. In addition, multiple focus-group studies identified various sources of distress in multiple cancer caregiver populations using qualitative research methods. An exception to the multitude of small, descriptive studies was a series of analyses (Kim, Carver, Schulz, Lucette, & Cannady, 2013; Kim, Carver, Spillers, Crammer, & Zhou, 2011; Kim, Carver, Spillers, Love-Ghaffari, & Kaw, 2012; Kim, Shaffer, Carver, & Cannady, 2014; Kim & Spillers, 2010; Kim, Spillers, & Hall, 2012) conducted using the

large database compiled by the American Cancer Society (ACS) through the National Quality of Life Survey for Caregivers (<http://www.cancer.org/research/survivaltreatmentresearch/family-caregivers-research>). The ACS studies provide the best knowledge base to date regarding psychosocial risk in relation to cancer family caregiving outcomes.

Since 2009, no articles were found that built on earlier work by rigorously testing conceptual models of risk and protective factors in relation to outcomes. Specifically, no studies concomitantly evaluated multiple variables to differentiate the strength of relationships and test for mediation and moderation in the model as a whole using advanced statistical and computing methods. However, the large amount of research describing negative psychological outcomes in caregivers across multiple patient populations is sufficient to lay a strong foundation from which models can be tested. In contrast, basic descriptive studies that identify, measure, and evaluate protective factors in family caregivers, positive aspects of care, and potential benefits to caregivers such as hope, spirituality, preparedness, optimism, and mastery are still needed. Of particular use would be studies that evaluate the way in which positive caregiver outcomes may offset negative outcomes.

A notable characteristic of research to date on risk factors in relation to outcomes is the paucity of studies conducted in underrepresented and underserved populations. Although there is a small but growing body of work focused on historically identified minority groups (Francis, Bowman, Kypriotakis, & Rose, 2011; Yennurajalingam et al., 2013) such as African American and Hispanic caregivers, less has been done on newly arrived immigrants (e.g., Africans, caregivers from Eastern Europe). Other groups that are underrepresented include caregivers with low literacy levels, those residing in medically underserved geographic areas, those with existing comorbid conditions, families of military veterans with limited resources, and caregivers without reliable access to technology. The risks that are prevalent in these underserved populations are not well described.

The second subgoal of the 2008 ONS research priority in caregiving was to conduct intervention studies to identify patients and caregivers at a higher risk of poor outcomes and to target interventions to meet their needs. Although several intervention studies were reported, few described targeted and tailored interventions. In addition, systematic reviews of intervention trials in oncology caregiving highlight methodologic weaknesses that impact generalizability in the clinical setting (Applebaum & Breitbart, 2013; Northouse, Katapodi, Song, Zhang, & Mood, 2010; Waldron, Janke, Bechtel, Ramirez, & Cohen, 2013). Despite work in other caregiver populations demonstrating that not all caregivers display significant distress as a result of providing care (Savundranayagam, 2014), convenience sampling of all available caregivers tends to be used rather than identifying those in need of intervention. Moreover, the limitations of research in underserved populations affect the progress of testing interventions that are targeted and tailored to the needs of specific caregiver populations. For example, access to technology may be limited in economically disadvantaged or geographically remote populations without dependable service. This is a particularly salient area for future

research as descriptive and intervention research is incorporating technology for data collection and intervention delivery (Godwin, Mills, Anderson, & Kunik, 2013). Oncology caregiver interventions have been delivered via web-based programs, YouTube, telephone (live or interactive voice response), DVD, and Listserv among others (Collinge et al., 2013; Silveira et al., 2011; Wittenberg-Lyles, Parker Oliver, Demiris, Swarz, & Rendo, 2014). The integration of technology, although considered novel and even common in some cases, needs to be explored in areas where these resources are not available. Unfortunately, it often is the case that the technology used to deliver an intervention becomes obsolete by the time the research study is done and findings are reported. It is vital that interventions delivered through technological means have a strong foundation and conceptual framework that can be readily adapted as technology advances at an exceedingly fast rate. It also is vital to know whether interventions delivered through technology are best used as stand-alone interventions or whether human interaction is an essential component.

The previous ONS research agenda for psychosocial and family issues included a comment stating that studies need to address cancer-related cost and resource use issues for patients and families. Advances in this area have been limited. Several articles reported data regarding the allocation of resources according to physician preference (Rocke, Beumer, Thomas, & Lee, 2014) and a few studies focused on cost to the caregiver, primarily related to assigning a financial value to caregivers' work (Yabroff, Borowski, & Lipscomb, 2013). A large portion of caregivers have little choice in changing work to accommodate cancer care as they become the primary wage earners and carriers of insurance during treatment and, at times, into survivorship. Less attention has been paid to the constraints of the existing healthcare structure, which affects curative and supportive care, including lost days of work, the cost of supportive care, economic factors that impact recommendations for and use of curative and palliative treatment, and the impact of economic burden (choices families must make to afford cancer care and the distress associated with those choices).

In summary, a review of the literature associated with ONS's 2009–2013 research priorities revealed accumulating evidence on the negative psychosocial impact of family caregiving but sparse progress otherwise. The ONS priority related to model testing was partially addressed through extensive exploration of factors related to negative psychosocial outcomes. However, important shortcomings persist. Model testing is not at a high level of analytic sophistication, protective factors have not been examined sufficiently, and the risks experienced by underserved populations have been neglected. Only modest progress has occurred in intervention research. Interventions are rarely targeted to those most in need, interventions specific to underserved populations are lacking, and approaches for adapting interventions to rapidly changing (and variably accessible) technologies are lacking. Cost and resource-use issues have hardly been touched. Progress toward previously set goals was lean, which presents an excellent opportunity to review the science again and reset goals and priorities.

State of the Science Overview

To supplement the literature review specific to the 2009–2013 ONS research priorities, caregiver literature was further analyzed to gain a broader view of the state of the science. There have been great advances in caregiver research using a dyadic, rather than an individual caregiver, approach (Regan et al., 2012). More than 20 studies were found that evaluated dyadic concepts such as marital adjustment, communication, quality of relationships, congruence (or incongruence) in symptom assessment, and dyadic decision-making (particularly at the end of life) (Yennurajalingam et al., 2013). The majority of this work focused on married dyads. Once again, a psychosocial focus predominates. Although psychosocial outcomes for the dyad are important indicators of quality of life, other outcomes such as rates of institutionalization and treatment adherence may be of more interest to insurance companies and other organizations that will potentially fund the translation of caregiver interventions into practice. In addition, the inclusion of the patient in dyadic caregiver research highlights the lack of research on caregiver-affected patient outcomes other than patient quality of life. Little is known regarding the impact of family caregivers on treatment outcomes such as symptom management, treatment adherence, and early detection of acute conditions (e.g., dehydration) that require supportive intervention. Finally, the emerging emphasis on dyadic research undervalues the effect of a cancer diagnosis on the family unit as a whole. Considering the current meanings of “family,” more research is needed on the influence of caregiver outcomes on children in the home, how to accommodate and integrate distance caregivers, and the involvement of extended and nontraditional families.

A prominent gap in oncology research, compared to caregiver research in other disease populations, relates to knowledge regarding the effect of caregiving on caregivers’ physical health. Seven articles to date reported the impact of stress caused by providing care on the cellular, organ, or systemic levels; these studies had small sample sizes, and cortisol has been the main biomarker of interest (Lengacher et al., 2012; Thomas et al., 2012). Systematic literature reviews of studies on the caregivers of patients with dementia underscored not only cellular and genetic changes because of caregiver stress but also changes in overall health, such as an increased incidence of cardiovascular disease and lowered immune function (von Känel et al., 2012). Because the onset and variability in the trajectory of psychological distress is vastly different in oncology, more work in this area is needed to determine whether oncology caregivers suffer similar health risks. In addition, studies with larger samples are required to determine whether changes at the biomarker level result in observable changes in health conditions. Research evaluating the impact of caregiver stress on biologic outcomes may be critical to preserving caregivers’ health, maintaining the patient in the home, and improving the quality of care delivered to the patient by the caregiver. More sophisticated, descriptive work in this area would set the stage for physiologic or combined psychological and physiologic interventions to be tailored to those at risk. In summary, considerable work has been done in the research area of family caregiving over the past four years. The state of the science in family caregiving is led not in oncology but in other caregiver populations, and data generated from other caregiving populations can be used to rapidly advance the science of oncology caregiving. Oncology caregiver research is in a prime position to use data from other caregiving

populations to move past the evaluation of caregiver burden, depression, and anxiety toward a focus on three priority areas: the impact of providing care on patient outcomes, the physiologic health of the caregiver, and employment and economic issues in caregiving.

Recommendations for Research

The following priority areas are recommended for future research in family caregiving. In all areas, a high priority should be given to studies providing samples that are large and diverse enough to concomitantly evaluate multiple variables longitudinally; that contain sophisticated designs focused on using novel statistical approaches and maximize potential by integrating qualitative and quantitative data; that go beyond the caregiver and dyad to evaluate the degree and duration of the impact of cancer diagnoses and treatments on the entire family unit as well as at the societal level; that move beyond the cancer center to communicate with stakeholders in the dyad's health, including employers, corporate health and wellness service providers, primary care providers, insurers, and other health services; and that optimize the use of technology.

Specifically, research should identify the impact of caregiver outcomes on patient clinical outcomes, and it should (a) conduct studies that examine the influence of the caregiver on the quality of patient-care delivered, (b) conduct studies determining the extent to which caregiver distress influences factors that affect patient and system resource use, such as symptom severity, emergency room visits, patient distress, and adherence to treatment, and (c) conduct intervention trials focused on the dyad and family to improve patient outcomes across the care trajectory. Additional research is needed to determine the impact of the stress of providing care on caregivers' physiologic health, specifically to (a) conduct studies that examine cellular responses to providing care to identify key biomarkers for future work, (b) examine longitudinal cohort studies to determine whether changes at the cellular level translate into meaningful changes in caregivers' comorbid conditions, and (c) conduct intervention trials focused on psychosocial and physiologic strategies to improve overall health. Finally, there is a need to explore, define, and determine the extent of economic burden and its impact on the families of people with cancer, including studies that (a) explore the impact of economic burden on both caregiver and patient outcomes, including quality-of-life outcomes and outcomes such as the use of supportive medication and adherence to treatment regimens, (b) describe ways in which the caregivers and families of people with cancer make short- and long-term lifestyle changes to afford cancer care, and (c) implement interventions providing strategies to ameliorate employment and economic burden.

G. Improving Healthcare Systems Delivery

Definition

The healthcare system can be viewed as a four-level nested model. The four levels are (a) the patient, (b) the care team that consists of healthcare providers, the patient, and the patient's family, (c) the organization (e.g., the hospital or clinic that provides the

infrastructure and resources for the care team), and (d) the political and economic environment (Ferlie & Shortell, 2001).

Significance and Background

Cancer care is a complex process because of the biology of cancer and the specialized care required for the delivery of optimal treatment (Levit, Balogh, Nass, & Ganz, 2013). In the United States, cancer care is affected by a fragmented, costly healthcare system. Structures and processes are needed to ensure a high-quality healthcare delivery system that is patient-centered and cost-effective. In addition, scientific evidence should be incorporated quickly and efficiently into clinical practice. Cancer care delivery must be evaluated using quality-monitoring measurement of patient outcomes, and patient outcomes should be shared publicly (Levit et al., 2013).

Patient-Centered Cancer Care

High-quality cancer care is patient-centered (Levit et al., 2013). Care coordination is a core component of patient-centered care, and it ensures that patients receive appropriate cancer care. Oncology nurse navigators and care coordinators are experienced oncology nurses whose roles and responsibilities in care coordination vary depending on the setting in which they are employed. Registered nurses and advanced practice nurses play an important role in care coordination, resulting in improved clinical outcomes. Improved outcomes include a reduction in healthcare costs because of a decrease in patient emergency visits and hospitalizations, increased patient confidence in self-managing care, and improved patient satisfaction (American Nurses Association [ANA], 2012). Patient care coordination provided by an advanced practice registered nurse at colorectal and surgical oncology clinics at Loyola University demonstrated a decrease in patient emergency department visits and hospitalizations and subsequent cost savings (Robles et al., 2011).

Nurses are in a key position to develop new, cost-efficient models for delivering the best clinical care and improving patient outcomes across the cancer care continuum. A recommendation from the ANA's (2012) white paper on care coordination calls for research to identify the quality outcome measures and best practices of effective, nurse-led care coordination. In addition, research is needed to conceptualize the oncology care coordinator's role within the nursing profession and healthcare team, and to measure the outcomes of the care coordinator's interventions (Crane-Okada, 2013).

Patient-centered care involves interdisciplinary teams working with patients and families in decision-making and goal-setting based on the patient's values and preferences, decreasing readmissions and patient complications (Kuntz, Tozer, Snegosky, Fox, & Neumann, 2014; Qamar, Pappalardo, Arora, & Press, 2011). The Oncology Medical Home is a patient-centered primary care model focused on improving patient outcomes, increasing patient satisfaction, and reducing healthcare costs (McDonald et al., 2007). The Oncology Medical Home has the potential to improve cancer care delivery through care coordination by the oncology healthcare team, by adhering to clinical practice guidelines, by improving patient outcomes, and by decreasing patient healthcare use (Eagle & Sprandio, 2011; Fox, 2013). Early findings suggest that the Oncology Medical

Home reduces emergency department and inpatient visits for patients with cancer receiving chemotherapy (Kuntz et al., 2014).

Recent descriptive studies (Prouty et al., 2014; Wittenberg-Lyles, Goldsmith, & Ferrell, 2013) identified challenges to effective patient-centered communication in cancer care. Providers must effectively inform patients and families of health-related information. Communication is affected by the lack of time providers are able to spend with patients (Prouty et al., 2014), and this breakdown in communication in cancer care has been related to patients' lack of understanding of the information provided, unrealistic expectations, and psychological distress (Prouty et al., 2014). Care coordination positively adds to the patient experience (ANA, 2012).

Research is emerging in the area of nurse-patient communication education (Wittenberg-Lyles et al., 2013) and its effectiveness on nurse and patient outcomes (Rask, Jensen, Andersen, & Zachariae, 2009). Testing of technology-based communication methods is an area of research importance. Berry et al. (2014) demonstrated lowered symptom distress in patients who used an electronic self-report tool to self-monitor symptoms and quality of life between visits with healthcare providers. The electronic tool also provided self-care education and coaching to report symptoms to healthcare providers.

The federally funded Patient-Centered Outcomes Research Institute ([PCORI], 2013) is designated to generate the best evidence for facilitating communication and informed decision-making by patients and healthcare providers. PCORI's research priorities are applicable to cancer care and oncology research. Three of the priorities relevant to improving healthcare systems delivery in cancer care are (a) comparing health system-level approaches to improving access, self-care, the innovative use of health-information technology, the coordination of care for complex conditions, and the effective deployment of the workforce, (b) comparing approaches to providing relative effectiveness of research information, empowering people to ask for and use information, and supporting shared decision-making between patients and their providers, and (c) improving the nation's capacity to conduct patient-centered outcomes research by building a data infrastructure, improving analytic methods, and training researchers, patients, and other stakeholders to participate in this research (PCORI, 2013).

Nurse-Led Patient Care Models

Oncology nurse practitioners play an essential role in today's healthcare delivery system. Nurse-led clinics demonstrate improved patient outcomes (Mason, DeRubeis, Foster, Taylor, & Worden, 2013; Pritham, Cureton, & Royce, 2009; Ruegg, 2013; Tetuan et al., 2014).

Outcomes of a weekly, nurse practitioner-led, symptom management clinic for patients receiving intensive chemoradiotherapy for oropharyngeal cancer included reduced rates of hospitalization, reduced chemotherapy dose deviations, and increased chemotherapy completion (Mason et al., 2013). Nurse-led clinics also showed benefits in patients

obtaining mammograms (Tetuan et al., 2014), colorectal cancer follow-up (McFarlane et al., 2012), cancer survivorship care (Pritham et al., 2009), and urgent care (Ruegg, 2013). Continued research is needed to identify effective advanced oncology nurse practice models that provide high-quality patient care and improve patient outcomes.

Evidence-Based Cancer Care

The development of clinical measures based on research that ensure safe, quality care for patients with cancer is a cornerstone of oncology nursing. Historically, ONS has been at the forefront of the development of quality indicators for oncology nursing practice. The most recent ONS Quality Initiative was the development and pilot testing of quality measure sets for breast cancer care and breast cancer survivorship. The delivery of evidence-based nursing care is also an ONS priority. In 1987, the American Nurses Association and ONS jointly developed the Standards of Oncology Nursing. Today, ONS supports a robust program of research-based practice guidelines, Putting Evidence Into Practice (PEP[®]). Additional evidence-based guidelines are developed by the National Comprehensive Cancer Network (NCCN) and the American College of Surgeons Commission on Cancer (COC). The evaluation of clinical screening aids is critical as care changes over time. The Distress Thermometer developed by NCCN is an example of a screening aid. It was evaluated by Tavernier (2014) for practice, and recommendations were made for clinical use.

As a number of practice guidelines from governmental agencies and professional organizations are developed, the efficacy and feasibility of these guidelines as adjuncts for practice require continued testing and evaluation. Efficacy-based research on guidelines in varied environments is emerging. Several studies have assessed guidelines for feasibility and usability (Farrington, Cullen, & Dawson; Kiely, 2014; Mayer et al., 2014, Tavernier, 2014). Data from these studies point to the need for additional research to evaluate practice guideline concepts for feasibility and utility in varied oncology environments (Farrington et al., 2010; Kiely, 2014; Mattsson, Knudsen, Lauritsen, Brixen, & Herrstedt, 2013). Many articles evaluated guidelines using quality improvement assessment strategies and program evaluation research methods (Mattsson et al., 2013). The *Clinical Journal of Oncology Nursing* devoted a supplemental issue in 2014 to implementing and evaluating three screening guidelines from the COC standards (i.e., supplement to Vol. 18, No. 1). Another feature of the literature is the increasing number of systematic and integrative reviews of practices that are being published (Hines, Ramis, Pike, Chang, 2014; Preyde & Synnott, 2009). Review articles facilitate the identification of evaluation research and methodologies that can help substantiate an ever-changing practice environment. In addition, research on how best to disseminate and implement best practices is needed.

Economic Evaluation of Cancer Care

An economic evaluation of nursing interventions is imperative. An evaluation of the costs and outcomes of alternative interventions provides nurses with information to select cost-effective choices. In a recent systematic review, Cook, Morrison, Eaton, Theodore, and Doorenbos (2014) found that only 16 nursing-related economic evaluations were published from 1997-2011, and none of the analyses was related to

cancer care. Although intervention studies often report the intervention's cost, a full economic evaluation addresses the costs and outcomes of the intervention, comparing them to one or more alternative interventions. This provides an evaluation of the intervention's cost-effectiveness, cost-utility, cost-benefit, and cost-consequence (Drummond, Sculpher, Torrance, O'Brien, & Stoddart, 2005). This knowledge is necessary to build the science of oncology nursing practice and demonstrate the quality of care delivered by oncology nurses. Economic evaluations should be a part of intervention research studies.

Future research must expand the knowledge of patient-centered cancer nursing care. There is a need to (a) evaluate best practices for oncology nurse-led care coordination, (b) examine interventions for improving advocacy and fostering provider communication with patients and families, and study the effects of communication on patient outcomes, and (c) design and test cost-efficient patient care models for improving patient outcomes across the cancer care continuum. There also is a need to evaluate the effects of nursing care on the promotion and maintenance of treatment quality and safety. This needs to be done to (a) understand predictors (risk models), cost settings, side effects, educational approaches, population health literacy, and the cognitive changes associated with adherence to self-care, (b) evaluate the influence of care providers and cost-effectiveness on quality and safety, (c) evaluate strategies for the identification and prevention of adverse events related to quality and safety, and (d) develop and test interventions that support the delivery of quality care indicators.

H. Risk Reduction

In the absence of a cure for cancer, research on risk reduction, such as health behaviors to help prevent cancer and increase cancer screening, is urgently needed. Cancer incidence and mortality rates have decreased overall in recent years (American Cancer Society [ACS], 2014). This statistic is attributable in part to a better understanding and awareness of risk factors, an adoption of healthy lifestyle behaviors, and improvements in cancer screening and early detection. However, a substantial number of cancers can still be prevented. For example, in 2014, about 176,000 of the estimated 585,720 cancer-related deaths were caused by tobacco use (ACS, 2014). About a third of cancer cases that occur in economically developed countries like the United States are related to obesity, inadequate physical inactivity, and poor nutrition, and could therefore be prevented (International Agency for Research on Cancer, 2002; World Cancer Research Fund International, n.d.). Cancers caused by infectious agents such as human papillomavirus, hepatitis B virus, hepatitis C virus, HIV, and *Helicobacter pylori* could be prevented through behavioral lifestyle changes and vaccinations. Decreasing excessive sun exposure and indoor tanning could lead to a reduction in the three million skin cancers diagnosed annually (ACS, 2014; World Cancer Research Fund International, n.d.). Populations in need of cancer prevention and early detection interventions include those who are at high risk because of lifestyle choices as well as those at high risk because of family histories.

Research on the primary and secondary prevention of cancer and cancer control in the United States is a critical field in which to position oncology nurses. This research is especially important in the context of cancer-related disparities as minority and underserved populations continue to bear the heavy burden of cancer morbidity and mortality.

Several important summaries addressed the need for and challenges of health promotion for cancer prevention throughout the world, including topics related to tobacco control, obesity, physical activity, and diet (ACS, 2014; Agency for Healthcare Research and Quality [AHRQ], 2014; Lawrence, 2014; Samat & Yoon, 2010). An abiding challenge is that data on cancer care for some underserved populations (e.g., people with limited English proficiency; lesbian, gay, bisexual, and transgender individuals; Asian and Hispanic subpopulations) are not available from national data sources (AHRQ, 2014).

Despite decades of research on improving screening, cancer screening rates remain lower than national targets. In 2010, only 72.4% of women ages 50–74 received a mammogram in the previous two years. From 2000-2010, the percent of women who received a mammogram declined for those in poor and low-income households and for non-Hispanic whites. During the same time period, women from poor, low-income, and middle-income households were less likely to receive a mammogram compared to women from high-income households (AHRQ, 2014). Stark differences in treatments continue. Women younger than the age of 65 with public insurance were less likely to receive radiation therapy than those with private insurance, and women younger than the age of 65 with public health insurance were less likely than those with private insurance to receive axillary node dissection or sentinel lymph node biopsy (AHRQ, 2014).

These challenges and disparities remain despite the presence of well-established models of health behavior and extensive research on programs promoting healthy lifestyle and cancer-screening behaviors. Future intervention research should go beyond long-held theoretical models; target diverse, underserved populations globally; integrate cultural leveraging to optimize intervention effects (Fisher, Burnet, Huang, Chin, & Cagney, 2007); address known and possible mechanisms of risk; and apply and disseminate evidence-based interventions to community and clinical settings.

Although chemoprevention and bilateral prophylactic mastectomy are identified as cancer prevention options (National Guideline Clearinghouse, 2010), strategies to decrease cancer incidence generally involve risk management through health behavior modification such as tobacco control, dietary change (to optimize energy balance and decrease obesity), and increasing physical activity. A synthesis from the American Society for Clinical Oncology stated that as the incidence of obesity increases throughout the United States, alarming evidence of obesity's link to many cancer types and poorer outcomes also is growing (Lawrence, 2014). More than 50 studies around the world consistently found that adults who increase their physical activity, either in intensity, duration, or frequency, can reduce their risk of developing colon cancer by

30%–40% relative to adults who are sedentary regardless of body mass index. The greatest risk reduction is seen in those who are most active (National Cancer Institute [NCI], 2014a). More than 60 studies published in North America, Europe, Asia, and Australia report that physically active women have a lower risk of developing breast cancer than inactive women. The amount of risk reduction achieved through physical activity varies widely, but the protective effect appears to be greatest with high-intensity activity (20%–80%) (NCI, 2014a).

Clinical trials of innovative interventions supporting the initiation and long-term maintenance of these health behaviors in diverse populations are important areas of nursing research (ACS, 2014; Wilhelmsson & Lindberg, 2007). Research on treatments and interventions that may reduce obesity-related cancers such as breast, prostate, colorectal, and esophageal cancers also are important (Lawrence, 2014). Patient-centered oncology nursing research addressing comorbid conditions such as weight and poor diet will move the science of risk reduction forward.

Predictions based on cancer incidence, survival, and cost of care estimate that the cost of direct cancer care will reach \$158 billion in 2020 (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011), clearly making the case for additional research on prevention and early diagnosis. As a risk-reduction strategy, cancer screening decreases mortality from breast, cervical, and colorectal cancers by increasing early detection (ACS, 2014). The survival rates of these cancers are inversely related to late-stage diagnosis, and higher survival rates (as high as 95%) are shown for early-stage diagnosis. The ACS and other professional organizations have recommended that cancer prevention should be the primary goal of colorectal cancer screening (Levin et al., 2008). Mammography and cervical cancer screening rates increased steadily over the past decade, and 70%–90% of women now report one-time screening. However, these rates leveled off in recent years. These high rates may reflect the success of the National Breast and Cervical Cancer Early Detection Program activities that were initiated in 1991 (Ryerson, Benard, & Major, 2002) as well as the tremendous number of intervention studies targeting barriers to breast cancer screening. Such interventions decreased the difference in mammogram screening rates (for one-time or initial screening) between women of racial or ethnic minority groups and Caucasian women. Disparity remains, however, particularly in terms of interval or ongoing screening (ACS, 2014; Cokkinides, Bandi, Siegel, Ward, & Thun, 2007; Rakowski et al., 2004).

Colorectal cancer screening remains suboptimal; about one in three adults ages 50-75 have not been tested for colorectal cancer as is recommended by the U.S. Preventive Services Task Force (Seeff et al., 2013). Despite substantial scientific evidence that routine screening for colorectal cancer reduces the incidence and mortality rates of this disease, screening rates have been slow to increase and disparities in screening remain (Atkin et al., 2010; Johnson et al., 2008; Mandel et al., 2000).

In addition to beliefs, cultural attitudes, and knowledge, research has identified the role of health care professionals to be pivotal in facilitating cancer screening (Breen, Wagener, Brown, Davis, & Ballard-Barbash, 2001; Meissner et al., 2004; Rawl, Menon,

Breslau, & Bursniss, 2012). Reminders from healthcare providers are generally the most effective strategy for promoting mammogram adherence in studies of women, regardless of age or ethnicity (Levy-Storms, Bastani, & Reuben, 2004; Lukwago et al., 2003; Schwartz, Taylor, & Willard, 2003; Tu et al., 2003). Structural influences, such as policy and socioeconomic factors, health insurance coverage, and access to a regular source of health care, also facilitate or impede screening (Breen et al., 2001).

The majority of screening intervention studies were conducted with patients with breast cancer. The knowledge gained from this research was extended only minimally to other cancer screening studies, most notably cervical and colorectal cancers. Programs such as the CDC's Colorectal Cancer Screening Demonstration Program report (Seeff et al., 2013) initial success. However, screening rates decline in relation to program close-out dates (Seeff et al., 2013). Disparities in screening rates continue for cervical cancer (by racial or ethnic minority group) and colorectal cancer (by gender and racial or ethnic minority group). Intervention research to enhance colorectal and cervical cancer screening, including research of human papillomavirus vaccine education and uptake, is needed (Anhang, Goodman, & Goldie, 2004; Saslow et al., 2007; Smith, Cokkinides, & Brawley, 2009). This research may be guided by successful intervention strategies and lessons learned from mammography screening trials (Meissner et al., 2004). Patient navigation programs focused on screening and outreach had the most demonstrable success, yet many challenges confront the widespread dissemination of such programs, including the varying definitions of roles, buy-in from stakeholders, program costs, and integration into the healthcare delivery system (Varner & Murph, 2010).

There are multiple health-behavior theories in the literature to guide health promotion research, but very few have been adequately tested (Bowen et al., 2009). Research on the understanding and promotion of healthy changes in behavior has been conducted in cardiovascular and diabetes specialty areas for many years. However, scientists and clinicians are still challenged by effectively accomplishing long-term lifestyle change. Many screening studies focus on one-time screenings as their outcomes, leaving gaps in knowledge about repeat and sustained screening changes. The ACS, American Diabetes Association, and American Heart Association proposed a common agenda to share knowledge across specialties and disciplines and promote health behavior change, thereby preventing chronic illnesses (Eyre et al., 2004). In addition, research comparing the explanatory values of popular health behavior theories showed that there is a continuing, and perhaps misplaced, focus on narrowly defined determinants of behavior isolated from social context (Pasick & Burke, 2008). For example, constructs such as perceptions of illness, experiences with discrimination, and racism shape women's lives and negate or attenuate the effects of common Health Belief Model variables on breast cancer screening (Fisher et al., 2007). Yet these variables are understudied.

Intriguing research suggests that a simultaneous approach to multiple behavior changes may be superior to changing behaviors sequentially (Hyman, Pavlik, Taylor, Goodrick, & Moye, 2007). A World Cancer Research Fund and American Institute for Cancer Research (2009) report on diet, physical activity, and cancer underscored the need to

address multiple aspects of risk reduction for cancer control. Health behavior theories and interventions emphasizing the multiple benefits of lifestyle change may prove more effective than those focusing on cancer prevention alone. Studies indicate that targeting healthy lifestyle behaviors during cancer screening encounters may be particularly effective (van der Aalst, van den Bergh, Willemsen, de Koning, & van Klaveren, 2010). Thus, future research must move away from single-level, explanatory, and descriptive models to more comprehensive, ecologic frameworks (Warnecke et al., 2008; Zapka & Lemon, 2004; Zapka, Taplin, Solberg, & Manos, 2003). Such conceptual frameworks may help oncology nurses draw from successes in breast cancer research to implement research on the prevention of other cancers (Meissner et al., 2004; Rawl et al. 2012).

The continued, unequal burden of cancer on poor, minority, and underserved populations underscores the need for more research on screening for multiple cancers in these populations. These groups often experience challenges within the healthcare system. For example, about 90 million Americans have low health literacy (Nielsen-Bohman, Panzer, & Kindig, 2004) with limited access to, understanding of, and practice of lifestyle behaviors for health promotion, risk reduction, and cancer prevention. These barriers lead to confusion and nonadherence among patients and healthy individuals. Therefore, risk reduction efforts need to speak to a broader definition of culture that encompasses groups within underserved populations, including children and adolescents. There is a critical need to accelerate the dissemination and implementation of efficacious interventions with strong practice collaboration for sustainability.

Although many descriptive studies exist on barriers within groups, little information is available on common elements between underserved groups. Such information is critical to the dissemination and implementation of cancer screening efforts as risk-reduction strategies. High costs may prohibit the widespread dissemination of individual models of cancer screening programs for each subpopulation. Therefore, the adaptation of programs to target common barriers as well as group-specific challenges may garner the most success and increase long-term sustainability.

Dissemination and implementation science calls for the effectiveness and sustainability testing of evidence-based practices. Oncology nurses can have a tremendous impact on these disparities through the growing field of dissemination and implementation science. The ONS Position on Prevention and Early Detection of Cancer in the United States supports the role of oncology nurses in screening improvements (Greene, 2009).

Lifestyle Factors and Cancer

Cancer is associated with several lifestyle factors. A 2011 review suggested that about 4% of cancers are linked to alcohol (Parkin, 2011). Another review showed that around 10% of cancers may be linked to diet. Greater than half of these cancers were caused by eating fewer than five portions of fruit and vegetables per day. Other factors included eating too much red meat, not eating enough fiber, and eating too much salt (Cancer Research UK, 2014). There is strong evidence that physical activity is associated with a reduced risk of developing cancer (NCI, 2014a). Obesity increases an individual's risk of

several cancers and other diseases, so it is important to maintain a healthy body weight. Skin cancer, which is primarily related to ultraviolet light exposure, is one of the most preventable yet increasingly common cancers in the United States (Lomas, Leonardi-Bee, & Bath-Hextall, 2012). However, smoking remains the leading cause of cancer, and many patients continue to smoke after diagnosis, increasing their risk of cancer recurrence and decreasing quality of life and survival rates.

Smoking and Patients With Cancer

Smoking is responsible for 30% of all cancer-related deaths and 87% of lung cancer-related deaths (ACS, 2010). A diagnosis of cardiovascular disease or cancer can provide a “teachable moment” for smoking cessation (McBride & Ostroff, 2003), but only patients with cardiovascular disease have high quit rates (Hajek, Taylor, & Mills, 2002) while greater than half of patients with cancer fail to stop smoking after diagnosis (Cataldo, Dubey, & Prochaska, 2010; Duffy et al., 2012; Sardari Nia et al., 2005). Patients with cancer are personally, physically, and situationally vulnerable to smoking and are likely to be long-term, heavy smokers who depend on smoking to deal with psychological distress. A sense of fatalism decreases the likelihood of smoking cessation in patients with cancer. The presence of smokers in a patient’s social network, particularly a spouse, is a strong predictor of relapse after a temporary quit attempt (Gritz et al., 1993). Many patients feel stigmatized for having a smoking-related cancer (Cooley, Lundin, & Murray, 2009). Continuing smokers show decreased response to radiotherapy and chemotherapy, impaired wound healing, increased infections, circulatory problems (Cataldo et al., 2010; Gritz, Dresler, & Sarna, 2005), increased risk of recurrence and second cancers, and decreased quality of life and survival rates (Gritz, Lam, Vidrine, & Fingeret, 2011). Continuing smokers tend to be younger, less educated, uninsured, and depressed (Berg et al., 2012; Underwood, 2012).

Smoking cessation yields several benefits, including decreased surgical complications (e.g., deep vein thrombosis, poor wound healing, pulmonary embolism) (Manassa, Hertl, & Olbrisch, 2003; Warner et al., 1989); improvements in pulmonary and immune function (U.S. Department of Health and Human Services, 2004); a decreased risk of a second cancer (Kawahara et al., 1998; Tucker et al., 1997); and improved quality of life and survival rates (Duffy et al., 2009). Although multiple clinical trials showed the efficacy of smoking cessation interventions, there were relatively few smoking cessation clinical trials that focused on smokers with cancer. Of the few that exist, only two were efficacious (Duffy et al., 2006; Emmons et al., 2013). Most studies were underpowered. Nonetheless, countless clinical trials showed that when smoking cessation services are offered, smokers quit (Doll, Peto, Boreham, & Sutherland, 2004).

Despite this evidence, less than half of cancer centers have tobacco treatment programs (Morgan et al., 2011). Smoking cessation counseling is recommended as evidence-based practice by the U.S. Preventive Services Task Force (2003). The 2014 Surgeon General’s Report on Smoking states that failure to provide smoking cessation services to patients with cancer is unacceptable (U.S. Department of Health and Human Services).

Barriers to Providing Smoking Cessation

A major institutional barrier to adopting smoking cessation services in cancer treatment centers is the failure to systematically integrate cessation into routine practice and documentation systems. A 2009 NCI conference, "Treating Tobacco Dependence," identified the need for smoking cessation interventions in cancer treatment centers (Morgan et al., 2011). NCI and the American Association for Cancer Research assembled a task force for the assessment of tobacco use in patients with cancer.

A barrier to nurses who want to implement cessation services is not a lack of time but a lack of expertise (Duffy, Reeves, Hermann, Karvonen, & Smith, 2008; Sarna et al., 2009). Medical and nursing education does not typically include training to treat health behaviors such as smoking. In addition, providers tend to think that patients with cancer already are overwhelmed by treatment. Providers may feel that asking patients to attend extra appointments and cope with withdrawal symptoms is asking too much, even though the evidence for this is poor (Patsakham, Ripley-Moffitt, & Goldstein, 2009). As a result, only 56% of physicians recommend their patients with cancer stop smoking (Schnoll et al., 2003), and most oncology providers do not offer smoking interventions beyond advice to quit even though 70% of patients with cancer are motivated to quit (Weaver et al., 2012). In addition, the misconception that nicotine replacement therapy (NRT) diminishes the effects of surgery because of vasoconstriction makes surgeons reluctant to provide NRTs to patients with cancer (Moller, Villebro, Pedersen, & Tonnesen, 2002).

Smoking Cessation Interventions

There are many ways in which smoking cessation services can be delivered. Computers and other electronic aids increase the likelihood of cessation compared to no interventions or generic self-help materials, but the effect is small. There also are outpatient groups (which many patients with cancer are too sick to attend) and on-the-spot, in-clinic interventions. The 1-800-QUITNOW programs are available in 48 states. There also are services offered by NCI, including (a) the booklet, *Clearing the Air*, (b) the quit-line, 1-877-44U-QUIT, (1-877-448-7848), (c) the website www.smokefree.gov, (d) a mobile text-messaging program, SmokefreeTXT, and (e) the LiveHelp Chat Service. However, all efficacious smoking cessation programs consist of both behavioral and pharmaceutical intervention (NCI, 2014b).

Behavioral Interventions

Although many behavioral interventions increase quit rates, there is insufficient evidence to support the use of any one specific behavioral intervention to help patients who successfully quit to avoid relapse. Brief advice to quit has a small increased effect, showing cessation rates 1%–3% higher than the unassisted quit rates of 2%–3% (Stead et al., 2013). Behavioral counseling increases quit rates in patients using pharmaceutical interventions (Stead & Lancaster, 2012).

Pharmaceutical Interventions

The Cochrane Collaborative Reviews showed that smoking cessation interventions providing counseling and pharmaceuticals (NRT, bupropion, and varenicline) are effective (Rigotti, Clair, Munafo, & Stead, 2012). Therefore, smoking cessation pharmacotherapies are recommended by the U.S. Department of Health and Human Services' clinical practice guidelines. NRT has been available as an over-the-counter smoking cessation pharmacotherapy since 1996. As a result, there has been wide-scale distribution of smoking cessation pharmacotherapies by municipalities (such as New York), insurance companies, and 1-800-QUITNOW telephone lines in addition to over-the-counter sales.

Inpatient Interventions

Many studies (Rigotti, Munafo, Murphy, & Stead, 2005; Rigotti, Munafo, & Stead, 2008) have shown that inpatient smoking cessation interventions with telephone follow-up services for hospitalized smokers are efficacious. Hospitalization provides an excellent opportunity for patients to quit smoking because they are a captive audience, are often motivated to quit because of illness, and often quit temporarily because of hospital smoking bans. Inpatient programs enroll a higher percentage of patients who smoke and result in higher cessation rates than outpatient programs. Despite the strong evidence for the efficacy of inpatient smoking interventions, implementation in hospitals is limited (Rice & Stead, 2008; Taylor & Curry, 2004).

Institutional-Level Interventions

There is support for nursing documentation templates in the electronic health record (EHR) for improving nurses' delivery of brief cessation counseling (Katz et al., 2013). The expectation that the EHR will be used, documentation of tobacco status, and increased referral to cessation counseling appear to increase quit rates (Boyle, Solberg, & Fiore, 2011). Clinical reminders enhance screening for smoking, which decreases mortality in patients with lung cancer (Bach et al., 2012; Gutierrez, Suh, Abtin, Genshaft, & Brown, 2013; Manser et al., 2013; Yuan, Butler, Stepanov, & Hecht, 2014) and informs diagnosis and treatment. Standardizing and integrating smoking cessation at the institutional level so that patients receive the same message at all points of contact is important. The sustainability of interventions can be enhanced by incorporating interventions into new nurse training using EHR documentation templates.

Nurse-Delivered Interventions

Meta-analyses by Rice and Stead (2008) and suggested that nurse-administered interventions are efficacious, particularly in hospitalized patients, and should be emphasized during a "teachable moment" such as immediately after a cancer diagnosis. However, nurse-administered cessation interventions are seldom implemented because of a lack of training and time (Duffy, Reeves, et al., 2008). Training health professionals about smoking cessation increases their delivery of these services and increases quit rates. Once knowledgeable, nurses are ideally positioned to deliver cessation interventions because (a) nurses are educated in patient education and psychosocial and physiologic interventions, (b) physician time is at a premium while nursing time is more cost-effective, (c) nurses have access to and immediate rapport with patients as well as respect from physicians, (d) nurses understand the patient's medical condition

and can tailor the intervention accordingly, and (e) nurses can read charts, initiate medication orders, and write nursing notes (Rice, Hartmann-Boyce, & Stead, 2013).

Electronic Cigarette Use

The frequency of electronic cigarette (e-cigarette) use has increased, and as many as 10% of American high school students used these devices as of 2012 while about 3.4% of American adults used them as of 2011 (Carroll Chapman, & Wu, 2014). An e-cigarette, personal vaporizer, or electronic nicotine delivery system is a battery-powered vaporizer that has the feel of tobacco smoking. They produce mist instead of smoke (Cheng, 2014; Grana, Benowitz, & Glantz, 2014). The benefits and risks of e-cigarette use are uncertain (Harrell, Simmons, Correa, Padhya, & Brandon, 2014; Odum, O'Dell, & Schepers, 2012). Evidence suggests that e-cigarettes may be safer than smoking tobacco products (Britton & Bogdanovica, 2014; Caponnetto et al., 2013). They may be as safe as other nicotine replacement products, but there are not enough data to draw conclusions (Britton & Bogdanovica, 2014; Caponnetto et al., 2013). E-cigarettes may carry a risk of addiction for users who do not already smoke (World Health Organization, 2013), but there is no evidence of ongoing use among those who have never smoked (Hajek, Etter, Benowitz, Eissenberg, & McRobbie, 2014). E-cigarettes may delay or deter smoking cessation (Grana et al., 2014).

Lung Cancer Screening Guidelines

In December 2013, the U.S. Preventive Services Task Force published a recommendation on lung cancer screening using low-dose computed tomography (Moyer, 2014) for asymptomatic adults ages 55-80 who have a 30-pack-year smoking history and currently smoke or have quit within the past 15 years. Lung cancer screening programs are required to provide smoking cessation services as participants undergoing lung cancer screening have increased motivation to quit smoking (Poghosyan, Kennedy Sheldon, & Cooley, 2012).

Smoking remains the leading cause of cancer, and many patients with cancer continue to smoke. Efficacious smoking cessation interventions are available. The challenges that remain are implementing these interventions in busy oncology practices and screening for lung cancer among long-term smokers.

Recommendations for research include the need to develop and test interventions to sustain cancer screening behavior beyond the completion of one-time screening, specifically to (a) develop and test interventions that increase first-time and interval screening in underserved and understudied populations, (b) develop and test culturally responsive interventions, including those that enhance healthcare providers' cultural competence, (c) apply findings from other areas with more extensive research (e.g., breast cancer screening) to increase screening for other cancers, and (d) conduct comparative effectiveness trials to apply evidence-based intervention strategies in cancer screening to clinical and community practice settings. There also is a need to develop and test interventions that help individuals adopt and maintain health behaviors that prevent or reduce the risk for cancer, specifically to (a) develop and test innovative, cost-effective interventions for health behavior change, (b) develop and test culturally

appropriate health behavior interventions for minority and underserved groups, and (c) develop and test interventions to change multiple health behaviors that can reduce or prevent cancer. Finally, the dissemination and implementation of evidence-based interventions in cancer screening and health behavior change should be considered. Specific recommendations include (a) adapting and testing efficacious interventions for implementation in clinic or community settings, (b) implementing and evaluating dissemination and implementation models for translating evidence-based interventions into practice, (c) developing and testing academic-practice partnerships to accelerate dissemination and implementation models, and (d) collaborating with healthcare systems and practices to test models of dissemination and the implementation of efficacious interventions to enhance sustainability.

I. Cross-Cutting Themes

Several innovative, cross-cutting themes are identified that should be considered as research studies are developed in the priority areas identified by the ONS Research Agenda. These innovative, cross-cutting themes include bioinformatics, biomarkers, comparative effectiveness research, and dissemination and implementation science. Some relevant background information regarding each theme is summarized in this section.

Bioinformatics

The integration of biomedical data to improve the management of chronic medical conditions is intimately linked to the era of precision health care. With the increasing availability of “omics” data and the digitalization of clinical examinations and medical records, the era of Big Data is a reality (Merelli, Pérez-Sánchez, Gesing, & D’Agostino, 2014). Big Data is a collection of data sets whose size is beyond the management capabilities of a typical software program that examines relational databases. The hope for the future is that these large amounts of heterogeneous digital data will be used to uncover hidden patterns. The discovery of these hidden patterns will allow for the creation of predictive models for real-life biomedical applications (Merelli et al., 2014).

In a recent review, Du and Elemento (2014) describe how the principles of bioinformatics and systems biology can be used to understand the complex biologic mechanisms associated with tumor growth and to develop better anticancer treatments. They noted the need for transdisciplinary research integrating the knowledge and expertise of oncology clinicians, mathematicians, systems biologists, bioengineers, and molecular geneticists to improve the care of patients with cancer. Their hope is that computational and mathematic models will be developed to identify key pathologic mechanisms for cancer, establish predictive biomarkers for cancer and its treatment, and develop individualized cancer treatments. Nurse scientists will need to work with these types of transdisciplinary teams to design studies that address the ONS Research Priorities (Nass & Wizemann, 2012).

Biomarkers

The era of precision health also is upon us. As noted in a National Research Council (2011) report on precision medicine, the specialty of oncology has led efforts to identify distinct tumor subtypes for a number of cancers (Anders, Zagar, & Carey, 2013; Lam, Jimenez, & Boven, 2014) based on tumor-specific characteristics and various molecular profiling techniques. The goal of these efforts was to develop mechanistically based interventions that can be tailored to address interindividual variability in cancer. The development of these mechanistically based interventions involve the collection of a variety of biomarkers (Flowers, Froelicher, & Aouizerat, 2013; Gilbertson-White, Aouizerat, & Miaskowski, 2011; Stephens, Miaskowski, Levine, Pullinger, & Aouizerat, 2013).

A biomarker is a biologic molecule found in the blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease (National Cancer Institute, n.d.). A biomarker may be used to confirm a diagnosis, investigate the underlying mechanism for a particular condition, identify patients at higher risk for a particular condition, or evaluate the efficacy of an intervention. In the context of the ONS Research Priorities, recent studies used a variety of biomarkers to investigate mechanisms that underlie common symptoms associated with cancer treatment (Alfaro et al., 2014; Hsiao, Araneta, Wang, & Saligan, 2013; Hsiao, Wang, Kaushal, & Saligan, 2013; Stephens et al., 2014) and the gerontologic effects of chemotherapy (Sanoff et al., 2014). Future studies need to incorporate one or more biomarkers to identify patients at higher risk for poor outcomes and the efficacy of a variety of interventions to improve the care of patients with cancer.

Comparative Effectiveness Research

The IOM (2009) defined comparative effectiveness research (CER) as the “generation and synthesis of evidence that compares the benefits and harms of alternative methods to prevent, diagnose, treat, and monitor a clinical condition, or to improve the delivery of care. The purpose of CER is to assist consumers, clinicians, purchasers, and policy makers to make informed decisions that will improve health care at both the individual and population levels.” As noted by Chen (2014), an urgent need for CER exists in oncology because of the continuing rapid development of diagnostic and therapeutic advances. Although clinicians and patients with cancer are faced with an increased number of diagnostic and treatment options, less is known about the impact of these options on treatment-related morbidity, quality-of-life outcomes, financial burden, and survival. Nurse scientists are uniquely qualified to design and conduct CER studies.

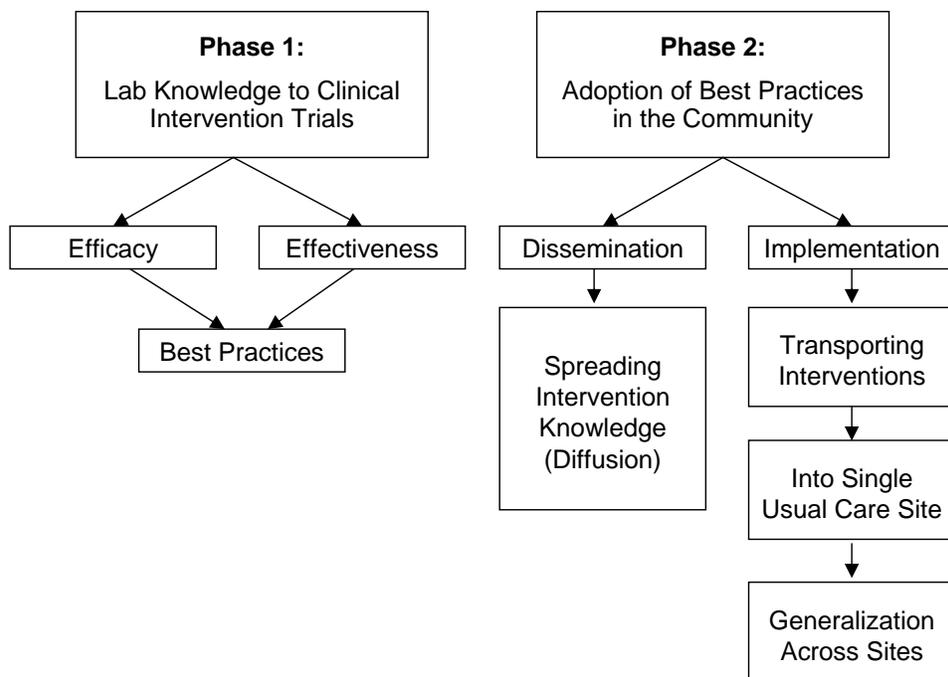
Dissemination and Implementation Science

The evidence base for the delivery of efficacious nursing care continues to expand. However, a gap exists between available evidence and current practice. An urgent need exists to develop, implement, and scale research-informed initiatives that directly enhance care quality while simultaneously contributing new knowledge to the field of implementation science in oncology nursing.

Dissemination and implementation research encompasses studies designed to evaluate the effectiveness of an intervention in a population and to assess a process of

transferring the knowledge, skills, and systems of support needed to deliver an intervention to a target audience. The selection of a conceptual model to guide the design of the intervention, study aims, outcomes measurement, and analysis and interpretation of results is an important decision. A wide range of models are available (Mitchell, Fisher, Hastings, Silverman, & Wallen, 2010; Tabak, Khoong, Chambers, & Brownson, 2012) to guide dissemination and implementation research.

Figure 1: Conceptual Model of Testing Interventions in Clinical Trials (Phase I) and Dissemination and Implementation Research (Phase 2) (Brekke, Eil, & Palinkas, 2007).



If oncology nursing interventions with known efficacy and cost-effectiveness are not utilized by providers, consumers, and healthcare delivery systems, the impact of this science will be modest. Research to accelerate the widespread implementation of research-tested interventions, reduce practice variation, and strengthen care quality is urgently needed in five key areas, (a) studies of strategies (e.g., audits and feedback, clinician reminders and alerts, decision support, practice facilitation) that promote the adoption of cost-effective interventions by clinicians, (b) 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 simultaneously maintaining efficacy, (c) evaluate research-practice partnerships that increase the likelihood that cost-effective interventions can be embedded within care delivery processes, (d) studies that enhance the usability, acceptability, and integration of informatics and other technologies that support the delivery of patient-centered, guideline-concordant care, and (e) test system-wide efforts to routinely achieve evidence-based care (e.g., the learning healthcare system) (Murphy & Patlak, 2010; Shaikh et al., 2014), including the development, implementation, and

evaluation of point-of-care information collection using patient-reported outcomes and sensor devices, coupled with clinical decision support.



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I. Cross-Cutting Themes

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