ONCOLOGY NURSING SOCIETY
2014–2018 RESEARCH AGENDA
DRAFT for Public Comment

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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. The ONS Research Agenda process
has been a multi-method, stakeholder-driven, consensus-building effort since its initial
development in 2001. 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 four cross-cutting
themes (Bioinformatics, Biomarkers, Comparative Effectiveness Research, and
Dissemination and Implementation Science) and eight priority content areas
(Symptoms, Survivorship, Self-Management, Risk Reduction, Family and Caregivers,
Palliative and End of Life Care, Improving Health Systems and Aging).

B. Cross-cutting themes

Four innovative cross-cutting themes were identified: Bioinformatics, Biomarkers,
Comparative Effectiveness Research, and Dissemination and Implementation Science.

1. Bioinformatics

   Use of large data sets to explain patient outcomes and increase our
   understanding of the complexity of disease, treatment, and patient responses
   Creation of predictive models
   Development of transdisciplinary teams

2. Biomarkers

   Identify underlying mechanism for a particular condition/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

Studies of strategies (eg. audit and feedback, clinician reminders/alerts, decision-support, practice facilitation) that promote the adoption of cost-effective interventions by clinicians;

Studies that examine the extent to which research-tested interventions (eg. exercise for fatigue, cognitive-behavioral therapy for sleep) can be tailored to a wide variety of service delivery models while at the same time preserving efficacy;

Evaluate research-practice partnerships that increase the likelihood that cost-effective interventions can be embedded within care delivery processes;

Studies to enhance the usability, acceptability and integration into workflow of informatics and other technologies support the delivery of patient-centered, guideline concordant care; and

Test system-wide efforts to routinely achieve evidence-based care (for example the learning healthcare system) (IOM 2010; Skaikh 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.

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 mechanism of individual and co-occurring symptoms and test mechanistic hypotheses within the context of intervention research

Determine factors associated with racial/ethnic disparities in symptom severity and develop and evaluate interventions that address these disparities

1. Fatigue

Explore motivational factors and barriers to increasing uptake of interventions

Disseminate exercise interventions in community settings

Gain a better understanding of the underlying biological mechanisms associated with CRF

Examine whether combining non-pharmacological and pharmacological approaches enhance the effect 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
Focus on other homogenous groups of patients’ other than women with breast cancer, especially those including men and older adults.
Determine optimal dose, frequency and duration of interventions.
Compare various treatments to determine the most effective approach for sleep disturbances.

4. Symptom Clusters
   Develop a taxonomy of symptom clusters that can guide future interventions.
   Understand the underlying bio-behavioral mechanisms associated with symptom clusters.
   Include more racially diverse samples of patients to test interventions.

5. Chemotherapy-Induced Peripheral Neuropathy
   Identification of well-validated, reliable, and clinically-useful assessment measures including physiological markers.
   Identification of risk factors for patients with severe and/or irreversible CIPN symptoms.
   Evidence-based pharmacological and non-pharmacological treatment options.

6. Psychological Distress
   Identify predictors of distress for cancer survivors and their families.
   Translational research to foster successful implementation of distress screening in clinical practice.
   Large-scale, well-designed trials establishing evidence of the effect of non-pharmacological interventions and psychosocial support that are feasible to deliver and cost-effective.

B. LATE EFFECTS OF CANCER TREATMENT AND SURVIVORSHIP CARE

1. Develop or test and implement interventions to prevent or minimize adverse outcomes related to long term * or late effects* and risks associated with the development of co-morbid 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, recurrence and survival.
   Conduct interventions that address social and work re-integration issues during and after cancer therapy.
   Evaluate outcomes of survivorship intervention research on health care 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 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 and the oncology nursing workforce related to survivorship.

C. PALLIATIVE AND END OF LIFE CARE

1. Explore models for training providers to effectively communicate with patients in palliative care and end of life phases of care.

2. Evaluate team-based approach models of communication on patient and family outcomes.

3. Explore and test interventions to improve shared decision making in palliative care and end of life phases of care.

4. Symptom management at end of life for children

5. Examine effects advanced care planning in palliative care on pediatric cancer patient outcomes

6. Explore models of palliative and end of life care from hospital to community for pediatric cancer patients and their families.

7. Explore preferences for decision making and care in the palliative and end of life phases of care among the growing diverse US population.

8. Explore and test models of care palliative care delivery, including but not limited to the interdisciplinary team, cost-benefit of services, timeliness of referrals, continuity of care and technology.

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

10. Evaluate inter-professional education models for improving end of life care.

D. SELF-MANAGEMENT

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

2. Research is needed to develop and test models of care in self-management across the cancer care continuum.
   Identify the needs of patients and caregivers regarding self-management during periods of transition, 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/specialties to improve self-management at all phase of the cancer care continuum.

3. Research is needed to develop and test self-management interventions directed at the individual and/or their family caregiver(s) which 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 the 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 caregiver’s overtime.
   Develop and test self-management interventions to assist patients in managing their cancer and other pre-existing chronic conditions.

4. Research is needed to develop and test interventions to improve adherence to prescribed and/or recommended plans of care.
   Develop and test strategies for improving adherence to prescribed treatment regimens.
   Develop and test strategies for improving adherence to 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 knowledge gap
   Describe how lifestyle factors such as nutrition, exercise, smoking, ETOH intake affect the symptom burden and treatment responses of older patients.
   Explore the impact of age, cancer and biased decisions related stigma on older patient outcomes.
   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.
*psychological comorbidities such as depression, anxiety, drug and alcohol addiction

2. Develop, test and implement Interventions to improve the care of the older patients
   Test interventions that promote engaged treatment decision making based on risks assessed through a comprehensive geriatric assessment (CGA). Which components of the CGA predict treatment outcomes (e.g. function status, HRQOL)?
   Determine how to adapt symptom management interventions, to decrease risk and enhance protective factors, to 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 those older oncology patients at higher risk of poorer outcomes and target interventions to maintain or improve these 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, and health care 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 levels of frailty and function) beyond progression and survival (e.g., impact of disease and treatment on HRQOL, function, cognition, independence).

F. FAMILY and CAREGIVERS
   1. Research should identify the impact of caregiver outcomes on patient clinical 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/family to improve patient outcomes across the care trajectory.

   2. Research should determine the impact of the stress of providing care on the caregiver’s physiologic health.
Conduct studies that examine cellular response to providing care in order 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 both psychosocial and physiological strategies to improve overall health.

3. Research is needed to explore, define, and determine the extent of economic burden and its impact on families of persons with cancer. Explore the impact of economic burden on both 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 persons 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 HEALTH CARE SYSTEMS


2. Evaluate the effect of nursing care on promoting and maintaining treatment quality and safety. Understand predictors (risk models), cost settings, side effects, educational approaches, population health literacy, and cognitive changes associated with adherence to self-care. Evaluate the influence of various care providers and cost effectiveness on quality and safety. Evaluate strategies for the identification and prevention of adverse events related to quality and safety. Develop and test interventions that support delivery of quality care indicators.

H. RISK REDUCTION

1. Develop and test interventions to adopt or maintain health behaviors that reduce risk for or prevent cancer (e.g., tobacco control, physical activity, dietary change, weight management). Develop and/or test innovative cost effective models. Develop and/or test culturally appropriate models for minority and underserved groups.
Develop and/or test innovative and cost-effective interventions to change multiple health behaviors in a population that can reduce or prevent cancer (e.g., obesity and tobacco cessation).

2. Develop and/or test interventions to sustain cancer screening behavior beyond completion of one-time screening.
   Develop and/or test interventions increase first-time and interval cancer 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.

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.
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, “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 four cross-cutting themes (Bioinformatics, Biomarkers, Comparative Effectiveness Research, and Dissemination and Implementation Science) and eight priority content areas (Symptoms, Survivorship, Self-Management, Risk Reduction, Family and Caregivers, Palliative and End of Life Care, Improving Health Systems and Aging).

A. Cross-Cutting Themes

Several innovative, cross cutting themes were identified that should be considered as scientists develop research studies with the priority areas identified in the Oncology Nursing Society’s 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 below.

A.1. Bioinformatics – Intimately linked to the era of precision health care is the integration of biomedical data to improve the management of chronic medical conditions. With the increasing availability of “omics” data as well as the digitalization of all clinical exams and medical records data, the era of Big Data is a reality (Merelli, Pérez-Sánchez, Gesing, & D’Agostino, 2014). A simple definition of 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 in the data. The discovery of these hidden patterns will allow for the creation of predictive models for real-life biomedical applications (Merelli, Pérez-Sánchez, Gesing, & D’Agostino, 2014).

In a recent review (Du & Elemento, 2014), Du and Elemento describe how the principles of bioinformatics and systems biology can be used to increase our understanding of the complex biologic mechanisms associated with tumor growth and to develop better anticancer treatments. They noted the need for transdisciplinary research that will integrate the knowledge and expertise of oncology clinicians, mathematicians, systems biologists, bioengineers, and molecular geneticists to improve the care of patients with cancer. The hope is that computational and mathematical models will be develop to identify key pathologic mechanisms for cancer, as well as 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 (Institute of Medicine, 2012).

A.2. Biomarkers – The era of precision health is upon us. As noted in a recent
National Research Council report on precision medicine (Council NR, 2011), 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 is to develop mechanistically-based
interventions that can be tailored to address inter-individual variability in the
cancer. The development of these mechanistically-based interventions involve
the collection of a variety of biomarkers (for reviews see Flowers, Froelicher, &
Aouizerat, 2013; Gilbertson-White, Aouizerat, & Miaskowski, 2011; Stephens,

A biomarker is defined as a biological 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; to investigate the underlying mechanism for a particular condition;
identify patients at higher risk for a particular condition; or evaluate the efficacy of
an intervention. Within the context of the ONS research priorities, recent studies
have used a variety of biomarkers to investigate the 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 gerontogenic effects of cancer chemotherapy
(Sanoff et al., 2014). Future studies need to incorporate one or more biomarkers
to be able to identify patients at higher risk for poorer outcomes, as well as the
efficacy of a variety of interventions to improve the care of oncology patients.

A.3. Comparative Effectiveness Research (CER) – The Institute of Medicine
defined 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" (Institute of Medicine, 2009). As noted by Chen in a recent
issue of Seminars in Radiation Oncology (Chen, 2014), an urgent need for CER
exists in oncology because of the continued and rapid development of diagnostic
and therapeutic advances. While, clinicians and cancer patients 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 these types of CER studies.

A.4. Dissemination and Implementation Science: The evidence base for the
delivery of efficacious nursing care continues to expand, however there remains
a continuing gap between available evidence and current practice. There is a need 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: i) evaluate the effectiveness of an intervention in a population; and/or ii) evaluate a process of transferring to a target audience the knowledge, skill and systems support needed to deliver an intervention. Selection of a conceptual model to guide design of the intervention, study aims, outcomes measurement, and analysis and interpretation of results is an important decision, and there is a wide range of available models (Mitchell, Fisher, Hastings, Silverman, & Wallen, 2010; Tabak, Khoong, Chambers, & Brownson, 2012) for dissemination and implementation research.

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

If oncology nursing interventions with known efficacy and cost-effectiveness are not utilized by providers, consumers and health care delivery systems, the impact of our science will be modest. Research to accelerate widespread implementation of research-tested interventions, reduce practice variation, and strengthen care quality is urgently needed in five key areas: (i) studies of strategies (eg. audit and feedback, clinician reminders/alerts, decision-support, practice facilitation) that promote the adoption of cost-effective interventions by clinicians; (ii) studies that examine the extent to which research-tested
interventions (eg. exercise for fatigue, cognitive-behavioral therapy for sleep) can be tailored to a wide variety of service delivery models while at the same time preserving efficacy; (iii) evaluate research-practice partnerships that increase the likelihood that cost-effective interventions can be embedded within care delivery processes; (iv) studies to enhance the usability, acceptability and integration into workflow of informatics and other technologies support the delivery of patient-centered, guideline concordant care; and (v) test system-wide efforts to routinely achieve evidence-based care (for example the learning healthcare system) (IOM 2010; Skaikh 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.

II. CONTENT AREAS

A. Symptoms

A.1. Significance and background for symptom research: Symptoms are defined as a subjective experience that reflects changes in biopsychosocial functioning, sensations or cognitions. Uncontrolled 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 been leading members of multidisciplinary teams that have 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 and colleagues (Berry et al., 2014) reduced symptom distress in ambulatory oncology patients through the use of an electronic self-report symptom and quality of life assessment and self care program. Future research needs to 1) 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, health care utilization and costs of care and 2) understand the differential effects of symptom management interventions (Given, Bradley, You, Sikorskii, & Given, 2010; Sikorskii et al., 2014).

A.2. 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 has been identified as one of the top three symptoms 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 monoamine pathways that regulate serotonin, dopamine and norepinephrine have been examined and implicated as mechanisms underlying CRF (Barsevick et al., 2013). A recent
study by Dhruva and colleagues (Dhruva et al., 2014) examined differences in cytokine genes among those with morning and evening patterns of fatigue and whether participant characteristics differ between these groups and found that different inflammatory genes were associated with high and low levels of fatigue and that patient characteristics differed by group suggesting that morning and evening fatigue may be distinct but related symptoms.

The efficacy of exercise has been firmly established as a treatment for CRF (Brown et al., 2011). In a meta-analysis, Brown and colleagues (J. C. Brown et al., 2011) found that CRF levels were reduced to a greater degree by interventions using a theory-driven approach and those with more intense resistance exercise. Psychoeducational interventions, management of concurrent symptoms, 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). Future research is needed to 1) explore motivational factors and barriers to increasing uptake of interventions, 2) disseminate exercise interventions in community settings, 3) gain a better understanding of the underlying biological mechanisms associated with CRF, 4) examine whether combining nonpharmacological and pharmacological approaches enhance the effect of individual treatments.

A.3. 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 adequately treated, undertreatment remains a widespread problem and has not changed over the last 2 decades (Fisch et al., 2012). Moreover, racial disparities in pain treatment exist (Anderson, Green, & Payne, 2009). Fisch and colleagues (Fisch et al., 2012) found that inadequate analgesia prescribing was twice as high for minority patients as compared to white patients.

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

Self-care management and psychosocial interventions are an important additive component to pharmacological management (Koller, Miaskowski, De Geest, Opitz, & Spichiger, 2012; Sheinfeld Gorin et al., 2012). Koller and colleagues (2012) evaluated the content, structure and efficacy of self-care interventions and found clinically meaningful differences in decreased pain intensity. However, no single component was found to be most efficacious. Drwecki and colleagues (2011) conducted laboratory experiments examining the role of empathy and
perspective taking in reducing racial disparities in pain treatment (Drwecki, Moore, Ward, & Prkachin, 2011). The results suggested that an empathy inducing perspective-based intervention reduced racial bias by upwards of 55% and improved pain treatment for black patients. Future research is needed to 1) implement systems-level interventions that promote uptake of evidence-based pain management, 2) understand factors associated with racial disparities and undertreatment of pain and evaluate interventions that address disparities.

A.4. **Sleep:** 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 as compared with the general population. Insomnia is the most common sleep disorder and the majority of research has focused on this type of disorder.

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

The majority of sleep interventions have used non-pharmacological approaches and focused on women with breast cancer. CAM treatments have been studied most often due to the diversity of interventions that fall within this category followed by cognitive behavioral therapies and then exercise. CBT has been the most rigorously studied intervention and has been found to have moderate treatment effects in a meta-analysis conducted by Langford and colleagues (Langford et al., 2012). CAM and exercise have also been found to be efficacious. Despite the common frequency of insomnia in ambulatory oncology patients, clinicians attended to self-reports of insomnia from patients only about half the time, however, they provided management strategies likely to be effective (Siefert, Hong, Valcarce, & Berry, 2014). Future studies need to 1) focus on other homogenous groups of patients other than women with breast cancer, especially those including men and older adults 2) determine optimal dose, frequency and duration of interventions, 3) compare various treatments to determine the most effective approach for sleep disturbances.

A.5. **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 whether at least two or three symptoms are needed for a cluster. Current evidence suggests that as little 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 that marks the presence of a cluster (pain) (Brown, Cooley, Chernecky, & Sarna, 2011), and that some symptoms seem to occur in a cascade pattern where one symptom contributes (insomnia) to development of other symptoms (fatigue and then depression) (Jim et al., 2013).

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

Our understanding of statistical techniques used for analysis of symptom clusters over time has advanced over the past several years (Xiao, Bruner, Jennings, & Hanlon, 2014). There has also been increased testing of interventions focused on symptom clusters, especially fatigue, depression, anxiety, and insomnia among early stage patients (Berger, Yennu, & Million, 2013). CBT, CAM, psychoeducation and exercise interventions have been found to have efficacy. Future research is needed to 1) develop a taxonomy of symptom clusters that can guide future interventions, 2) understand the underlying biobehavioral mechanisms associated with symptom clusters, and 3) include more racially diverse samples of patients to test interventions.

A.6. Cancer Treatment-Related Cognitive Impairment: Cognitive impairment has been defined as those 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 most common (C. E. Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005). Neuroimaging studies have also 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 pathophysiological mechanisms include: neurotoxic injury in the brain, microvascular injury, secondary central and/or systemic inflammatory processes, or dysregulation of the HPA axis resulting in changes in endogenous hormones (estrogen). Cancer treatment may also 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 usage, and genetics may also contribute to cognitive deficits in cancer survivors (Bender & Thelen, 2013). Cognitive deficits may also 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 contribute to the difficulty of assessing and effectively treating this symptom (Bender & Thelen, 2013). There are no definitive cognitive function assessment standards (C. Jansen, 2013); however, the International Cognition and Cancer Task Force has recommended a set of neuropsychological assessments for research purposes (Wefel, Vardy, Ahles, & Schagen, 2011) and the NIH supported, Patient Reported Outcomes Measurement and Information System (PROMIS), www.nihpromis.org has recommended assessing perceived cognitive concerns and cognitive abilities(Lai, Wagner, Jacobsen, & Cella, 2014). Researchers have explored pharmacological (e.g., methylphenidate, memantine, modafinil, and donepezil) and non-pharmacological interventions (e.g., cognitive training, exercise, cognitive behavioral therapy) (Von Ah, Jansen, Allen, Schiavone, & Wulff, 2011). To date, only cognitive training has been designated as likely to be effective in improving cognitive performance (Von Ah et al., 2012).

Future research should address the following areas: 1) identification of sensitive and clinically useful cognitive assessment measures; 2) identification of risk factors (e.g. demographic, treatment, genetic factors) of post-treatment cognitive decline as only a subset of patients have long-term cognitive changes; 3) development of longitudinal studies that examine cognitive changes in context to age-related decline to thoroughly understand its implications; and 4) development of translational evidence-based interventions to address cognitive performance and enhance coping with cognitive changes.

A.7. Chemotherapy-Induced Peripheral Neuropathy: Chemotherapy-induced peripheral neuropathy (CIPN) is a common and distressing problem for cancer patients receiving neurotoxic chemotherapeutic agents such as taxanes, epothilones, bortezomib, thalidomide, and vinca alkaloids (Smith et al., 2013; Wood et al., 2014). While effective in treating cancer, these agents damage the nerve cell axon, myelin sheath and cell body in the dorsal root ganglion (Han & Smith, 2013). The exact pathophysiology however, has not been elucidated. Diagnostic features that distinguish CIPN include: symmetrical, distal, length dependent ‘glove and stocking’ distribution; predominately sensory symptoms including pain, numbness and tingling; and onset after chemotherapy which may be rapid, progressive and irreversible (Stubblefield et al., 2009). Other symptoms may include muscle weakness which can impair functioning and mobility (Miltenburg & Boogerd, In Press) and result in falls and other injuries (Tothagen, 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 varies 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 both sensory and functional elements (Smith, 2013). To date, there are no known agents for the prevention of CIPN (Hershman et al., 2014). In regards to treatment, randomized clinical trials have identified duloxetine as moderately effective in reducing pain associated with CIPN (Hershman et al., 2014; Smith et al., 2013). Treatments addressing neuropathic pain in other populations such as gabapentin, tricyclic antidepressants, and a compounded topical gel of baclofen, amitriptyline HCL, and ketamine need further research but, may also offer pain relief (Hershman et al., 2014).

Future research is needed that addresses: (1) identification of well-validated, reliable, and clinically-useful assessment measures including physiological markers; (2) identification of risk factors for patients with severe and/or irreversible CIPN symptoms; and (3) evidence-based pharmacological and non-pharmacological treatment options.

A.8. Psychological Distress: Psychological distress has been identified as the sixth vital sign and affects a subgroup of survivors. In fact, researchers have shown that 20% to 40% of the 28.8 million cancer survivors worldwide incur psychological distress (National Comprehensive Cancer Network, 2013). Psychological distress has been noted on a continuum from normal feelings of sadness and fears to overwhelming and potentially disabling symptoms such as depression and anxiety. Practice guidelines have mandated screening for psychological distress (Holland, Watson, & Dunn, 2011; Jacobsen & Wagner, 2012; National Comprehensive Cancer Network, 2013); however, researchers have found that screening remains limited with only 70% of member institutions in compliance (Donovan & Jacobsen, 2013). In addition, evidence has been 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 including ONS identified strategies for the successful implementation of distress screening (Pirl et al., 2014). The Patient Health Questionnaire-4 and the Distress Thermometer have been identified as acceptable, reliable and valid instruments to assess psychological distress (Donovan, Grassi, McGinty, & Jacobsen, 2014; Pirl et al., 2014).

Although, one recent large, epidemiological study identified worsening health overtime as a significant predictor of psychological distress (Brinkman et al., 2013), more research is needed regarding identifying predictors of distress for cancer survivors and their families. Other priorities include: (1) translational research to foster successful implementation of distress screening in clinical practice and (2) large-scale, well-designed trials establishing evidence of the effect of non-pharmacological 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)

Long-term effects are residual problems that are caused by a disease or its treatment and may continue for months or years after treatment ends. Long-term side effects of cancer treatment include 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. (National Cancer Institute)

Survivorship care issues are related to the ability to get health care and follow-up treatment, identification and management of late effects of treatment, second cancers, and quality of life. (National Cancer Institute)

Significance and background:

In 2014, there are approximately 14.5 million survivors with a history of cancer in the United States representing 5% of the population (this number excludes in situ cancers and non-melanoma skin cancers). This is estimated to grow to almost 19 million survivors by 2024. Currently, the majority (64%) of survivors were diagnosed 5 or more years earlier and almost half (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, 2010; Shi, 2011; Wu, 2014; Zucca, 2012) Comorbid illnesses contribute to issues facing survivors. (Dowling, 2013; Hewitt, 2003; Snyder, 2013; Yarbroff, 2004) This results in poorer quality of life due to physical and emotional problems. (Weaver, 2012)

Health care delivery issues addressing cancer survivorship include evaluating different models of care (e.g. who delivers the survivorship care) (Halpern, 2014; Hoekstra, 2014; Nekhlyudov, 2014; Oeffinger, 2006) and aspects of that care (e.g. survivorship care plans, self-management programs) (McCorkle, 2011; Mayer, 2014).

B.1. Develop or test and implement interventions to prevent or minimize adverse outcomes related to long term or late effects and risks associated with comorbid illnesses.
B.1.1. 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.1.2. Design healthy lifestyle behavior interventions to maintain a healthy weight improve physical, functional, social and psychological outcomes; minimize risk of recurrence; and prolong survival.

B.1.3. Conduct intervention trials that address social and work reintegration and growth during and after cancer therapy.

B.1.4. Evaluate outcomes of survivorship intervention research on economic burden and healthcare utilization.

B.2. Explore factors associated with the delivery of quality cancer care to survivors.

B.2.1. 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 unique needs of specific cancer populations.

B.2.2. Explore approaches that address system barriers to implementation of IOM recommendations.

B.2.3. Participate in health informatics initiatives to enhance cancer survivorship care delivery.

B.2.4. Explore effective ways to care for the growing number of survivors, with attention placed on older adult survivors and minority populations.

B.2.5. Conduct intervention trials that mitigate disparities in care in survivors who are members of populations that experience these disparities.

B.2.6. 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 WHO Definition of Palliative Care (2014)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the
prevention and relief of suffering by means of early identification and impeccable 
assessment and treatment of pain and other problems, physical, psychosocial 
and spiritual. Palliative care:

provides relief from pain and other distressing symptoms;
affirms life and regards dying as a normal process;
intends neither to hasten or 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 the family cope during the patients illness and in their own bereavement;
uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
will enhance quality of life, and may also 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 those 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 health care settings (in the home, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics). Palliative care encompasses hospice and specialty (provided by certified interdisciplinary teams) or basic (provided by non-certified 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 (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 percent of the United States population will be over age 65. One in four adults will develop 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 (Simith et al, 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 an overall fragmented healthcare system, continue to present
challenges for the provision of person-centered, family-focused palliative/end of life care (IOM, 2014).

Due in part due 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 3-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% and by 2011 this proportion increased to 85% (Morrison, et al, 2011). Palliative care is rapidly becoming a routine part of healthcare and most healthcare systems, spurring the development of evidence-based research on the effectiveness of palliative care interventions (Walling et al, 2008).

Since the 1997 Institute of Medicine (IOM) report Approaching Death: Improving Care at the End of Life and 2001 report Improving Palliative Care for Cancer, many new programs, policies, and systems of care have been introduced to improve the quality of palliative/end of life care. National clinical practice guidelines, such as those created through the National Consensus Project (2014), are available to guide the implementation of quality palliative/end of life care.

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

*For recommendations for research in symptom management and family caregiver support please see those sections.*

**C.1. Communication and decision-making**

Communication is a central component of palliative care and an area in need of research. Studies have shown that the overall quality of communication between health care providers and patients with advanced illness is poor, particularly in areas such as prognosis and goals of care (Epstein & Street, 2007). There is also a lack of evidence-based models of training nurses to effectively communicate with patients and families in palliative/end of life care settings (Fletcher & Panke, 2012). A team-approach in communication in palliative/end of life care may also serve as a potential model, since it is suggested that palliative/end of life care be delivered using a team-based approach (Epstein & Street, 2007).
Technical advancements and lack of accurate prognostication have created additional challenges in decision-making along the cancer journey (Gwilliam et al., 2011; Krishnan et al., 2013; Zier et al., 2012). As we have more clinical success with saving lives, we simultaneously risk more frequent use of technological advancements in potentially inappropriate clinical situations leading to difficult decisions for patients, families, staff, and health care systems. More research is needed regarding nursing roles and strategies to understand decisional control preferences and support shared decision-making (Adams et al., 2011; Yennurajalingam et al., 2013). Often at end-of-life the patient is no longer able to make decisions for themselves; thus, another area of research is how to improve surrogate decision making (Wendler & Rid, 2011; White et al., 2012).

C.2. Palliative care for children
Palliative care for children represents a special, albeit closely related field to adult palliative care. Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

Pediatric-related research needs may be especially pressing. There need for research in the following areas for children near the end of life: symptom management (Pritchard et al, 2010; Wolfe et al., 2000); bereavement support; studies examining the effect of advance care planning and palliative care on outcomes and on the patient experience (Lotz et al, 2013); and studies of 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).

C.3. Diversity in palliative/end of life care
Over the next two decades, the increase in the proportion of minority older adults will substantially outpace that of non-Hispanic whites. For example, the population of older non-Hispanic whites is expected to increase by only 59% compared to 160% for minorities (HHS, 2014). The United States is an increasingly diverse society, and culturally mediated beliefs and values can affect access to palliative/end of life care, advanced care planning, communication about prognosis, pain and symptom management (Carr, 2012; Johnson, 2013; Mack, et al, 2010; Waite et al, 2013 ). Geographic and socioeconomic factors may also impact access to care (NINR, 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 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 values and preferences of patients and their families must be supported; differences based on disparities in health or healthcare must be eliminated. These profound and complicated differences create an imperative in palliative care research. Research is needed to explore the impact of issues such as advance care planning and barriers to accessing palliative/end of life care in diverse populations. Models of care delivery are needed to facilitate access to quality palliative/end of life care in diverse communities.

C.4. Palliative Care Delivery
Based on the results of recent research, there is a call for integrating palliative care in the trajectory of cancer (Bruera & Hui, 2010). For example, Temel and colleagues (2010) randomly assigned patients who were diagnosed with stage IV lung cancer to either early PC plus standard disease-directed therapies or standard disease-directed therapies only. Patients in the concurrent early PC and standard treatment group reported better QOL and fewer depressive symptoms compared to patients in the standard treatment only group. Patients in the concurrent early PC group received fewer aggressive end of life care (defined as chemotherapy within the last 14 days of life, no hospice care, or hospice admission 3 days or less before death), but had longer survival compared to patients in the standard treatment only group (11.6 months vs. 8.9 months, p=0.02). Bakitas and colleagues (2009) conducted an RCT to test the effect of a nurse-led PC intervention (Project ENABLE) on QOL, symptom intensity, mood, and resource use in 322 patients with advanced cancer (GI, lung, GU, breast). QOL and mood were better for the intervention group. Based on this evidence, the American Society of Clinical Oncology issued a Provisional Clinical Opinion that all seriously ill cancer patients 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 in the following:

1. Definition of integrated/interdisciplinary team
2. Development of criteria for referrals
3. Cost benefits for services provided
4. Timeliness and appropriateness of hospice referrals
5. Strategies to facilitate early and appropriate referrals
6. Models of care that addresses decision-making, transitions, and continuity of care.
7. Incorporation of virtual networks and new technologies to better assess, monitor, and deliver palliative/end of life care

Furthermore, more research is needed to test the effectiveness of innovative palliative care models in specific settings (Cheng et al, 2013; Murphy et al, 2013).
C.5. Biomedical and Health Informatics

There are a number of key opportunities within palliative care research to explore informatics, a diverse field using information and informatics to improve health and healthcare. For example, 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 (Demiris et al., 2012; Carpenter et al., 2014) and may assist with making health care decisions (Volandes et al., 2013). Finally, research using the electronic health record offers opportunities to identify patients with unmet palliative care needs and implement quality metrics for palliative care.

C.6. Professional Education and Development

Hospice and palliative medicine is now an established medical specialty, and professional nursing organizations such as Hospice and Palliative Nurses Association are providing certifications for nurses who specialize in palliative/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. These areas include:

1. Lack of evidence that points to the transfer of knowledge to most clinicians/nurses caring for patients and families
2. Single-profession education silos, which serves as a barrier for knowledge and skills to deliver palliative/end of life care in an interdisciplinary, team-based approach.

Although many palliative care focused curriculums, such as the End of Life Nursing Education Consortium (ELNEC), have developed and established core curriculums to educate nurses in the delivery of quality palliative/end of life care, whether these curriculums translate to improved patient care is yet to be determined (Curtis et al., 2013). Models of professional education, such as interprofessional education, should also be tested to determine its effectiveness on improving care (Aziz, Grady, & Curtis, 2013).

D. Self-Management

Definition:

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

Significance and Background:
The importance of self-management was initially recognized as it related to diabetes and arthritis. In the 1980’s, 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, n.d.; Wagner & McCorkle, 2010).

Self-management is one of the essential components of chronic disease management (Institute of Medicine, 2012). Core self-management skills include problem-solving, decision-making, resource utilization, forming partnerships with health care providers, and taking action as well as goal setting and building or enhancing self-efficacy (Institute of Medicine, 2012; McCorkle et al. 2011). The Chronic Care Model (Wagner, 1998) identifies these essentials components as well as the areas which are currently deficient and need to be further addressed through research. Areas of deficiency include: 1) inadequacy of patients’ preparation to manage their illnesses; 2) lack of standardized approaches by providers, partly due to increased demands of high patient volumes; 3) lack of care coordination; and 4) lack of active follow-up to ensure the best patient and provider outcomes (The Chronic Care Model, 2014). Each of these areas of deficiency are explored in the context of the individual with cancer in the following sections.

D.1. 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 these patients do not have the necessary skills to self-manage their cancer and treatment effects along with co-existing 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; Given et al., 2004; Koller, Hasemann, Jaroslawski, 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 health care 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). All of these studies utilized a qualitative approach to analysis, and none addressed the sustainability of the interventions over time. With the movement towards oral chemotherapeutic agents, studies addressing adherence to these agents have 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 self-management regimens prescribed in cancer care plans are currently missing in the literature. Interventions targeted at assisting patients and their family caregivers to be successful with self-management strategies are needed. Self-management interventions need to be adapted to the patient’s needs and changes in their health status over time.

D.2. Lack of standardized approaches
Guidelines are commonly used to assist providers in standardizing approaches in order to manage individuals with a chronic condition. Many of these guidelines include recommendations for self-management. Another strategy includes ONS PEP cards which provide an evidence-based approach to symptom self-management. Symptom self-management has been the most widely studied phenomenon. Some studies have incorporated or tested guidelines for the management of specific symptoms (Hammelef, Friese, Breslin, Riba, & Schneider, 2014; Lovell et al., 2013; Stevinson, Lydon, Amir, 2014) while others have contributed knowledge to the development of guidelines for the management of symptoms (Koller, Miaskowski, De Geest, Opitz, & Spichiger, 2013b; Rustøen et al., 2014; Sherwood et al., 2005). Very little research has been conducted in the use of guidelines to promote and improve self-management outcomes in the cancer population.

D.3. Lack of care coordination
Care coordination is an essential component of chronic disease management. Lack of care coordination can lead to confusion for individuals in regards to self-management. Patients may be left to their own to figure out 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 co-existing chronic conditions (Hershey, Tipton, Given, & Davis, 2012). Schulman-Green et al. (2012)
have noted that coordinating self-management activities across disciplines could facilitate and improve self-management. McCorkle et al. (2011) have suggested that the development of collaborative care plans coordinated across disciplines should serve as a guide for self-management interventions across the cancer continuum. Research related to the use of strategies to improve care coordination across the cancer continuum to improve self-management is currently lacking. Studies have suggested care coordination as a strategy to improve self-management in individuals with cancer (Lovell et al., 2013; McConigley et al. 2011; Regan, Mills, & Ristevski, 2012).

D.4. Lack of follow-up
With more individuals not only being diagnosed with cancer, but also transitioning to survivorship, the need for active follow-up regarding self-management needs to occur. Assessment of self-management needs 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: 1) not interpreting or recognizing symptoms related to reoccurrence and treatment effects; 2) not taking appropriate action regarding management of symptoms; 3) not meeting their health goals; and 4) not improving their quality of life and psychosocial outcomes (Dingley & Roux, 2013; Martin, Turner, Bourne, & Batehup, 2013; Palmer, Bartholomew, McCurdy, Basen-Engquist, & Naik, 2013; Sheppard, 2007). Research regarding interventions to improve self-management that addresses the frequency and type of follow-up needed in the individual with cancer overtime is currently missing in the literature.

D.5. Recommendations for Research:

D.5.1. Research is needed to develop and test measures of self-management outcomes across the cancer care continuum.

D.5.1.1. Develop and test new and established self-management measures for multiple populations including various minority groups, ethnicities and those with coexisting comorbidities.

D.5.1.2. Develop and test new and established measures to access self-management outcomes across the cancer care continuum.

D.5.2. Research is needed to develop and test models of care in self-management across the cancer care continuum.
D.5.2.1. Identify the needs of patients and caregivers regarding self-management during periods of transition, treatment to survivorship.

D.5.2.2. 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.

D.5.2.3. Develop and test models of care to improve coordinated care across disciplines/specialties to improve self-management at all phase of the cancer care continuum.

D.5.3. Research is needed to develop and test self-management interventions directed at the individual and/or their family caregiver(s) which address health-related outcomes across the cancer care continuum.

D.5.3.1. Develop strategies that promote self-management in children, adults and family caregivers across cultures and ethnicities.

D.5.3.2. Conduct intervention studies to improve patient engagement in the self-management activities.

D.5.3.3. Develop and test interventions to improve care coordination and address the changing self-management needs of individuals with cancer and their family caregiver’s over time.

D.5.3.4. Develop and test self-management interventions to assist patients in managing their cancer and other pre-existing chronic conditions.

D.5.4. Research is needed to develop and test interventions to improve adherence to prescribed and/or recommended plans of care.

D.5.4.1. Develop and test strategies for improving adherence to prescribed treatment regimens.

D.5.4.2. 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. Most of these new cases will occur in older adults. The majority of new cancer cases
already occur in three older groups – 65 to 74, 75 to 84, and 85 or greater (Varmus, 2014).

As the geriatric population grows and our ability to treat cancer improves, the number of older adults who are survivors of cancer will increase. At present, over 13 million cancer survivors are living in the United States. This number is expected to rise to about 18 million by 2020. More than half of these people are over 65 years of age 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. We have a lack of high quality data to guide patient care. The IOM made several recommendations to improve our evidence base for older adults. For example, it is important to understand the efficacy of and side effects associated with targeted therapies in these patients. There is a need for both elderly specific trials and for increased participation in general trials.

Many of these older individuals will require significant, ongoing care across the continuum of the patient’s treatment. Oncology care relies on the delivery of interdisciplinary care. This approach requires collaboration across settings – primary care, surgery, radiation oncology, medical oncology, palliative care, and end of life care. In terms of providing 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**

Special vulnerabilities of older individuals – such as co-existing medical conditions (referred to as ‘co- or multi-morbidities”) - can shorten life independent of the effects of cancer and can complicate the delivery of cancer therapies. The median age of onset of most of the common cancers is between the ages of 60 and 72. The number of people over the ages of 65, 75, and 85 will increase markedly over the next three decades, with nearly a doubling of the number over 65 and nearly a tripling of those over 85. Age must be considered as a major risk factor for cancer; over half of all cancers are diagnosed in people over the age of 65.

Older cancer patients who are otherwise in good health are likely to receive surgery, radiotherapy, and/or drug therapy. Older cancer patients 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). Co-morbidities however have to be considered.

*Social and psychological aspects of the care of older patients, finances, living, residence, including the heavy burden placed on family caregivers,
deserves increased attention. There is a lack of information on the safety and efficacy of cancer treatment for the older patient with cancer.

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

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 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. 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 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, 2014).

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

There are gaps in our knowledge about the cancer care for older adults. Research is clearly needed and we identify a few priority areas.

**E.1. Carry out descriptive work to obtain information needed to fill knowledge gap**

- **E.1.1.** Describe how lifestyle factors such as nutrition, exercise, smoking, ETOH intake affect the symptom burden and treatment responses of older patients.

- **E.1.2.** Explore the impact of age, cancer and biased decisions related stigma on older patient outcomes.

- **E.1.3.** 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.

*psychological comorbidities such as depression, anxiety, drug and alcohol addiction

**E.2. Develop, test and implement Interventions to improve the care of the older patients**

E.2.1. Test interventions that promote engaged treatment decision making based on risks assessed through a comprehensive geriatric assessment (CGA). Which components of the CGA predict treatment outcomes (e.g. function status, HRQOL)?

E.2.2. Determine how to adapt symptom management interventions, to decrease risk and enhance protective factors, to promote positive outcomes in older patients.

E.2.3. Test interventions for palliative, supportive, and end of life care for older adults who are unable to tolerate active curative treatment.

E.2.4. Test interventions to improve outcomes in family caregivers with chronic medical conditions who are caring for an older adult with cancer.

E.2.5. Test interventions to improve patient-clinician communication and self-management for the patient.

E.2.6. Identify those older oncology patients at higher risk of poorer outcomes and target interventions to maintain or improve these outcomes.

**E.3. Evaluate factors associated with the delivery of care**

E.3.1. Evaluate how multiple comorbidities (e.g., diabetes, obesity, heart failure, arthritis) affect the symptom burden and treatment responses of older adults with cancer.

E.3.2. Evaluate factors that influence the delivery of quality and safety of care, and health care utilization among older adults with cancer.

E.3.3. Evaluate the efficacy of using technology to improve outcomes in older adults undergoing cancer treatment.

E.3.4. Investigate patient outcomes (at levels of frailty and function) beyond progression and survival (e.g., impact of disease and treatment on HRQOL, 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, affecting 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-setting process. In defining this content area for the 2014-2018 Research Agenda, we go beyond the historical focus on negative emotional outcomes for family members and caregivers and emphasize the biological, behavioral, and socio-economic dimensions of family caregiving. The range of relationships that comprise “family,” i.e. dyads, nuclear, extended, and non-traditional configurations, is acknowledged and thus we define family as an experience, rather than a formal relationship. We further define family caregivers 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/or emotional support.

Significance and Background
Currently, 34 million people in the United States provide unpaid care to family members (AARP, 2008). Family caregivers assist with a multitude of activities, ranging from personal care and household tasks, to symptom management to medical and nursing procedures in the home. In the cancer population, caregivers play an essential role in access to treatment, as cancer treatment is provided primarily on an outpatient basis with frequent visits needed for administration of treatment and surveillance of patient response. In fact, 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 mean that caregivers are involved with much more than transportation to multiple medical appointments. They also serve as informal case managers, coordinating care and communication among multiple health professionals over extended periods of time. They are truly partners to health professionals in the quest to achieve optimal treatment outcomes and patient quality of life. Research to date has underscored negative psychological and physical consequences on family members of persons with cancer including anxiety, depressive symptoms, burden, altered immune function, poor overall health, and increased overall mortality (Northouse, Katapodi, et al., 2012; Williams & McCorkle, 2011). However, despite considerable research on cancer 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-see report)**

Using multiple databases (including PubMed, CINAHL, and PsychINFO), a review of published research between 2009 and 2014 was conducted for two purposes. The first was to assess the extent to which the 2009-2013 ONS research priorities had been addressed. The second was to gain a broader overview of the current state of the science of family caregiving research in oncology. Searches using the key words “cancer” and “caregiver” or “family” in the title/abstract field generated over 500 articles published between 2009 and 2014 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 (E.1).” More specific sub-goals pertained to model-testing and targeted interventions.

The first sub-goal was to “research to test patient and family models that encompass both risk factors and protective factors and their relationship to outcomes.” Our literature review revealed the predominance of studies focused on psychosocial risk in relation to quality of life outcomes (e.g. depressive symptoms, caregiver burden, and anxiety). Most were small, single institution, cross-sectional, descriptive studies. A myriad of articles reported on particular stressors and their relationship to caregiver depressive symptoms, burden, and anxiety. In addition, multiple focus group studies identified various sources of distress in across multiple cancer caregiver populations using qualitative research methods. An exception to the plethora of small descriptive studies is a series of analyses (Kim et al. references) conducted with the large database compiled by the American Cancer Society in 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 in order to differentiate the strength among 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 now 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. While there is a small but growing body of work focusing on historically identified minority groups (Francis et al., 2011; Yennurajalingam et al., 2013) (for example African American and Hispanic caregivers), less has been done on newly arrived immigrants (e.g., Africans and caregivers from Eastern Europe). Other groups that are underrepresented include caregivers with low literacy, 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. Risks prevalent in these underserved populations are not well-described.

The second sub-goal from the 2008 ONS research priority in caregiving was to conduct “intervention studies that identify patients and caregivers at higher risk of poorer outcomes and 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 methodological weaknesses that impact generalizability to the clinical setting (Applebaum & Breitbart, 2013; Northouse et al., 2010; Waldron et al., 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 most in need of intervention. Moreover, the limitations in research with underserved populations previously noted impacts progress in testing interventions 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 both descriptive and intervention research is incorporating technology for data collection and intervention delivery (Godwin et al., 2013). Oncology caregiver interventions have been delivered via web-based programs, YouTube, telephone (both live and interactive voice response), DVD, and Listserves, among others (Collinge et al., 2013; Silveira et al., 2011; Wittenberg-Lyles et al., 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 is often the
case that the technology used to deliver an intervention becomes obsolete by the time the research study is done and findings 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 is also 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 also included a comment 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 allocation of resources according to physician preference (Rocke et al., 2014) and there are also a few studies that have focused on cost to the caregiver, primarily related to assigning a financial value to caregivers’ work (Yabroff et al., 2013). A large portion of caregivers have little choice in changing work to accommodate cancer care as they become primary wage earners and carriers of insurance during treatment and at times into survivorship. Less attention has been paid to constraints from the existing healthcare structure that impact curative and supportive care including lost days from work, the cost of supportive care, economic factors that impact practitioners’ recommendations for and patient/caregivers’ 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 with respect to the 2009-2013 ONS research priorities revealed accumulating evidence on the negative psychosocial impact of family caregiving, but sparse progress otherwise. The ONS priority related to model testing has been 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 risks experienced by underserved populations is a neglected area. 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 also are lacking. Cost and resource-use issues have hardly been touched. Progress toward previously set goals has been 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, we further analyzed caregiver literature to gain a broader overview of the current state of the science. There have been great advances in caregiver research utilizing a dyadic, rather than
individual caregiver, approach (Regan et al., 2012). Over twenty 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) (Winters-Stone et al., 2014; Yennurajalingam et al., 2013). The majority of this work has 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 who will potentially fund translating caregiver interventions to practice. Furthermore, 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 in oncology 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 impact of a cancer diagnosis on the family unit as a whole. Considering the current meanings of “family,” more research is needed on the impact of caregiver outcomes on children in the home, how to accommodate and integrate distance caregivers, and the involvement of extended and non-traditional families.

A prominent gap in oncology research, compared with caregiver research in other disease populations, is a lack of knowledge regarding the effect of caregiving on caregivers’ physical health. Seven articles to date have reported the impact of stress from providing care on the cell, organ, or system level; these studies have 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 with caregivers of dementia patients have underscored not only cellular and genetic changes due to caregiver stress, but also changes in overall health, such as increased incidence of cardiovascular disease and immune function (von Kanel et al., 2011). 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 if oncology caregivers’ suffer similar health risks. Similarly, studies with larger samples are requisite to determining if changes at the biomarker level result in observable changes in health conditions. Research evaluating the impact of caregiver stress on biological 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 physiological or combined psychological and physiological interventions to be tailored to those at risk.
In summary, much work has been done in the area of family caregiving over the past four years. The state of the science in family caregiving is not being led 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 prime position to utilize 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 physiological health of the caregiver, and employment and economic issues in caregiving.

F.4. Recommendations for Research: The following are priority areas recommended for future research in the area of family caregiving. Within all areas, high priority should be given to studies that:

- Provide samples that are large and diverse enough to concomitantly evaluate multiple variables longitudinally,
- Contain sophisticated designs with a focus on utilizing novel statistical approaches and maximizing the potential from integrating qualitative and quantitative data,
- Go beyond the caregiver and dyad to evaluate the degree and duration of the impact of cancer diagnosis and treatment on the entire family unit, as well as at the societal level,
- Move beyond the cancer center to communicate with stakeholders in the dyad’s health including employers and corporate health and wellness service providers, primary care providers, insurers, and other health services, and
- Optimize the use of technology.

Specifically,

A. Research should identify the impact of caregiver outcomes on patient clinical 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/family to improve patient outcomes across the care trajectory.

B. Research should determine the impact of the stress of providing care on the caregiver’s physiologic health.

- Conduct studies that examine cellular response to providing care in order 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 both psychosocial and physiological strategies to improve overall health.

C. Research is needed to explore, define, and determine the extent of economic burden and its impact on families of persons with cancer.

Explore the impact of economic burden on both 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 persons 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 Health Care Systems Delivery

Definition
The health care system can be viewed as a four-level nested model. The four levels are (1) the patient; (2) the care team which consists of health care providers, patient, and family; (3) the organization, i.e., hospital, clinic, that provides the infrastructure and resources for the care team; and (4) the political and economic environment (Ferlie & Shortell, 2001).

Significance and Background
Cancer care is a complex process due to the biology of cancer and the specialized care required for the delivery of optimal treatment (IOM, 2013). In the U.S., cancer care is further impacted by a fragmented and costly health care system. Structures and processes are needed to ensure a high-quality health care delivery system which is patient-centered and cost-effective. Additionally, 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 (IOM, 2013).

Patient-Centered Cancer Care
High-quality cancer care is patient-centered (IOM, 2013). Care coordination is a core component of patient-centered care and ensures that the patient receives appropriate cancer care. Oncology nurse navigators or care coordinators are experienced oncology nurses whose role and responsibilities in care coordination vary depending on the setting in which
they are employed. Both registered nurses and advanced practice nurses play an important role in care coordination that results in improved clinical outcomes. Improved outcomes include a reduction in health care costs due to a decrease in patient emergency visits and hospitalizations, increased patient confidence in self-managing care, and improved patient satisfaction (ANA, 2012). Patient care coordination provided by an APRN at colorectal and surgical oncology clinics at Loyola University demonstrated a decrease in patient ED visits and hospitalizations and subsequent cost savings (Robles et al., 2011).

Nurses are in a key position for developing new cost-efficient models for delivering the best clinical care and improving patient outcomes across the cancer care continuum. A recommendation from the American Nurses Association’s white paper on care coordination (2012) calls for research to identify quality outcome measures and best practices of effective nurse-led care coordination. In addition, research is needed to conceptualize the oncology nurse-led care coordinator’s role within the nursing profession and the health care 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; thus, decreasing readmissions and patient complications (Bertakis & Azari, 2011; Qamar, Pappalardo, Arora & Press, 2011; Kuntz, Tozer, Snegosky, Fox & Neumann, 2014). The Medical Home is a patient-centered primary care model focused on improving patient outcomes, increasing patient satisfaction, and reducing health care costs (AHRQ, 2007). The Oncology Medical Home has the potential for improving cancer care delivery through care coordination by the oncology health care team, adhering to clinical practice guidelines, improving patient outcomes, and decreasing patient health care utilization (Eagle and Sprandio, 2011; Fox, 2013). Early findings suggest that the Oncology Medical Home reduces emergency department (ED) and inpatient visits for cancer patients receiving chemotherapy (Kuntz et al., 2014).

Recent descriptive studies (Prouty et al., 2014; Wittenberg-Lyles, Goldsmith & Ferrell, 2013) have 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 and breakdown in communication in cancer care has been related to patient lack of understanding the information provided, unrealistic expectations, and psychological distress (Prouty et al., 2014). Communication is affected by the lack of time providers are able to spend with patients (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 and colleagues (2014) demonstrated lowered symptom distress among patients who used an electronic self-report tool to self-monitor symptom and quality of life between visits with their health care provider. The electronic tool also provided self-care education and coaching to report symptoms to their health care provider.

The federally funded Patient-Centered Outcomes Research Institute (PCORI, 2013) delegated to generate best evidence for facilitating communication and informed decision-making by patients and health care providers (PCORI, 2013). PCORI’s research priorities are applicable to cancer care and oncology research. Three of the priorities relevant to improving health care systems delivery in cancer care include (a) comparing health system-level approaches to improving access, self-care, innovative use of health information technology, coordinating care for complex conditions, and deploying workforce effectively; (b) comparing approaches to providing comparative effectiveness research information, empowering people to ask for and use the 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 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 health care delivery system. Nurse-led clinics have demonstrated improved patient outcomes (Mason, DeRubeis, Foster, Taylor & Worden, 2011; Tetuan et al., 2014; Pritham, Cureton & Royce, 2009; Ruegg, 2013).

Outcomes of a weekly nurse practitioner-led symptom management clinic for patients receiving intensive chemoradiotherapy for oropharyngeal cancer included reduced rates of hospitalization, chemotherapy dose deviations, and increased chemotherapy completion (Mason et al, 2011). Nurse-led clinics have also shown benefits in patients obtaining mammograms (Tetuan, 2014), colorectal cancer follow-up (McFarlane et al., 2012), cancer survivorship care, (Pritham, Cureton & Royce, 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 improved patient outcomes.
Evidence-Based Cancer Care

The development of clinical measures based on research that insure safety and quality care for oncology patients is a cornerstone of oncology nursing. Historically, the Oncology Nursing Society (ONS) has been in the forefront of the development of quality indicators for oncology nursing practice. The most recent ONS Quality Initiative is the development and pilot testing of quality measure sets for breast cancer care and breast cancer survivorship. The delivery of evidence-based nursing care has also been an ONS priority. In 1987, the American Nurses Society and the 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 National Comprehensive Cancer Network (NCCN) and the American College of Surgeons Commission on Cancer (CoC). 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 the number of practice guidelines from both governmental agencies and professional organizations have been developed, efficacy and feasibility of the guidelines as adjuncts for practice requires continued testing and evaluation. Guideline efficacy-based research in varied environments is emerging. Several studies found assessed guidelines for feasibility and usability (Farrington, Cullen and Dawson; Kiely, 2014; Mayer et al., 2014, Tavernier, 2014). Data from these studies point to the need for further evaluation research of practice guidelines concepts for feasibility and utility in varied oncology environments (Farrington et al., 2010; Kiely, 2014; Mattsson, Knudesen, & Lauritsen, 2013). Many of the publications found evaluated guidelines using quality improvement assessment strategies and program evaluation research methodology (Browning, & Kasper, 2013; Mattson et al., 2013). The Clinical Journal of Oncology Nursing devoted a supplemental issue (2014) to implementing and evaluating three screening guidelines from the American College of Surgeons Commission on Cancer (COC) standards. Another feature in the literature is the increase number of systematic and integrative reviews of practices being published (Hines, Ramis, Pike, Chang, 2014; Preyde & Synnott, 2009). Reviews articles facilitate setting the stage for identification of further evaluation research and use of methodologies that can lead to the substantiation of an ever changing practice environment. In addition, research on how best to disseminate and implement best practices is needed.

Economic Evaluation of Cancer Care

Economic evaluation of nursing interventions is imperative. Evaluation of the costs and outcomes of alternative interventions provides nurses with information for making decisions in selecting cost-effective interventions. In
a recent systematic review, Cook and colleagues (2014) found that only 16 nursing-related economic evaluations were published from 1997 to 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 and compares it to one or more alternative interventions; thus, providing an evaluation of the intervention’s cost-effectiveness, cost-utility, cost-benefit and cost-consequence (Drummond, Sculpher, Torrance, O’Brien & Stoddart, 2005). This knowledge pertaining to nursing interventions is necessary for building the science of oncology nursing practice and demonstrating the quality of care delivered by oncology nurses. Economic evaluations should be a part of intervention research studies.

**G.1. Future Research Recommendations**

G.1.1. Expand the knowledge of patient-centered cancer nursing care.

G.1.1.1. Evaluate best practices for oncology nurse-led care coordination.

G.1.1.2. Examine interventions for improving advocacy and fostering communication with patient and families across providers and the effect on patient outcomes.

G.1.1.3. Design and test cost-efficient patient care models for improving patient outcomes across the cancer care continuum.

G.1.2. Evaluate the effect of nursing care on promoting and maintaining treatment quality and safety.

G.1.2.1. Understand predictors (risk models), cost settings, side effects, educational approaches, population health literacy, and cognitive changes associated with adherence to self-care.

G.1.2.2. Evaluate the influence of various care providers and cost effectiveness on quality and safety.

G.1.2.3. Evaluate strategies for the identification and prevention of adverse events related to quality and safety.

G.1.3.4. Develop and test interventions that support delivery of quality care indicators.
H. RISK REDUCTION

In lieu of cure for cancer, research on risk reduction such as health behaviors to prevent cancer and increase cancer screening is urgently needed. Cancer incidence and mortality rates have decreased overall in recent years (ACS, 2014), attributable in part to higher understanding and awareness of risk factors, adoption of healthy lifestyle behaviors, and improvements in cancer screening and early detection. However, a substantial proportion of cancers could be prevented. For example, in 2014, almost 176,000 of the estimated 585,720 cancer deaths will be caused by tobacco use (ACS 2014). According to the World Cancer Research Fund, an estimated one-third of the cancer cases that occur in economically developed countries like the U.S. are related to overweight or obesity, physical inactivity, and/or poor nutrition, and thus could also be prevented (World Cancer Research Fund, 2014). Cancers caused by infectious agents, such as human papillomavirus (HPV), hepatitis B virus (HBV), hepatitis C virus (HCV), human immunodeficiency virus (HIV), and Helicobacter pylori (H. pylori) could also be prevented through behavioral life-style changes and vaccinations. Decreasing excessive sun exposure indoor tanning could lead to reduction in the three million skin cancers diagnosed annually (ACS, 2014; World Cancer Research Fund, 2014).

Oncology nursing research on cancer risk reduction and cancer screening is a critical area to position oncology nurses to contribute to primary and secondary prevention of cancer and cancer control in the U.S. This is especially important in the context of cancer-related disparities, because minority and underserved populations continue to bear a heavy burden of increased cancer morbidity and mortality.

Several important summaries have recently addressed the need for and challenges of health promotion for cancer prevention throughout the world, including tobacco control, overweight/obesity, physical activity, and diet (ACS, 2014; Samet & Yoon, 2010; Lawrence, 2014; AHRQ, 2013). An abiding challenge is that national data on cancer care for some underserved populations, such as, people with limited English proficiency, individuals who speak a language other than English at home, lesbian, gay, bisexual, and transgender individual, and Asian and Hispanic subpopulations, are not available from the national data sources (AHRQ, 2013).

Despite decades of research into improving screening rates, cancer screening remains lower than national targets. For example, in 2010, only 72.4% of women ages 50-74 had received a mammogram in the past 2 years. From 2000 to 2010, the percentage of women who received a mammogram declined for women from poor and low-income households and for non-Hispanic Whites; and from 2000 to 2010, women from poor, low-income, and middle-income households were less likely to receive a mammogram compared with women from high-income households (AHRQ, 2013). Stark differences in treatments also remain: among women under age 65, those with public insurance were less likely than those with
private insurance to receive radiation therapy, among women under age 65, those with public health insurance were less likely than those with private insurance to receive axillary node dissection or sentinel lymph node biopsy (AHRQ, 2013).

These challenges and disparities remain, despite well-established models of health behavior change and extensive research on programs to promote healthy lifestyle and cancer screening behaviors. Intervention research is needed that goes beyond long-held theoretical models; targets diverse and underserved populations globally, integrates cultural leveraging to optimize intervention effects (Fisher et al. 2007), addresses known and possible mechanisms of risk, and applies and disseminates evidence-based interventions to both community and clinical settings.

Although chemoprevention and bilateral prophylactic mastectomy have been identified as cancer prevention options (NGC, 2010), current 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 physical activity or exercise. The recent synthesis from the American Society for Clinical Oncology (ASCO) states that as overweight and obesity rates increase across the U.S., there is growing and alarming evidence of its link to many cancer types and to poorer outcomes for those diagnosed with cancer (Lawrence, 2014). Colorectal cancer has been extensively studied in relation to physical activity, with more than 50 studies examining this association (NCI, 2014). Many studies in the U.S. and around the world have 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 to 40 percent relative to those who are sedentary regardless of body mass index (BMI), with the greatest risk reduction seen among those who are most active (NCI, 2014). Over 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. While the amount of risk reduction achieved through physical activity varies widely the magnitude of the protective effect appears greatest with high-intensity activity (between 20 to 80%) (NCI, 2014).

Clinical trials of innovative interventions that support initiation and long-term maintenance of these health behaviors in diverse populations are important areas for nursing research (Wilhelmsson & Lindberg, 2007; ACS, 2014) as well as research on effective treatments and interventions that may reduce obesity-related cancers such as breast, prostate, colorectal, esophageal cancers (Lawrence, 2014). Oncology nursing research that is patient-centered and addressed co-morbid conditions such as weight and poor diet will move the science in risk reduction forward.

Predictions based on the most recent data available on cancer incidence, survival, and costs of care estimate cost of direct cancer care in 2020 to reach
$158 billion (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011) clearly making the case for research into prevention and early diagnosis. As a risk reduction strategy, cancer screening has been shown to decrease mortality from breast, cervical, and colorectal cancer by increasing early detection (ACS, 2014). Survival from these cancers is inversely related to late stage diagnosis, with higher survival rates -- as high as 95%-- shown for those with early stage diagnosis of cancer. Colorectal cancer screening by endoscopy also can prevent cancer, and the American Cancer Society and other professional organizations have recommended that cancer prevention should be the primary goal of colorectal cancer screening (Levin et al., 2008). Mammography screening rates and cervical cancer screening have increased steadily over the past decade to at least 70-90% of women reporting one time screening, but these rates have leveled off in recent years. The growing trend 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 have decreased the gap between racial or ethnic minority groups and Caucasian women’s mammogram screening rates for one-time or initial screening, but disparity remains, particularly in terms of interval or ongoing screening (American Cancer Society, 2014; Cokkinides et al., 2007; Rakowski et al., 2004).

Colorectal cancer screening remains sub-optimal with about one in three adults aged 50 to 75 years not tested for colorectal cancer as recommended by the United States Preventive Services Task Force (USPSTF) (CDC, 2013). Despite substantial scientific evidence that routine screening for colorectal cancer reduces both incidence and mortality from this disease, screening rates have been slow to increase, and disparities in screening remain. (Mandel et al. 2000; Atkin et al. 2010; Johnson et al. 2008).

In addition to beliefs, cultural attitudes, and knowledge, research has identified the pivotal role of healthcare professionals in facilitating cancer screening (Rawl, et al, 2012; Breen et al. 2001; Meissner et al., 2004). Reminders from healthcare providers are generally the most effective strategies for promoting mammogram adherence in studies of women, regardless of their 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, have been recognized as facilitating or impeding screening (Breen et al., 2001).

The majority of screening intervention studies was completed on breast cancer, however, the knowledge gained from this research has been extended only minimally to other cancer screening studies (most notably, cervical and colorectal). Programs such as the CDC’s Colorectal Cancer Screening Demonstration Program report initial success, however, screening rates decline in relation to program close out dates (Seef et al. 2013). Disparities in screening
rates continue for cervical cancer by racial or ethnic minority groups and for colorectal cancer by gender and racial or ethnic minority groups. Intervention research to enhance colorectal and cervical cancer screening, including HPV vaccine education and uptake, is needed (Anhang, Goodman, & Goldie, 2004; Saslow et al., 2007; Smith et al., 2009). This research may well be guided by successful intervention strategies and lessons learned from mammography screening trials (Meissner et al., 2004). Patient navigation programs with a focus on screening and outreach have had the most demonstrable success, yet many challenges remain in widespread dissemination of such programs, including varying definitions of the role, buy-in from stakeholders, program costs and integration of such roles into the healthcare delivery system (Warner and Murph, 2010).

Multiple health behavior theories for guiding health promotion research are in the research literature, but very few have been tested adequately (Bowen et al., 2009). Research to understand and promote health behavior change has been conducted within the cardiovascular and diabetes specialty areas for many years, but scientists and clinicians still are challenged in their efforts to effectively accomplish long-lasting lifestyle change. Many screening studies focus on one-time screening as the outcome, leaving gaps in knowledge about repeat and sustained screening improvements. A common agenda to share knowledge across specialties and disciplines, promote health behavior change, and thereby prevent chronic illnesses has been proposed by the American Cancer Society, American Diabetes Association, and American Heart Association (Eyre, Kahn, Robertson, & ACS/ADA/AHA Collaborative Writing Committee, 2004). In addition, recent research comparing the explanatory value of popular health behavior theories with regards to cancer screening show that that there is 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 or negate or attenuate the effect of common Health Belief Model variables on breast cancer screening (Fisher et al. 2007), yet are understudied.

Intriguing new research suggests that a simultaneous approach to multiple behavior change may be superior to changing behaviors sequentially (Hyman, Pavlik, Taylor, Goodrich, & Moye, 2007). A recent World Cancer Research Fund/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 focusing on cancer prevention in isolation. In fact, recent studies indicate that targeting healthy lifestyle behaviors during cancer screening encounters may be particularly effective (van der Aalst, van Klaveren, de Koning, 2010). Thus, we need to move away from single-level explanatory and descriptive models to more comprehensive and ecologic frameworks (Warnecke et al., 2008; Zapka & Lemon, 2004; Zapka, Taplin, Solberg, & Manos, 2003). Using such conceptual
frameworks may help oncology nurses forge ahead with implementation of health promotion research for prevention of other cancers while drawing from successes in breast cancer research (Meissner et al. (2004). Rawl et al (2012) discovered such parallels and summarized past research, current challenges, and recommendations for future research.

The continued unequal burden of cancer on poor, minority, and underserved populations underscores the need for much more research on screening for other cancers in these populations, which often experience challenges within the healthcare system. For example, about 90 million Americans have low health literacy (Nielsen-Bohlman, 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 and even children and adolescents.

Additionally, while a plethora of descriptive studies exist on within-group barriers, there is little information on common elements between underserved groups. Such information is critical to dissemination and implementation efforts in cancer screening as a risk reduction strategies. High costs may prohibit widespread dissemination of individual models of cancer screening programs for each sub-population. Therefore, adaptation of programs to target common barriers as well as group-specific challenges may garner the most success and increase long-term sustainability of such programs. Dissemination and implementation science calls for effectiveness and sustainability testing of evidence-based practices. Oncology nurses can have a tremendous impact on addressing these disparities through the growing area 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.

**Smoking and Cancer Patients (NOTE: References to be included in next version)**

Smoking is responsible for 30% of all cancer deaths and 87% of lung cancer deaths. While a cardiovascular or cancer diagnosis and treatment can provide a “teachable moment” for smoking cessation, cardiovascular patients have high quit rates, while over half of cancer patients fail to stop smoking after their diagnosis. Cancer patients are personally, physically, and situationally vulnerable to smoking. Cancer patients are likely to be long term, heavy smokers who depend on smoking to deal with psychological distress. Fatalism has been shown to decrease the likelihood of smoking cessation among cancer patients. Having smokers in the social network, particularly a spouse, is a strong predictor of relapse after a temporary quit attempt. Many patients feel stigmatized as a result of having a smoking-related cancer. Continuing smokers show decreased response to radiotherapy and chemotherapy, impaired wound healing, increased infections and circulatory problems, increased risk of recurrence and second cancers, and decreased quality of life and survival rates. Continuing smokers tend to be younger, less educated, uninsured, and depressed.
Smoking cessation has yielded several benefits including decreased surgical complications (e.g., deep vein thrombosis, poor wound healing, and pulmonary embolism), improvements in pulmonary and immune function, decreased risk of a second cancer, and improved quality of life, and survival. While there have been multiple clinical trials showing the efficacy of smoking cessation interventions, there have been relatively few smoking cessation clinical trials that have focused on smokers with cancer and of these, only two (ref) were found to be efficacious. However, most previous studies were under-powered. Nonetheless, countless clinical trials have shown that when smoking cessation services are offered, smokers quit.

Despite the evidence, less than half of cancer centers have tobacco treatment programs. Smoking cessation counseling is recommended as evidence-based practice by the US Preventive Services Task Force. Moreover, the latest Surgeon General’s Report on Smoking that failure to provide smoking cessation services to cancer patients is unacceptable.

Barriers to Providing Smoking Cessation

The major institutional barrier to adopting smoking cessation services in cancer centers is the failure to systematically integrate cessation into routine practice and documentation systems. In fact, a 2009 National Cancer Institute (NCI) Conference on “Treating Tobacco Dependence” identified the need for smoking cessation interventions in cancer centers. Currently, the National Cancer Institute and the American Association for Cancer Research have assembled a task Force for the assessment of tobacco use in cancer patients.

The major barrier to nurses implementing cessation services is not lack of time, but lack of expertise. Medical and nursing education does not typically include training to treat in health behaviors such as smoking. Moreover, providers tend to think that cancer patients are already overwhelmed by their treatment and they may feel that asking their patients to attend extra appointments and cope with withdrawal symptoms may be asking too much, albeit the evidence for this is poor. As a result, only 56% of physicians recommend that their smokers with cancer stop smoking, and most oncology providers do not provide smoking interventions beyond advice to quit, even though 70% of cancer patients are motivated to quit smoking. In addition, a misperception that nicotine replacement therapy (NRT) will diminish the effect of surgery due to vasoconstriction, also makes surgeons reluctant to provide NRTs to cancer patients who smoke.

Smoking Cessation Interventions

There are many ways in which smoking cessation services can be delivered. Computer and other electronic aids increase the likelihood of cessation compared with no intervention or generic self-help materials, but the effect is small. There are also outpatient groups (which many cancer patients are too sick to attend) and on-the-spot,
in-clinic interventions. The 1-800-QUIT NOW programs are available in 48 states. There are also services offered by the NCI including: 1) NCI Booklet “Clearing the Air”; 2) NCI Quitline at 1–877–44U–QUIT (1–877–448–7848); 3) Smokefree.gov; 4) SmokefreeTXT; and 5) NCI LiveHelp Chat Service (see Appendix 9). However, all efficacious smoking cessation programs consist of both behavioral and pharmaceutical intervention.

Behavioral Interventions

There is insufficient evidence to support the use of any specific behavioral intervention to help smokers who have successfully quit for a short time to avoid relapse. Brief advice to quit has a small increased effect (1 to 3%) on cessation rates (Stead LF, Buitrago D, Preciado N, Sanchez G, Hartmann-Boyce J, Lancaster T., 2013) above unassisted quit rates of 2 to 3%. (Stead LF, Buitrago D, Preciado N, Sanchez G, Hartmann-Boyce J, Lancaster T., 2013). However, behavioral counseling has been shown to increase quit rates among those using pharmaceutical interventions. (Stead LF, Lancaster T., 2012)

Pharmaceutical Interventions

Cochrane Collaborative Reviews have shown that smoking cessation interventions that provide counseling and pharmaceuticals (nicotine replacement therapy-NRT, bupropion, and varenicline) are effective. Hence, smoking cessation pharmacotherapies are recommended in the United States Department of Health and Human Services clinical practice guidelines, and NRT has been available as over-the-counter smoking cessation pharmacotherapies since 1996. As a result, there has been wide-scale distribution of smoking cessation pharmacotherapies by municipalities (such as New York), insurance companies, the 1-800-QUIT-NOW telephone lines, and over-the-counter sales of NRT.

Inpatient Interventions

Countless studies have shown that smoking cessation interventions with telephone follow-up 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 due to illness, and often quit temporarily due to 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 has been limited.

Institutional Level Interventions

There is support for nursing documentation templates in the EHR for improving nurses’ delivery of brief cessation counseling (Katz et al., 2013). Following the introduction of an expectation to use the Electronic Health Records (EHR) for physicians, documentation of tobacco status and increased referral to cessation counseling do appear to increase (Boyle R, Solberg L, Fiore M., 2011). Clinical reminders have been shown to enhance

**Nurse Delivered Interventions**

Meta-analyses by Rice suggested that nurse-administered interventions are efficacious, particularly among hospitalized patients and meta-analyses suggest that nurse-administered cessation interventions are efficacious and should be emphasized during a “teachable moment”, such as immediately after a cancer diagnosis. However, nurse-administered cessation interventions nurse-administered cessation interventions are seldom implemented due to lack of training and time. Training health professionals about smoking cessation has been shown to increase their delivery of these services and increase quit rates. Once knowledgeable, nurses are ideally positioned to deliver cessation interventions because: 1) nurses are educated in patient education, psychosocial, and physiological interventions; 2) physician time is at a premium while nursing time is more cost-effective; 3) nurses have access to and immediate rapport with patients as well as respect from physicians; 4) nurses understand the patient’s medical condition and can tailor the intervention accordingly; and 5) nurses can read charts, initiate medication orders, and write nursing notes. (Rice et al., 2013).

**Social Engineering**

The price, the age-of-sales laws and text-messaging cessation support seem to be effective for adolescent smoker of all SES (Brown T, Platt S, Amos A., 2014). Among adults, raising the price of tobacco products appears to be the tobacco control intervention with the most potential to reduce health inequalities from tobacco.

**H.1. Key Points:**

**H.1.1. Develop and test interventions to adopt or maintain health behaviors that reduce risk for or prevent cancer (e.g., tobacco control, physical activity, dietary change, weight management).**

H.1.1.1. Develop and/or test innovative cost effective models

H.1.1.2. Develop and/or test culturally appropriate models for minority and underserve groups.
H.1.1.3. Develop and/or test innovative and cost-effective interventions to change multiple health behaviors in a population that can reduce or prevent cancer (eg., obesity and tobacco cessation).

**H.1.2. Develop and/or test interventions to sustain cancer screening behavior beyond completion of one-time screening.**

H.1.2.1. Develop and/or test interventions increase first-time and interval cancer for underserved and understudied populations (e.g., ethnic minorities, urban poor, rural residents, older adults, sexual minorities).

H.1.2.2. Develop or test culturally responsive interventions, including those that enhance healthcare providers’ cultural competence.

H.1.2.3. Apply findings from other areas with more extensive research (e.g., breast cancer screening) to increase screening for other cancers.

H.1.2.4. Conduct comparative effectiveness trials to apply evidence-based intervention strategies in cancer screening to clinical and community practice settings.

**H.1.3. Develop and/or test dissemination and implementation of evidence-based interventions in cancer screening.**

H.1.3.1. Adapt and test efficacious interventions for implementation in clinic or community settings.

H.1.3.2. Implement and evaluate dissemination and implementation models for translating evidence-based interventions to practice.
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Cross Cutting Themes


A thematic analysis of theoretical models for translational science in nursing: mapping the field.


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E. Aging
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**H. Risk Reduction**


