



## **ONCOLOGY NURSING SOCIETY 2009–2013 RESEARCH AGENDA**

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## I. EXECUTIVE SUMMARY

### A. Project background

The Oncology Nursing Society (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 Foundation Endowment provided support for the ONS 2009-2013 Research Agenda meeting. The ONS Research Agenda process has been a multi-method, stakeholder-driven, consensus-building effort since its initial development in 2001. The ONS Research Agenda's purpose is to provide guidance for research initiatives to meet ONS's mission to promote excellence in oncology nursing and quality cancer care. The agenda has been revised every two years in response to rapid advances in oncology practice.

The 2009 meeting content leaders, content experts, and advanced practice nurses (APNs) carefully reviewed many documents, including the 2008 ONS Research Priorities Survey results, to revise the 2007 ONS Research Agenda. Three additions were made in 2009: a) a seventh content area was added (end of life); b) the draft agenda was posted on the ONS website for public comments for two weeks; and c) the Executive Summary will be adapted and published in the *Oncology Nursing Forum* in late 2009. This document is not intended to set priorities for ONS for any other initiatives, such as education or policy. Our goal is that the research agenda can inform other works of ONS and the ONS Foundation. High-priority topics are specified for each of the seven content areas, which are ordered in a logical fashion with no preference for any particular area.

### B. How to use this document

This document can be used to inform ONS' and the ONS Foundation's planning for their research initiatives as well as external individuals and groups regarding scientific priorities. This document can be used as a framework to achieve the missions of ONS and the ONS Foundation:

- (1) To increase the knowledge base for oncology nursing practice through identifying leading edge/critical priority areas of oncology nursing research
- (2) To develop future oncology nurse researchers who will be prepared to implement ongoing programs of research and to seek support from major sponsors
- (3) To prepare clinical nurses as critical consumers of research findings that can be applied to practice

### C. Cross-cutting themes

As you read this research agenda, you will note themes that apply to more than one content area. The themes identified by content leaders and experts fall into three broad categories and include:

#### (1) Individual/Population Issues

- **Cultural** sensitivity or cultural competence

- **Health Disparities** (race or ethnicity, gender, income, education, sexual orientation, culture, geography, access, health literacy, medically underserved)
- **Lifespan orientation**; special needs at phases
- **Family as the care recipient**
- **Global health issues**
- **Ethics**

## (2) Design/Methods Issues

- **Models** outside oncology nursing
- **Mechanisms** (biological, psychological, behavioral, socio-cultural) underlying responses to cancer and treatment
- **Longitudinal, multi-site or multi-level designs** (when appropriate to the question)
- **Intervention work** that builds on adequate descriptive work
- **Targeted interventions** for specific groups/populations (what works, for whom, and in what context, and for which outcomes)
- **Behavioral change** as an overarching theme underlying several intervention approaches
- **Informatics** or technologic innovations
- **Outcomes evaluation** using a multi-dimensional approach: *implementation outcomes* (feasibility, fidelity, penetration, sustainability, uptake and costs), *service outcomes* (efficiency, effectiveness, patient-centeredness), and *client outcomes* (satisfaction, function, symptoms)

## (3) System Issues

- **Interdisciplinary teams**
- **Mentored** grants to optimize capacity building simultaneously with knowledge generation
- **Partnerships and team building** with other professional organizations (e.g., American Society of Clinical Oncology, Association of Pediatric Oncology Nurses, etc.)
- **Workforce issues** of medical oncologists and oncology-certified APN or Nurse Practitioners
- **Cost** and cost-effectiveness measures embedded
- **Partnerships** joining researchers and service organizations to promote implementation
- **Health policy** implications of projects

**D. Relationship to ONS Strategic Plan:** The 2009-2013 ONS Research Agenda represents the core work of ONS, “establishing priorities for oncology nursing research,” and contributes directly to the knowledge strategy, “generation and application of research.” The ONS Research Agenda provides important direction for the research, evidence-based practice, and quality components of the ONS mission to promote excellence in oncology nursing and quality cancer care.

## II. CONTENT AREAS AND PRIORITY TOPICS FOR RESEARCH 2009-2013

### A. *Health Promotion*

A.1. Develop or test interventions to adopt or maintain health behaviors (e.g., tobacco control, physical activity, dietary change, stress management) that reduce risk factors for or prevent cancer

A.1.1. Test the applicability of findings from other areas (e.g., diabetes), focusing more specifically on the underserved (e.g., ethnic minorities, urban poor, rural residents, older adults, sexual minorities)

A.1.2. Develop or test early interventions for risk reduction (e.g., with youth, on attitudes and beliefs, to enhance access and referral to human papilloma virus vaccine, with those at higher risk for hereditary cancers)

A.1.3. Develop or test innovative and cost-effective interventions targeting multiple health behaviors

A.2. Develop or test interventions to increase first-time and interval cancer screening, with an emphasis on underserved and understudied populations (e.g., ethnic minorities, urban poor, rural residents, older adults, sexual minorities) and those at higher risk for hereditary cancers

A.2.1. Develop or test culturally sensitive interventions, including those that enhance healthcare providers' cultural competence

A.2.2. Apply findings from other areas with more extensive research (e.g., breast cancer screening) to increase screening for other cancers

A.2.3. Develop or test cost-effective and accessible multi-component and/or technology-based interventions

### B. *Cancer Symptoms and Side Effects*

B.1. Develop an in-depth understanding of cancer-related symptoms and side effects in children and adults across cultures and ethnicities

B.1.1. Develop scientific knowledge of individual or multiple symptoms and side effects to

- Determine causal pathways
- Identify short- and long-term outcomes
- Develop measures (subjective and objective)
- Develop and evaluate nursing interventions to prevent or ameliorate symptoms

B.1.2. Develop and evaluate systems of care that integrate

scientific knowledge of symptoms and side effects into oncology clinical practice

### **C. *Late Effects of Cancer Treatment and Long-Term Survivorship Issues***

**Definitions:** Long-term effects are any side effects or complications from therapy that continue beyond the end of treatment. Late effects occur months to years after treatment has been completed.

C.1 Develop or test interventions to minimize adverse outcomes related to long-term or late effects and risks associated with the development of comorbid illnesses

C.1.1 Conduct intervention trials to reduce risks of long-term and late effects of treatment and risk of chronic illness

C.1.2 Design physical activity and healthy eating interventions for survivors to improve physical, functional, and psychological outcomes, recurrence, and survival

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

C.2.1 Identify models of care to support the Institute of Medicine's recommendation for survivorship care (e.g., treatment summaries, surveillance recommendations) and develop interventions to address system barriers in implementing them

C.2.2 Explore effective ways to manage the growing number of survivors and the challenges of the oncology and nursing workforce shortages

### **D. *End of Life (EOL) Issues***

Although there is no exact definition of EOL, it is a period of time marked by disability or disease that is progressively worse until death. The National Institutes of Health issued a state-of-the-science conference statement on improving EOL care. This priority area was added in 2009 due to limited research to date in this increasingly important area.

D1. Develop knowledge of mechanisms and management of symptoms for patients with cancer near EOL

D.1.1 Develop or test efficacious, feasible, cost-effective, and culturally sensitive interventions for patients with cancer near EOL

D.1.2 Validate culturally sensitive symptom measures for assessing symptoms for patients with cancer near EOL

D.2. Develop knowledge that promotes quality of life (QOL) for patients with cancer near EOL and their families

D.2.1. Conceptualize, develop, and validate specific measures of QOL for diverse groups

D.2.2. Develop or test efficacious, feasible, cost-effective, culturally sensitive interventions for supporting QOL in patients with cancer near EOL and their families

## **E. Psychosocial and Family Issues**

E.1. Design or test interventions to reduce negative outcomes (e.g., depression, burden, symptom distress) and improve positive outcomes (e.g., coping, benefits of illness, QOL) in patients with cancer and their family caregivers

E.1.1. Evaluate patient and family models that encompass risk factors and protective factors and their relationship to outcomes

E.1.2. Design or test Interventions that identify patients and caregivers at higher risk of poorer outcomes and target interventions to meet their needs; these studies need to address cancer-related cost and resource utilization issues for patients and families

E.2. Examine the impact of high risk for cancer, including a family history of cancer, on individuals and families

E. 2.1. Explore family communication and family functioning in disclosing test results, conflict and regret about pursuing genetic testing, role of significant others in decisions to pursue testing, and genetic testing in minority families

E.2.2. Develop or test interventions using decision aids, risk communication strategies, and educational support for probands (persons who chose to be tested) and families considering genetic testing

## **F. Nursing-Sensitive Patient Outcomes (NSPOs)**

F.1. Evaluate the effect of nursing care on promoting and maintaining treatment adherence

F.1.1. Understand the predictors (risk model), costs, settings, side effects, educational approaches, population, health literacy, and cognitive changes associated with adherence to oral chemotherapeutic agents

F.1.2. Evaluate the influence of various care providers and cost effectiveness regarding adherence to care issues

F.1.3. Explicate the issues of adherence in all aspects of a plan of care, including clinical trial participation, medications such as oral chemotherapeutic agents, diet, and self-care strategies

F.1.4. Evaluate strategies for the identification and prevention of adverse events related to treatment, such as vascular devices

F.1.5. Develop or test interventions that support adherence to care

F.2. Expand knowledge regarding relationships between physical function and nursing-sensitive patient outcomes

F.2.1. Explicate the relationship between nursing interventions and physical functioning in patients with cancer

F.2.2. Evaluate the relationship between physical function and falls with injury in patients with cancer

## **G. Translation Science**

G.1. Develop implementation science methods and techniques designed to improve the capacity of clinicians to screen, assess, and deliver effective interventions and optimize oncology nursing care quality and outcomes

G.1.1. Investigate methods to exploit technology and system redesign to link screening, assessment, interventions, and outcomes

G.1.2. Promote research-practice partnerships to integrate efficacious, cost-effective interventions into clinical care

G.2. Identify cognitive-behavioral, psychoeducational, rehabilitative, and self-management interventions (individual and multilevel) with demonstrated effectiveness in targeted populations, and refine, manualize, and evaluate those interventions for use by clinicians to address multiple outcomes. Based on feedback from a survey of ONS members, interventions that address pain, sleep, fatigue, and mood disturbances should be prioritized for funding

G.2.1. Conduct exploratory analyses and test resultant hypotheses in experimental designs to develop new knowledge that allows interventions to be effectively targeted (i.e., develop knowledge that contributes to identifying what interventions work best for whom, under what conditions or contexts, at what cost, and to achieve what outcomes)

G.2.2. Modify interventions for use by clinicians to target multiple outcomes simultaneously (e.g., symptom distress and functional status) and examine implementation, service, and client outcomes

## **COMPLETE 2009–2013 ONS RESEARCH AGENDA**

### ***A. Health Promotion***

A.1. Develop or test interventions to adopt or maintain health behaviors (e.g., tobacco control, physical activity, dietary change, stress management) that reduce risk factors for or prevent cancer

A.1.1. Test the applicability of findings from other areas (e.g., diabetes), focusing more specifically on the underserved (e.g., ethnic minorities, urban poor, rural residents, older adults, sexual minorities)

A.1.2. Develop or test early interventions for risk reduction (e.g., with youth, on attitudes and beliefs, to enhance access and referral to human papilloma virus vaccine, with those at higher risk for hereditary cancers)

A.1.3. Develop or test innovative and cost-effective interventions targeting multiple health behaviors

A.2. Develop or test interventions to increase first-time and interval cancer screening, with an emphasis on underserved or understudied populations (e.g., ethnic minorities, urban poor, rural residents, older adults, sexual minorities) and those at higher risk for hereditary cancers

A.2.1. Develop or test culturally sensitive interventions, including those that enhance healthcare providers' cultural competence

A.2.2. Apply findings from other areas with more extensive research (e.g., breast cancer screening) to increase screening for other cancers

A.2.3. Develop or test cost-effective and accessible multi-component and/or technology-based interventions

### **Progress 2004–2008**

Since 2003, when Research in Health Promotion was first identified as an ONS priority topic, only one health promotion study has been conducted using ONS Foundation funding. Over the past five years, research on health behaviors within the oncology nursing literature has addressed barriers to change (Niederdeppe & Levy, 2007), special populations (Andrews, Felton, Wewers, Waller, & Tingen, 2007; Jandorf, Gutierrez, Lopez, Christie, & Itzkowitz, 2005; Underwood, 2006), innovative strategies for intervention delivery (Vandelanotte, Spathonis, Eakin, & Owen, 2007), and individually relevant outcomes (Nies & Sun, 2008). Health behavior theories have been evaluated for their relevance to breast cancer risk reduction and screening (Ham, 2006; Spector, 2007; Wood, 2008). Multidisciplinary, multicomponent, and community-based

interventions have been identified as promising models for the adoption and maintenance of healthy choices (Bull, Eakin, Reeves, & Kimberly, 2006; Cokkinides, Bandi, Ward, Jemal, & Thun, 2006; Fowler, Rodney, Roberts, & Broadus, 2005; Greenwald, 2005; Kushi et al., 2006; Meyskens & Tully, 2005; Yancey & Tomiyama, 2007).

Several studies on nurses' smoking rates and smoking cessation interventions have been conducted over the past five years. Sarna et al. (2008) documented a decline in smoking rates among nurses in the Nurses' Health Study over the past 25 years, an encouraging trend, in part, because nurses who smoke may be less likely to offer tobacco control interventions to their patients. However, Chinese nurses, even with a very low rate of smoking, rarely offered smoking cessation interventions to patients, unless the nurses had specific training (Chan, Sarna, Wong, & Lam, 2007). A high prevalence of smoking (23.5%) was noted among Japanese nursing students (Suzuki, Ohida, Yokoyama, Kaneita, & Takemura, 2005). A framework for evaluating tobacco cessation education within nursing curricula to promote evidence-based practice was proposed by Heath and Andrews (2006). Nurses who were current or former smokers identified the need for smoking cessation interventions as well as additional support for concerns about confidentiality and guilt (Bialous, Sarna, Wewers, Froelicher, & Danao, 2004). Research on tobacco control continues to be needed in light of emerging statistics indicating that previous declining trends in tobacco use have not changed substantially in recent years (Cokkinides et al., 2006). Doolan and Froelicher (2006) found that smoking cessation research was needed particularly with older adults, sexual minorities, Native Americans, Alaskan Natives, Hispanics, and Asian Americans.

Similar to research on cancer prevention, cancer screening studies primarily continue to target breast cancer screening and mammography, given that screening guidelines now identify breast self-examination as optional (Smith, Cokkinides, & Brawley, 2009). Research on breast cancer screening, including some work on breast and cervical cancer screening, has expanded in the past five years to address questions about the cost of screening promotion programs (Andersen, Urban, Ramsey, & Briss, 2004; Saywell, Champion, Skinner, Menon, & Daggy, 2004) and screening in nonadherent women (Skinner et al., 2007), high-risk women (MacDonald, Sarna, Uman, Grant, & Weitzel, 2006; Martin & Degner, 2006), and diverse and underserved populations (Alkhasawneh, 2007; Anderson, Jun, & Choi, 2007; Ceber, Soyer, Ciceklioglu, & Cimat, 2006; Chen, 2009; Farmer, Reddick, D'Agostino, & Jackson, 2007; Fowler, 2006a, 2006b; Grindel, Brown, Caplan, & Blumenthal, 2004; Grindel, McGehee, Patsdaughter, & Roberts, 2006; Hall et al., 2005; Hall, Hall, Pfriemer, Wimberley, & Jones, 2007; Ho, Yamal, Atkinson, Basen-Engquist, Tortolero-Luna, & Follen, 2005; Kim & Sarna, 2004; Lee-Lin et al., 2008; Lee-Lin & Menon, 2005; Lee-Lin, Menon et al., 2007; Lopez-McKee, McNeill, Bader, & Morales, 2008; Nahcivan & Secginli, 2007; Powe & Cooper, 2008; Russell, Champion, & Skinner, 2006; Russell, Perkins, Zollinger, & Champion, 2006; Steven et al., 2004; Thomas, 2004; Wu & Bancroft, 2006; Yarbrough, 2004). Descriptive studies and some early intervention work on cervical, colorectal, and prostate cancer screening also have been conducted (Lee, Fogg, & Menon, 2008; Lee-Lin, Pett et al., 2007; Menon, Belue, Skinner, Rothwell, & Champion, 2007; Menon et

al., 2008; Olifee, 2006; Rawl et al., 2005). Hudson et al. (2007) indicated that interventions to enhance colorectal cancer screening may fare better if they provide more general health behavior change education, rather than focusing on colorectal cancer screening alone.

### **Rationale and Background**

Oncology nursing research on health promotion has primarily addressed symptom management and lifestyle change in cancer survivors. In lieu of a cure, health promotion in the context of cancer risk reduction and cancer screening is a critical role for oncology nurses who are well positioned to contribute to primary and secondary prevention of cancer and cancer control in the United States, particularly with respect to cancer-related disparities.

Although chemoprevention and bilateral prophylactic mastectomy have been identified as cancer prevention options, 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. In a review of epidemiologic studies on the association between physical activity and risk of breast cancer, the most active participants had, on average, a 30–40% decreased risk for breast cancer compared to sedentary women (McTiernan, 2003). Similar results were found for the association between physical activity and colorectal cancer (Slattery, 2006). Although a strong evidence base has yet to be established, psychoneuroimmunological studies suggest that stress management may be an effective health promotion intervention for cancer prevention (Antoni et al., 2008; Bryla, 1996). Clinical trials of innovative interventions that support adoption as well as long-term maintenance of these health behaviors in diverse populations are important areas for nursing research (Wilhelmsson & Lindberg, 2007).

As a health promotion strategy, cancer screening has been shown to decrease mortality from breast, cervical, and colorectal cancer by increasing early detection (Cokkinides, Bandi, Siegel, Ward, & Thun, 2007). 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 more than 50% of women, but these rates have leveled off in recent years. This leveling off undoubtedly reflects 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. Interventions have decreased the gap between racial or ethnic minority groups and Caucasian women's mammogram screening rates, but some disparity remains, particularly in terms of interval or ongoing screening (American Cancer Society, 2007; Cokkinides et al., 2007; Rakowski et al., 2004). In addition to beliefs, cultural attitudes, and knowledge, research has identified the pivotal role of healthcare professionals in facilitating breast cancer screening (Breen, Wagener, Brown, Davis, & Ballard-Barbash, 2001; Fox, Murata, & Stein, 1991; Fox & Stein, 1991;

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.).

Research focused on screening for other cancers (most notably, cervical and colorectal) pales in comparison to breast cancer screening studies, and the knowledge gained from this research has been extended only minimally to other cancer screening studies. In contrast to trends in breast and cervical cancer screening, screening rates for colorectal cancer have continued to rise but are still less than 50% across racial or ethnic groups (Cokkinides et al., 2007). Disparities in cervical cancer screening by racial or ethnic minority groups and in colorectal cancer screening by gender and racial or ethnic minority groups also have been documented. Intervention research to enhance colorectal and cervical cancer screening, including human papilloma virus 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).

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 carried out 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. Much work still must be done. 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).

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 health promotion to reduce cancer prevention and risk reduction. Health behavior theories and interventions emphasizing the multiple benefits of lifestyle change may prove more effective than focusing on cancer prevention in isolation. 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) 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, health promotion efforts need to speak to a broader definition of culture that encompasses groups within underserved populations and even children and adolescents. We must consider culture and literacy in our interventions and develop and test innovative, new approaches to address these concerns. Oncology nurses can have a tremendous impact on addressing these disparities. Their role in health promotion is supported by the ONS Position on Prevention and Early Detection of Cancer in the United States. Overall, ONS believes these health promotion priorities will:

- Allow oncology nurses to keep pace with (even stay ahead) of leading edge research nationally
- Increase the focus on well populations with whom nurses may have an increased impact
- Increase the pool of fundable applications that also meet national research agendas (e.g., on health disparities, health literacy, and interdisciplinary research).

## **Future Research Recommendations**

### **Priority 1**

- Descriptive and intervention research on promoting and maintaining health behaviors, such as healthy eating patterns, exercise or physical activity, and stress management
- Descriptive and intervention research on promoting and maintaining health behaviors in special populations that experience health disparities (e.g., ethnic minorities, urban poor, rural residents, older adults, sexual minorities)
- Pilot or feasibility research, particularly for the development of intervention studies that evaluate health behavior change targeted to messages about cancer prevention and/or groups at high risk for particular cancers
- Efficacy evaluation of making multiple health behavior changes versus changing one specific behavior; identify special populations for which multiple versus singular behavior change might be most efficacious.

### **Priority 2**

- Descriptive and intervention research on promoting and maintaining screening for early detection of cancer, with an emphasis on cancers other than breast cancer
- Descriptive and intervention research on promoting and maintaining screening or early detection in special populations that experience health disparities (e.g., ethnic minorities, urban poor, rural residents, older adults, sexual minorities)

- Development of strategies (tools, resources, programs) that effectively communicate screening guidelines for multiple types of cancers
- Pilot or feasibility research, particularly for the development of intervention studies, that tests lessons learned from research on breast cancer screening to other types of cancer

## **B. Cancer Symptoms and Side Effects**

B.1. Develop an in-depth understanding of cancer-related symptoms and side effects in children and adults across cultures and ethnicities

B.1.1. Develop scientific knowledge of individual or multiple symptoms and side effects to

- Determine causal pathways
- Identify short- and long-term outcomes
- Develop measures (subjective and objective)
- Develop and evaluate nursing interventions to prevent or ameliorate symptoms

B.1.2. Develop and evaluate systems of care that integrate scientific knowledge of symptoms and side effects into oncology clinical practice

### **Rationale and Background**

Understanding the nature and management of individual and multiple symptoms related to cancer and/or its treatment has long been a priority of oncology nursing. A symptom is a subjective experience that reflects the individual's interpretation of a change in bodily sensation, functioning, and/or cognition (Dodd, Janson, et al., 2001). Each symptom is perceived in a unique way by the individual based on the experience as well as the context of that experienced (Rutledge & McGuire, 2004). Because of the complexity of symptoms, most research has focused on individual symptoms.

The development of knowledge about symptoms has included the understanding of causal pathways or mechanisms. When discussing mechanisms, a purely physiologic understanding of symptoms would be insufficient. Other mechanism domains that underlie symptoms have been identified, including psychological, behavioral, or sociocultural (Parker, Kimble, Dunbar, & Clark, 2005). A combination of mechanisms may be required to explain the symptom experience.

Symptom intervention in oncology nursing has focused on pharmacologic and nonpharmacologic strategies to alleviate symptoms such as fatigue (Jacobsen, Donovan, Vadaparampil, & Small, 2007; Kangas et al., 2008; Mitchell, Beck, Hood, Moore, & Tanner, 2007; Mitchell, Berger, Mitchell, & Berger, 2006), sleep-wake disturbances (Berger et al., 2005), depression (Barsevick & Much, 2004; Barsevick, Sweeney, Haney, & Chung, 2002; Fulcher et al., 2008), and pain (Wiffen & Rees, 2007; Wong & Wiffen, 2002). Research evaluating interventions for many common cancer

symptoms has been sufficient to develop evidence-based guidelines for their management (Gobel, Beck, & O'Leary, 2006).

Considerable interest has focused on the problem of multiple co-occurring symptoms (symptom clusters) in oncology populations (Dodd, Janson, et al., 2001; Dodd, Miaskowski, & Lee, 2004; Dodd, Miaskowski, & Paul, 2001; Miaskowski, 2006; Miaskowski & Aouizerat, 2007). The definition of a symptom cluster, originally described by Dodd (Dahl, 2004; Dodd et al., 2004), was refined by Kim, McGuire, Tulman, and Barsevick (2005) to include “two or more symptoms that are related and occur together” (p. 278). Each cluster of symptoms is stable and independent of other clusters. The clustered symptoms may or may not share a common etiology. Despite the definition, clarity is lacking regarding how to operationally define a symptom cluster concerning the number of symptoms and the nature of the relationship between or among them.

A variety of different methodologies have been used to identify and describe the symptom cluster; the most common strategies have included expert opinion, group comparison, identification of patient subgroups, examination of shared variance (e.g., latent factors, mediators), and prediction of a common influence on patient outcomes (Badger et al., 2005; Barsevick, 2007a, 2007b; Barsevick, Whitmer, Nail, Beck, & Dudley, 2006). Much of this work has focused on the most prevalent cancer symptoms of fatigue, pain, and depression; sufficient evidence has emerged to suggest that some combination of these symptoms could constitute a symptom cluster (Chen & Tseng, 2006; Given, Given, Azzouz, & Stommel, 2001; Given, Given, Azzouz, Kozachik, & Stommel, 2001; Kim et al., 2008; Miaskowski et al., 2006). However, the evidence has been based largely on correlation methods that do not address the issue of a common underlying causal mechanism for a symptom cluster.

### **Progress 2004–2008**

Several individual symptoms as well as symptom clusters have been identified by oncology nurses as research priorities.

### **Sleep-Wake Disturbances**

Since early 2007, sleep-wake disturbances have gained increasing interest for investigation by multidisciplinary teams that include nursing scientists. Several review articles and book chapters have been published (Berger, 2006; Berger & Mitchell, 2008; Berger, Sankaranarayanan, & Watanabe-Galloway, 2007; Page & Berger, 2006; Sateia & Lang, 2008). Two book chapters will be published in early 2009 by ONS that focus on sleep-wake disturbances in people with cancer (Berger & Mitchell, 2009; Erickson & Berger, in press)

The sleep-wake disturbances section in volume I of the ONS Putting Evidence Into Practice (PEP<sup>®</sup>) cards was updated in 2008 using the same key terms as in the initial body of work. Based on the update, a major revision to the 2008 PEP<sup>®</sup> card was that the *Cognitive Behavioral Therapy (CBT)* category was moved to the “Likely to Be Effective” classification. Several recent studies reviewed in Page & Berger (2009) reported positive benefits of *Complementary Therapies* category interventions to

improve sleep-wake disturbances, but the evidence for this category has not been established.

**Future research** needs to include large randomized controlled trials to demonstrate the effectiveness of *Complementary Therapies, Education/Information, and Exercise* interventions on sleep-wake disturbances.

### **Hot Flashes and Hormonal Disturbances**

As of April, 2009, four manufacturers (American Medical Electronics, Corp.; Bahr Management, Inc.; BioMedical Monitors, LLC; UFI Serving Science) indicate their militarized devices look promising and will continue to be tested and refined. These new devices are advantageous due to their small size, light weight, and capability for multi-day objective hot flash monitoring.

Following the 2005 State-of-the-Science Conference on Management of Menopause-Related Symptoms, the National Institutes of Health established a multisite research network to conduct clinical trials of promising treatments for the most common symptoms of the menopausal transition in various populations, including women at high risk for or diagnosed with cancer. The 2008 funded initiative—Menopause Strategies: Finding Lasting Answers for Symptoms and Health—is coordinated by principal investigators (PIs) Andrea Z. LaCroix, PhD, and Garnet Anderson, PhD, both from the Fred Hutchinson Cancer Research Center in Seattle, WA. In addition to the Data Coordinating Center, five clinical research centers are included: Indiana University School of Nursing in Indianapolis (Janet S. Carpenter, PhD, RN); Harvard Medical School, Boston, MA (Lee Cohen, MD, and Hadine Joffe, MD); Kaiser Permanente, Northern California, Oakland (Barbara Sternfeld, PhD, and Bette Caan, PhD); University of Pennsylvania School of Medicine, Philadelphia (Ellen Freeman, PhD); Group Health Center for Health Studies, Seattle, WA (Katherine Newton, PhD and Susan Reed, MD).

**Future research** directions include examining genetics of hot flashes and other hormonal disturbances in patients with cancer, investigating the etiology of hot flashes and other hormone-related symptoms to identify novel treatment options, and investigating the efficacy and acceptability of treatments for hot flashes and other hormonal disturbances.

### **Changes in Cognitive Function**

Cognitive function is the information-processing component of behavior with multiple dimensions, including attention, learning and memory, executive functioning, mental flexibility, psychomotor speed, visuospatial ability, and language (Lezak, Loring, Hannay, & Fischer, 2004). Changes in cognitive function have been associated with cancer therapies (Bender et al., 2007; Corn et al., 2008; Jain, Krull, Brouwers, Chintagumpala, & Woo, 2008). Recent meta-analyses have documented cognitive function related to treatment (Anderson-Hanley, Sherman, Riggs, Agocha, & Compas, 2003; Falletti, Sanfilippo, Maruff, Weih, & Phillips, 2005; Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005). The domains of cognitive function that most commonly

deteriorate during the cancer experience include attention, learning and memory, executive function, and psychomotor speed.

The science of cognitive function has been limited by the lack of pretreatment evaluation, comprehensive multidimensional neuropsychological assessments, methodologic deficiencies, and failure to account for competing explanations, including mood, treatment side effects, and other medications (Bender et al., 2007; Kayl, Wefel, & Meyers, 2008). The long-term consequences of cancer and its treatment also remain unclear. Research to date suggests that adults with cancer have cognitive deficiencies prior to treatment when compared with healthy age-matched counterparts, which suggests that factors other than treatment could influence cognitive functioning (Ahles, 2007). Candidate mechanisms include difficulty coping with a cancer diagnosis, lingering effects of surgery or anesthesia, tumor-related factors, symptoms, and concomitant medications. Little is known about the pathophysiologic mechanisms underlying changes in cognitive function. Potential mechanisms include genetic susceptibility, DNA damage and telomere length, disruption of integrity of the blood-brain barrier, cytokine dysregulation, and reduction of estrogen and testosterone (Ahles).

Assessment of cognitive function remains challenging because it requires the conduct of lengthy neuropsychological assessments. Clinical screening measures of cognitive function are not sensitive to the subtle changes that occur during the cancer experience (Vardy et al., 2006). Only a few interventions have demonstrated efficacy in managing changes in cognitive function. Methylphenidate use improved motivation to perform activities and stamina. Behavioral interventions, including use of compensatory strategies and physical exercise, are being investigated (Ferguson et al., 2007; Kayl et al., 2008).

**Future research** related to changes in cognitive function should focus on (a) description of the long-term effects of cancer and cancer therapy on cognitive function, (b) identification of sensitive measures of cognitive function that can be applied in the clinical setting, (c) physiologic mechanisms underlying changes in cognitive function, and (d) development and testing of interventions to ameliorate changes in cognitive function. Longitudinal studies should include pretreatment evaluations of cognitive function to distinguish baseline function from the effects of treatment.

### **Symptom Clusters**

Progress is being made in understanding the biologic etiology of cancer-related symptoms. A number of different mechanisms have been proposed, including disturbance in hypothalamic-pituitary-adrenal (HPA)-axis functioning (Badger et al., 2005; Bower, Ganz, Aziz, et al., 2005; Bower, Ganz, Aziz, & Fahey, 2002) and inflammation processes (Collado-Hidalgo, Bower, Ganz, Irwin, & Cole, 2008; Reyes-Gibby et al., 2007, 2008). Cytokines, soluble proteins that mediate cell-to-cell communication among immune cells, are activated by inflammatory processes. Several lines of evidence suggest that increased inflammatory marker levels could result in cancer-related symptoms (Lee et al., 2004). Animal studies have demonstrated that

direct application of the cytokine interleukin-1 into the brain led to “sickness behavior,” with symptoms such as fatigue, cognitive changes, appetite suppression, and lower physical activity. In humans, the administration of recombinant proinflammatory cytokines to boost immune defenses against cancer has resulted in similar symptoms. This converging evidence provides a rationale for further examination of the association between cancer-related symptoms and immune system activation. Review articles examining the link between cancer-related symptoms and inflammatory markers also provide initial support for further exploration of inflammatory processes in the etiology of cancer-related symptoms (Irwin, Miller, Irwin, & Miller, 2007; Reyes-Gibby et al., 2007; Schubert et al., 2007).

The basis for inflammation and the development of symptoms is unclear. One possibility is alterations in the physiologic systems that regulate immune system activity such as the HPA axis. Adrenal cortex-derived steroids have potent effects on immune cell development, maturation, trafficking, and cytokine production (Bower, Ganz, & Aziz, 2005; Irwin et al., 2007; Reyes-Gibby et al., 2007, 2008). Therefore, the influence of genes in the cytokine pathway should be examined on multiple symptoms such as fatigue, pain, and depression.

**Future research** on symptom clusters should examine biologic pathways that could influence multiple symptoms. In addition, research is needed to determine whether assessment and management of a specific symptom cluster has positive effects on patient outcomes. Interventions that have been shown to influence more than one symptom need to be evaluated for their effect on a symptom cluster. The adverse effects of targeted therapy agents should be evaluated as well as the potential benefits with regard to short- and long-term outcomes.

For some symptoms, research has been sufficient to recommend incorporating specific interventions into clinical practice based on ONS PEP<sup>®</sup> guidelines (Gobel et al., 2006) and National Comprehensive Cancer Network (2008) supportive care guidelines.

### ***C. Late Effects of Cancer Treatment and Long-Term Survivorship Issues***

C.1. Develop or test interventions to minimize adverse outcomes related to long term or late effects and risks associated with the development of comorbid illnesses. [Long-term effects are any side effects or complications from therapy that continue beyond the end of treatment. Late effects occur months to years after treatment is completed (Aziz, 2007)].

C.1.1. Conduct intervention trials to reduce risks of long-term and late effects of treatment and the risk of chronic illness

C.1.2. Design physical activity and healthy eating interventions for survivors to improve physical, functional, and psychological outcomes, as well as recurrence and survival

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

C.2.1. Identify models of care to support the Institute of Medicine's recommendation for survivorship care (e.g., treatment summaries, surveillance recommendations) and develop interventions to address system barriers in implementing them

C.2.2. Explore effective ways to manage the growing number of survivors and the challenges of the oncology and nursing workforce shortages

### **Progress 2004–2008**

Over the past five years, cancer survivorship has received tremendous emphasis and increased awareness. In the United States, there are more than 11 million cancer survivors, or about 4% of the population (National Cancer Institute, 2009); this number is expected to grow dramatically as more survivors live longer and the population ages. Cancer survivors report poorer health than the general population, lower QOL, more lost productivity, and more health limitations. Chronic comorbid conditions such as hypertension and heart disease are common among survivors and many will have more than one co-morbid condition (Ogle, Swanson, Woods & Azzouz, 2000). The recognition of long-term and late effects contributing to premature death in disease-free survivors has increased the need for surveillance guidelines, identification of long-term and late effects, and interventions to minimize adverse cancer treatment effects. An Institute of Medicine report (2006) described the state of the science and identified eight domains of cancer survivorship research: descriptive and analytical (e.g., physiologic and psychological effects), intervention research (e.g., to prevent or reduce adverse physiologic or psychological effects), examination of survivorship sequelae in understudied cancer sites, follow-up care and surveillance, economic sequelae, health disparities, family and caregiver issues, and instrument development. The National Cancer Institute's Office of Cancer Survivorship (2009) identified five focal areas of research: chronic and late effects of cancer and its treatment, interventions, healthy lifestyle behaviors, benefit finding and posttraumatic growth, and family. Over the past five years, the small grants program supported by the ONS Foundation has awarded several small grants on long term or late effects. Examples of ONS members conducting survivorship research that is funded by the National Cancer Institute include: interventions for persistent effects (J. Carpenter, hot flashes), description of symptoms in older cancer survivors (S. Heidrich), information and lifestyle behaviors of survivors (D. Mayer), an intervention for rural survivors (K. Meneses), family interventions (L. Northouse), and an exercise intervention to reduce late effects (M.T. Knopf). The Lance Armstrong Foundation is committed to survivorship care and research. Eight National Cancer Institute -designated comprehensive cancer centers are members of the LIVESTRONG Survivorship Center of Excellence Network: the University of Pennsylvania; Dana-Farber Cancer Institute; Fred Hutchinson Cancer Research Center; Memorial Sloan-Kettering Cancer Center; Ohio State University; University of California, Los Angeles; University of Colorado; and University of North Carolina. And, in 2008, the Lance Armstrong Foundation reported providing almost \$2 million to leading research

institutions and almost \$1 million for community program grants (Lance Armstrong Foundation, 2009).

### **Rationale and Background**

**Priority C.1.** Many cancer survivors experience long-term or persistent effects of cancer treatment (e.g., peripheral neuropathy, fatigue, vasomotor symptoms associated with premature menopause of endocrine therapy, neurocognitive problems, alterations in sexuality and fertility) and are at risk for potentially serious health issues related to late effects of cancer treatment (e.g., osteoporosis, infertility, cardiac disease). Also, the majority of patients who undergo cancer treatment become physically deconditioned during the course of therapy, develop persistent fatigue, and may experience adverse psychological responses to the diagnosis and treatment. Sedentary behavior, being overweight, obesity, and diets high in calories and fat are prevalent among the US population. These health behaviors are associated with increased risk for cancer, diabetes, and heart disease. Therefore, data are compelling for health promotion in cancer survivors to maintain a healthy weight and participate in cardiovascular fitness activities to enhance their physical and psychological recovery from treatment and minimize their risk for chronic illness. Preliminary data from several studies with survivors of breast and colorectal cancer suggest that routine physical activity may decrease the risk of recurrence and improve survival (Hamer, Stamatakis & Saxton, 2009; Holick, Newcomb, Trentham-Dietz, et al., 2008; Holmes, Chen, Feskanich, Kroenke & Colditz, 2005; Meyerhardt et al., 2006).

**Priority C.2.** The number of survivorship programs is limited, and even in institutions where they exist, they provide care to only a select population of cancer survivors. System issues, financial considerations, and provider issues that support or impair the ability to provide high-quality survivorship care should be explored. Consensus guidelines on surveillance and follow-up for different cancer sites are just emerging and will need to be evaluated related to patient outcomes. In addition, the growing number of cancer survivors and the predicted shortage of oncology specialists pose serious challenges and a need to explore models for the delivery of survivorship care.

### **D. End of Life Issues**

Although no exact definition of EOL exists, it is a period of time marked by disability or disease that is progressively worse until death (National Institutes of Health, 2004).

D.1. Develop knowledge of mechanisms and management of symptoms for patients with cancer near EOL

D.1.1 Develop or test efficacious, feasible, cost-effective, culturally sensitive interventions for patients with cancer near EOL

D. 1.2 Validate culturally sensitive symptom measures for assessing symptoms in patients with cancer near EOL

## Rationale and Background

Only limited symptom research has been conducted with patients with cancer near EOL. Most therapy given near EOL is palliative (symptom management focused) rather than curative as patients continue to experience a variety of symptoms, the most common of which are fatigue, pain, dyspnea, dry mouth, drowsiness, and constipation (Doorenbos, Given, Given, & Verbitsky, 2006; McMillan & Small, 2002; McMillan & Weitzner, 2000; Tranmer et al., 2003). Most studies in the literature seemed to focus on describing the patient's symptom experience (Abraham, Kutner & Beaty, 2006; Doorenbos et al.; Mystakidou et al., 2005; Schonwetter, Roscoe, Nwosu, Zilka, & Kim, 2006; Silveira, Kabeto & Langa, 2005; Tranmer et al.), and a few described symptom management (Braga et al., 2007; Rolnick et al., 2007). However, few studies could be identified that reported testing an intervention for symptoms in patients with cancer near EOL (Keefe et al., 2005; McMillan et al., 2006; McMillan & Small, 2007). In addition, information about differences in cultural and ethnic groups in the United States and worldwide is largely missing from these studies, as are symptom measures that have been validated on groups with varying ethnic backgrounds (Braga et al.; Mystakidou et al.; Tranmer et al.). Thus, additional research is needed that tests interventions for patients with cancer near EOL and for symptom measures that have been validated on culturally diverse groups.

D. 2: Develop knowledge that promotes QOL for patients with cancer near EOL and their families

D.2.1 Conceptualize, develop, and validate specific measures of QOL for diverse groups

D.2.2 Develop or test efficacious, feasible, cost-effective, and culturally sensitive interventions for supporting QOL in patients with cancer near EOL and families

Oncology nursing research about QOL with populations near EOL have contributed substantially to the study of this complex, multidimensional, dynamic concept (Jocham, Dassen, Widdershowven, & Halfens, 2006). This research is fundamental to achieving the international goal of palliative or EOL care, which is to enhance QOL for patients and family members (Ferrell et al., 2007). QOL near EOL literature has focused primarily on patients. However, near EOL, the QOL of caregivers and families is equally important (Cohen, 2001). In a literature review of QOL research with populations near EOL, only 50 articles were published since 1990 (Jocham et al.), reflecting a paucity of research in this critical area. Following their review, Jocham et al. concluded that continued conceptual development of QOL near EOL was needed as well as valid and reliable ways to measure this concept.

QOL-EOL measures must be specific to populations near EOL. For example, existential issues (e.g., spirituality, hope, finding meaning and purpose) are an important domain of QOL in this population (Melin-Johansson, Odling, Axelsson, & Danielson, 2008; Sherman et al., 2005) and very often are not part of QOL measures (Cohen, Mount, Tomas, & Mount, 1996). The role of physical function measures in QOL-EOL requires

further debate (Jordhoy et al., 2007). QOL-EOL measures also must be validated with different cultural and age groups as QOL may be defined differently in different populations at EOL (Duggleby & Raudonis, 2006).

Based on their literature review, Jocham et al. (2006) recommended that oncology nurses develop and evaluate strategies or interventions to improve QOL near EOL for patients with advanced cancer and their families as very few studies have reported such strategies (Duggleby et al., 2007; McMillan & Small, 2007). QOL-EOL interventions must be targeted, tailored, and culturally sensitive and delivered using innovative strategies that are acceptable to patients near EOL and their families. They should be evaluated using innovative data collection techniques and research methods such as mixed-method designs. Intervention studies targeting patients with advanced cancer also should examine the impact on QOL on family caregivers and vice versa to determine relationships of QOL between these two populations and possible intervention diffusion effects. Systematic programs of research in the area of QOL near EOL are key to achieving the goal of high-quality EOL care.

## ***E. Psychosocial and Family Issues***

E.1. Design or test interventions to reduce negative outcomes (e.g., depression, burden, symptom distress) and improve positive outcomes (e.g., coping, benefits of illness, QOL) in patients with cancer and their family caregivers

E.1.1 Research to test patient and family models that encompass risk factors and protective factors and their relationship to outcomes

E.1.2 Design or test Interventions that identify patients and caregivers at higher risk of poorer outcomes and target interventions to meet their needs; these studies need to address cancer-related cost and resource utilization issues for patients and families

### **Rationale and Background**

Despite the existence of many descriptive studies that document the stressful effects of cancer on family caregivers, only a few intervention studies have been conducted that include partners or other family caregivers (Cochrane & Lewis, 2005; Kim & Given, 2008). Intervention studies have lagged far behind descriptive research, and the quality of some existing research is limited (Cochrane & Lewis). In view of the increasingly complex cancer care offered in community settings, well-designed randomized clinical trials are needed that help patients and their family caregivers to increase their preparation, self-efficacy, and coping skills to manage illness, reduce caregiver burden and emotional distress, and improve QOL (Given, Sherwood, & Given, 2009; Keefe et al., 2003; Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004; Northouse, Mellon, Harden, & Schafenacker, 2009; Schumacher et al., 2008).

Intervention research is beginning to identify patients and family members at higher risk of greater distress or poorer outcomes and target interventions to those most in need.

For example, in a recent study, McCorkle et al. (2009) screened patients for distress and offered those with greater distress a psychiatric consultation, in addition to intervention sessions with an APN, which resulted in better outcomes. Interventions also are needed that target at-risk caregivers and distinguish between those who are burdened or depressed (Given et al., 2009). Caregivers of patients in the advanced phase of cancer may be an at-risk group because they report more depression than patients (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007) and seldom seek mental health services for their heightened anxiety and emotional distress (Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005). Female patients and female caregivers also may be an at-risk group, because a meta-analysis found that they are more distressed than male patients and male caregivers (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Older adult caregivers (> 65 years of age) of patients who among the oldest old (> 85 years of age) are another at-risk group for which research is needed.

Comprehensive screening tools are needed that identify high-risk patients and family members who may be experiencing a range of psychosocial stressors that interfere with patients' and caregivers' abilities to manage the illness and maintain QOL. A few studies have reported on ways to identify high-risk patients and/or family members using the Family Relationship Inventory (Edwards & Clarke, 2004), the Distress Thermometer (Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008) and predictors of depressed mood (Lewis, Fletcher, Cochrane, & Fann, 2008). Not all patients and caregivers need intensive programs of care. Determining what program is optimal for which patients and caregivers will produce better outcomes and use fewer healthcare resources.

In a time of limited resources, the cost and potential cost savings associated with interventions must be examined. According to Mandelblatt et al. (2008), a number of interventions have examined the economic benefit of interventions to increase cancer screening, but few have addressed cost and the effects of behavioral interventions in cancer survivorship. In addition, the value added by family members to patient outcomes should be documented in terms of duration of symptoms, QOL, untoward hospitalizations, emergency department visits, and caregiver outcomes (Given et al., 2009). To translate efficacious nursing interventions to practice settings, the cost of delivering interventions and their ability to reduce healthcare costs must be addressed.

### **Progress 2004–2008**

A priority topic in the 2004–2008 ONS Research Agenda was to develop new models of individual and family adjustment to cancer and its treatment, incorporating concepts representing positive aspects of health and adaptation to illness. The use of qualitative approaches to describe meaningful and integrative positive health experiences was noted. In addition, the lack of a common language, the relatively unfocused nature of research on positive concepts, specification of only a few mechanisms by which positive adjustment occurs, and the minimal number of interventions specifically targeting positive concepts were indicated.

Since 2004, the small but subtle shift toward research on positive health and adjustment noted by the previous agenda-setting team has continued. Considerable additional qualitative research has significantly increased researchers' understanding of the positive aspects of the cancer experience. This body of work is international (Lindqvist, Widmark, & Rasmussen, 2006; Mattsson-Lidsle, Snickars-von Wright, Lindholm, & Fagerstrom, 2007; Taleghani, Yekta, Nasrabadi, & Silvia, 2008), providing a basis for understanding global similarities and differences. However, only a few studies have explored positive health concepts in diverse cultural and ethnic groups in the United States (Hamilton, Powe, Pollard, Lee, & Felton, 2007; Leak, Hu, & King, 2008; Morgan et al., 2005). Concepts most often explored include hope, spirituality, meaning, relationship with God or a higher power, commitment, healing, and transcendence (Chou, Liaw, Yu, & Tang, 2007; Prince-Paul, 2008; Reb, 2007). Research on these concepts is now sufficiently well developed that we could begin to draw out the differences between strengths that individuals bring to the cancer experience and transformative changes that may occur as a result of the cancer experience or as a result of an intervention (Fife, Monahan, Abonour, Wood, & Stump, 2008). Model development and instrument testing remain limited, with a few notable exceptions (Cole, Hopkins, Tisak, Steel, & Carr, 2008; Morrill et al., 2008; Reb). A few studies have tested interventions aimed at increasing positive adjustment. Examples include a study to test the effect of an animal-assisted activity on sense of coherence (Johnson, Meadows, Haubner, & Sevedge, 2008), an intervention to test the effect of a storytelling intervention on stress outcomes (Crogan, Evans, & Bendel, 2008), the effect of a life review intervention on spiritual well-being and happiness (Ando, Morita, Okamoto, & Ninosaka, 2008), and interventions using art as a way of self-transcendence (Lane, 2008; Walsh, Radcliffe, Castillo, Kumar, & Broschard, 2007).

The growth of studies addressing concepts of positive health, adaptation, and transformation has provided an important counterweight to the studies of distress that predominate in patient/family psychosocial and behavioral research. However, the 2009 agenda-setting team did not see research on positive adaptation versus distress as an either/or choice for the new ONS research priorities. Instead, as researchers have already started to do (Morrill et al., 2008; Thompson, 2007; Whitford, Olver, & Peterson, 2008), concepts pertaining to both resilience/adaptation *and* stress/distress need to be incorporated into family-focused psychosocial and behavioral research. Doing so will lead to a better understanding of which individuals are most in need of intervention and which interventions are most efficacious.

A review of funding by ONS from 2004–2008 indicated that only 3 small grants of the 19 proposals that were submitted pertaining to family caregiving and family adjustment were funded by ONS during that period of time (16%). Furthermore, no *major* ONS funding or grants related to family caregiving and family adjustment to cancer has been awarded during the past four years, even though this area of research has been identified as an increasingly important priority for oncology nursing (Doorenbos et al., 2008).

A review of the ONS 2008 research priorities indicates that ONS members ranked caregiving and family adjustment to cancer in the top 20 of all ONS priorities. Interest in

both of these content areas increased dramatically since 2004. Caregiving was ranked 48th in 2004 and moved to 15th in 2008. Family adjustment to cancer was ranked 39th in 2004 and increased to 18th in 2008. In summarizing the findings of the 2008 survey, Doorenbos et al. (2008) stated that the high rankings of caregiving and family adjustment to cancer indicate the increasing importance of family caregiving roles and the need to focus on family psychosocial issues. These investigators and members of the team that developed the ONS PEP<sup>®</sup> card on caregiver burden contend that oncology nursing research needs to test interventions to help families manage caregiving demands and facilitate family adjustment to cancer (Doorenbos et al.; Honea et al., 2008).

E. 2 Examine the impact of having a high risk for cancer, including a family history of cancer, on individuals and families

E. 2.1 Explore family communication and family functioning in disclosing test results, conflict and regret about pursuing genetic testing, role of significant others in decisions to pursue testing, and genetic testing in minority families

E.2.2 Develop or test interventions using decision aids, risk communication strategies, and educational support for probands and families considering genetic testing

### **Rationale and Background**

Progress in genetic testing is occurring at a rapid rate and continues to raise a number of psychosocial questions because of its widespread availability (Meiser, 2005). Interest in this area is increasing, as evidenced by an entire issue of *Psychosocial Oncology* that was devoted to genetic testing and counseling (Patenaude, 2008). However, research remains limited. Families need more information to understand the basics of genetic illnesses and to address the risks and challenges they face, knowing that they are at higher risk of developing cancer (Baumann, 2006). A large proportion of families undergoing genetic testing receive inconclusive results, and as a result, the impact of uncertainty in the context of genetic testing is an area for research (Meiser). Some partners of women at risk of breast and ovarian cancer reported elevated distress in adjusting to their wives' health threat (Mireskandari et al., 2006). Because partners play a critical role in facilitating decision making and providing support, more research is needed on ways to involve partners and provide them with information and support (Mireskandari et al.). Much more exploratory research is needed about family communication and family functioning in respect to disclosing test results, perceived conflict and regret about one's decision to pursue genetic testing, and family genetics among minority families. Intervention research is especially limited in this area. Possible areas for future intervention research include ways to provide risk communication to the proband, use of decision aids for genetic testing, and ways to support the proband to disclose test results to family members.

### **Progress 2004–2008**

Since 2004, a growing number of studies have addressed this priority area. Researchers have found that knowledge of cancer risk is limited (Katapodi & Aouizerat, 2005; Weinrich et al., 2007) and that a lack of congruence exists between perceived risk and objective risk factors (Katapodi & Aouizerat; Lancaster, 2005). Interpretation of inconclusive test results may be rooted in individuals' perceived inherited risk (Maheu & Thorne, 2008), whereas emotional responses may be moderated by coping style (Shiloh, Koehly, Jenkins, Martin, & Hadley, 2008). A meta-analysis of the predictors of breast cancer risk and the relation between perceived risk and cancer screening found that perceived cancer risk depends on a number of psychological and cognitive variables such as age, education, race or culture, and worry (Katapodi, Lee, Facione, & Dodd, 2004). The findings from that meta-analysis also indicated that women who perceived that they had a higher breast cancer risk were more likely to seek genetic testing. Although intervention studies are limited, the results of a randomized clinical trial of a genetic testing decision aid found to improve outcomes of genetic counseling were reported recently (Wakefield et al., 2008). Research on the dynamics of communication of genetic testing results within families remains limited although it is increasing (Clarke, Butler, & Esplen, 2008; Koehly et al., 2008; MacDonald et al., 2007; Van Oostrom et al., 2007), and research with diverse cultural perspectives is beginning (MacDonald et al., 2008). Recently discussed ethical issues pertaining to genetic testing and families include the potential role for genetics services in contacting at-risk relatives of deceased carriers of BRCA2 mutations (Ormondroyd et al., 2008). Although increasing, research on family communication and functioning in relation to genetic testing is still in its early stages.

A review of the grants funded by ONS that are pertinent to the impact of inherited risk of cancer on families indicated that three small grants were submitted from 2004–2008, but none of the small grants was funded. One major grant pertaining to genetic risk and families was funded during the four years. More research proposals need to be developed and funded in this area.

From the review of the 2008 ONS member survey, priorities pertaining to high-risk families and family genetics were not among the priorities identified (Doorenbos et al., 2008). Family genetic risk may have been included in the broader area of family adjustment to cancer, but that is not evident from the discussion of survey findings. However, four individuals wrote in “genetics” as an important research priority. In view of the importance of genetics and the family, items pertaining to genetics and families need to be clearly delineated in future surveys.

## **F. *Nursing-Sensitive Patient Outcomes (NSPOs)***

F.1. Evaluate the effect of nursing care on promoting and maintaining treatment adherence

F.1.1. Understand predictors (risk model), costs, settings, side effects, educational approaches, population, health literacy, and cognitive changes associated with adherence to oral chemotherapeutic agents

F.1.2. Evaluate the influence of various care providers and cost-effectiveness related to adherence of care issues

F.1.3. Explicate the issues of adherence in all aspects of a plan of care, including clinical trial participation, medications such as oral chemotherapeutic agents, diet, and self care strategies

F.1.4 Evaluate strategies for the identification and prevention of adverse events related to treatment, such as vascular devices

F.1.5 Develop or test interventions that support adherence to care

### **Progress 2004–2008**

The NSPO focus on treatment adherence with oral agents was due to: the growing number of oral agents available, shifting responsibility from inpatient care to the outpatient setting, and the need for the patient to closely follow-up and adhere to care. Prior to 2005–2009, no studies were funded by the ONS Foundation that targeted specific areas of infection, maintenance or promotion of physical function, functional status, and treatment. In 2004–2005, three studies were funded, with one focusing on prevention of adverse events, one on nursing interventions, and one on prevention of fatigue. Since then, three studies were funded (2006–2007), one on workforce issues (pain and nursing quality as related to certification) and two on adherence to treatment.

For this review, treatment adherence focused on work that has been completed since the last agenda on adherence to oral agents but was expanded to additional nursing outcome efforts that study predictors and correlates of change in physical functioning during cancer treatment and adherence to all aspects of care. Several reviews of adherence research (Kelly & Agius, 2007; Palmieri & Barton, 2008) found the studies reviewed to be deficient in overall quality. Several intervention studies were located that tested different modalities to increase adherence to oral chemotherapeutic agents in adults (Espie et al., 2008) and adolescents (Malbasa et al., 2007) and to pain medication (Valeberg et al., 2008). Several clinical articles were found that would be useful in helping to identify future research studies (Greer, Pirl, Park, Lynch, & Temel, 2008; Lette & Lette, 2008; Miaskowski, Shockney, & Chlebowski, 2008). A variety of studies were located that dealt with adherence to various components of cancer treatment, reflecting a broader range of intervention research (Chung & Hwang, 2008; Daley et al., 2007; Fahey et al., 2008).

From 2005–2009, there was a call for innovative studies possibly using health message education for behavior change. Several studies were found that tested psycho-educational interventions, cognitive/behavioral interventions, nutritional interventions (Demark-Wahnefried & Moyad, 2007; Kangas, Bovjerg, & Montgomery, 2008; Knobf,

Insogna, DiPietro, Fennie, & Thompson, 2008; Wyatt et al., 2007), and exercise (Pinto, Rabin, Abdow, & Papandonatos, 2008), but none used health message education.

**Underserved or Minority Populations and Treatment Adherence:** The 2005–2009 report identified the need to research adherence in minority populations. No studies were found that focused solely on minorities. Three interventions studies were found that focused on screening adherence in urban and minority populations.

### **F.1 Rationale and Background**

Further research is needed to fully develop the area of adherence. Adherence to oral chemotherapeutic agents and all aspects of the care trajectory for patients with cancer, including the setting (inpatient and ambulatory care) and how care is organized and managed (cancer center, hospital and community setting), is needed to identify patient and care provider obstacles. The barriers to adherence (i.e., side effects, cost, education, care provider approach, health literacy, the patient's cognitive status, and caregiver involvement) need to be considered. Adherence to care is a multifaceted problem. Predictive models of adherence to various aspects of care are not available. Research on the treatment effectiveness of education, both cognitive and behavioral, for various aspects of cancer treatment, but it is limited in scope.

Knowledge about education, both cognitive and behavioral, and exercise interventions is more advanced in the area of breast cancer and needs further development in other types of cancers. The research in the area of breast cancer also needs to be extended, but the body of outcomes research to date could be used as a model for extending research into other types of cancer.

As models of all aspects of adherence predictors are developed, future studies could use the data to develop and test interventions for oral medication adherence and an adherence-to-care regimen. The impact of rendering a higher percentage of care in the outpatient setting and the cost-effectiveness of such practices need further consideration. Beyond adherence to medication, many nursing sensitive interventions that correlate with the recommendations from the ONS PEP<sup>®</sup> cards need further research.

### **F.1. Future Research Recommendations**

Additional empirical research is needed to investigate the short- and long-term issues related to adherence in all aspects of the care trajectory for patients with cancer. Models that consider the variables that influence adherence need to be developed and tested. This calls for descriptive and predictive research that allows for the testing of indexes that are related to adherence to explain the interrelationship between variables that affect adherence and nonadherence. As patients and caregivers assume more responsibility for care, the facilitators and barriers need to be identified. Interventions that support the facilitating mechanisms and address barriers need to be developed and tested.

NSPOs research related to adherence needs to bridge all aspects of care, including clinical trials participation, medication, diet, exercise, self-care, and cancer prevention strategies. Research about adherence needs to address the uniqueness and diversity of all populations and groups. How patients and their families receive, process, and respond to information on adherence to care is important. Intervention research should include individual and group interventions and use of novel approaches such as community-based patient navigators. Many newer technologies are available for general education and health care. Innovative studies using these newer technologies for cancer care interventions need to be conducted so that the interventions can be identified and tested for promotion of positive outcomes in patients with cancer.

F.2. Expand knowledge regarding relationships between physical function and nursing-sensitive outcomes

F.2.1 Explicate the relationship between nursing interventions and physical functioning for patients with cancer

F.2.2 Evaluate the relationship between physical function and falls with injury for patients with cancer

## **F.2 Rationale and Background**

Functional ability has been defined as the capacity to perform normally expected activities and tasks in pursuit of the fulfillment of life roles (ONS, 2004). The concept of physical function includes the biologic, psychological, and social perspectives, and is a key determinant in patient perceptions of QOL. The concern regarding physical functioning and late effects of cancer treatment only recently have been documented; these deficits are anticipated to increase as anticancer therapies become more complex and as the age threshold for active treatment continues to expand (Hewitt, Rowland, & Yancik, 2003; Snyder et al., 2008).

Perhaps because of the variety of identified inputs that contribute to physical functioning, empirical research in this area has been underdeveloped. Clinicians often may accept physical function declines, in part, because the primary goal may be eradication of cancer. This perspective neglects the persistent and deleterious effects of physical function declines in patients. In addition to alterations in social, family, and work roles, the risks of increased adverse events (e.g., falls, fractures) require clinicians to assess physical function before, during, and after cancer therapy, and to intervene appropriately.

## **F.2 Progress 2004–2008**

### **Physical Function**

Research in studying the concept of physical function in patients with cancer has expanded, with an observed increase in publications. The studies often measure physical function in conjunction with related concepts, such as pain, fatigue, or health-related QOL. Additional data are available to link commonly used treatments for cancer and changes in physical function. Specifically, androgen-deprivation therapy (Alibhai,

Gogov, & Allibhai, 2006; Bylow, Mohile, Stadler, & Dale, 2007), surgery (Amemiya et al., 2007), radiation therapy (Silver, Dietrich, & Murphy, 2007), and systemic chemotherapy (Given, Given, Sikorskii, & Hadar, 2007; Goodwin, 2007; Visovsky, 2006) all have been implicated in physical function declines in patients.

### **Intervention Studies**

In prior research agenda plans, a specific recommendation was made to increase efforts to develop and test efficacious interventions for physical function. A series of literature reviews and empirical analyses suggest that exercise and physical activity are likely to improve physical function in patients with cancer (Conn, Hafdahl, Porock, McDaniel, & Nielsen; 2006; Knobf, Musanti, & Dorward, 2007; Luctkar-Flude, Groll, Tranmer, & Woodend, 2007). Since the previous report, several studies have been published, including an increased number of randomized trials that test the effects of interventions on physical functioning, which is encouraging. One three-arm randomized trial associated the receipt of relaxation instruction with an increase in the number of usual activities performed for patients (Christman & Cain, 2004). In one underpowered randomized trial, a marginal benefit of a diet and exercise regimen on physical functioning was observed (Demark-Wahnefried et al., 2006). In another randomized trial of a cognitive-behavioral intervention, improvements in physical function were noted; however, personal and health characteristics of patients moderated the effect of the intervention (Doorenbos, Given, Given, & Verbitsky, 2006). These studies would suggest that modest improvements in physical functioning are obtainable with nursing interventions, yet attention to sample size and study power, as well as confounding variables, is important.

### **Physical Function and Falls With Injury**

A recent policy decision by the Centers for Medicare and Medicaid Services to deny hospital reimbursements in cases where injurious falls have occurred may provide a key advantage to link care providers and researchers to address a problematic area (Neergaard, 2008). A literature review conducted in February 2009 identified one peer-reviewed, data-based clinical study that examined the relationship between physical function and falls in a sample of patients receiving androgen-deprivation therapy for prostate cancer (Bylow et al., 2008). Anecdotal reports from hospital leaders indicate a pervasive problem with injurious falls in patients with cancer. Although linking physical function with injurious falls may seem logical, continued research in a multivariate context is required to disentangle this relationship. Following descriptive research in this population, novel interventions will be ready for development and testing.

### **Research Funding Review**

The National Institutes of Health and the list of funded research projects from ONS were reviewed to identify active grants from 2006–2009 that explicitly study the physical function of patients with cancer.

- a. National Institutes of Health CRISP (9)
  - i. Morbidity Following Breast Cancer Treatment.  
PIs: Charles McGarvey/Lynn Gerber, National Institutes of Health

- Clinical Center  
Z01 CL060058-05
- ii. Family Home Care for Cancer-Community Based Model  
PI and Nurse Scientist: Barbara A. Given, Michigan State University  
R01 CA079280-14
  - iii. Interdisciplinary Studies to Enhance Long-Term Survival  
PI: Karen Syrjala, Fred Hutchinson Cancer Research Center  
R01 CA112631-02
  - iv. PNI-Based Stress Management in Early Breast Cancer  
PI and Nurse Scientist: Nancy McCain, Virginia Commonwealth University  
R01 CA114718-03
  - v. A Couple's Approach to Enhance Breast Cancer Survivorship  
PI: Donald Baucom, University of North Carolina–Chapel Hill  
R01 CA107477-05
  - vi. RENEW Research—Out to ENhance Wellness Older Survivors  
PI: Wendy Demark-Wahnefried, MD. Anderson Cancer Center  
R01 CA106919-04
  - vii. Customizing Family's Symptom Management Skills Post HSCT  
PI and Nurse Scientist: Deborah Eldredge, Oregon Health and Science University  
R21 CA115374-02
  - viii. A RENEW Intervention for Elderly Cancer Survivors  
PI: Paul Lastayo, University of Utah  
R21 CA114523-01A1
  - ix. Trajectories of Serious Illness: Patients and Caregivers  
PI: James Tulsky, Duke University  
R01 NR008249-05

b. ONS Foundation Research Grants (0)

No funded grants were identified from 2001–2009 that explicitly focused on the promotion and maintenance of physical function; however, a \$10,000 grant was announced in collaboration with the Rehabilitation Nursing Foundation to study rehabilitation issues in patients with cancer. Given the broad scope of the call for proposals, this mechanism could support studies of physical function in patients with cancer.

## F.2 Future Research Recommendations

In addition to continued empirical research to investigate the efficacy of interventions to maintain or improve physical function, studies that explicitly link physical function changes to injurious falls in this population is a ripe area of research, given recent national healthcare policy decisions. Physical function deficits also may impact other significant clinical outcomes, including pressure ulcers, hospital length of stay, and cost of care. The impact on costs to insurers, providers, and patients requires further analysis. A related issue is the need to evaluate the costs associated with the delivery of efficacious interventions in this setting. A gap is noted in the measurement and

conceptualization of physical function; subjective and objective measures have been reported widely in the literature. Psychometric properties of such measures remain problematic, which may impact the ability to detect meaningfully significant findings. Disparities in physical function deficits have been reported by income and race or ethnicity (Cheville, Troxel, Basford, & Kornblith, 2008). Thus, linking research programs focused on health disparities with those studying physical function may stimulate interest in this area. In addition, finding research focused on physical function in older adults is not surprising (Schubert, Gross, & Hurria, 2008), but targeted studies also may be appropriate with patients with cancer younger than age 65. Physical function limitations may exert negative effects on role function and impact long-term survivorship (Sherwood et al., 2008).

## **G. Translation Science**

G. 1. Develop implementation science methods and techniques designed to improve the capacity of clinicians to screen, assess, and deliver effective interventions and optimize the quality of oncology nursing care as well as patient outcomes

G.1.1. Investigate methods to exploit technology and system redesign to link screening, assessment, interventions, and outcomes

G.1.2. Promote research-practice partnerships to integrate efficacious, cost-effective interventions into clinical care

### **Rationale and Background**

The evidence base for cost-effective oncology nursing practice continues to expand; however, a gap continues to exist between available evidence and current practice. If oncology nursing interventions with known efficacy and cost-effectiveness are not utilized by providers, consumers, and service systems, the impact of our science will be modest. Recently, evidence-based guidelines have been developed within the ONS Putting Evidence Into Practice (PEP<sup>®</sup>) model, and an opportunity exists to test the impact of these resources to improve clinical outcomes (Doorenbos et al., 2008b). Research-driven initiatives should be developed that directly enhance care quality and contribute to the field of translational research and implementation science in oncology nursing.

Implementation science refers to studies designed to evaluate the *effectiveness* of an intervention in a population and/or evaluate a process of *transferring to a target audience the knowledge, skill, and systems support* needed to deliver an intervention. A model of translational research that incorporates both of these aspects of implementation science has been proposed by Brekke, Ell, and Palinkas (2007).

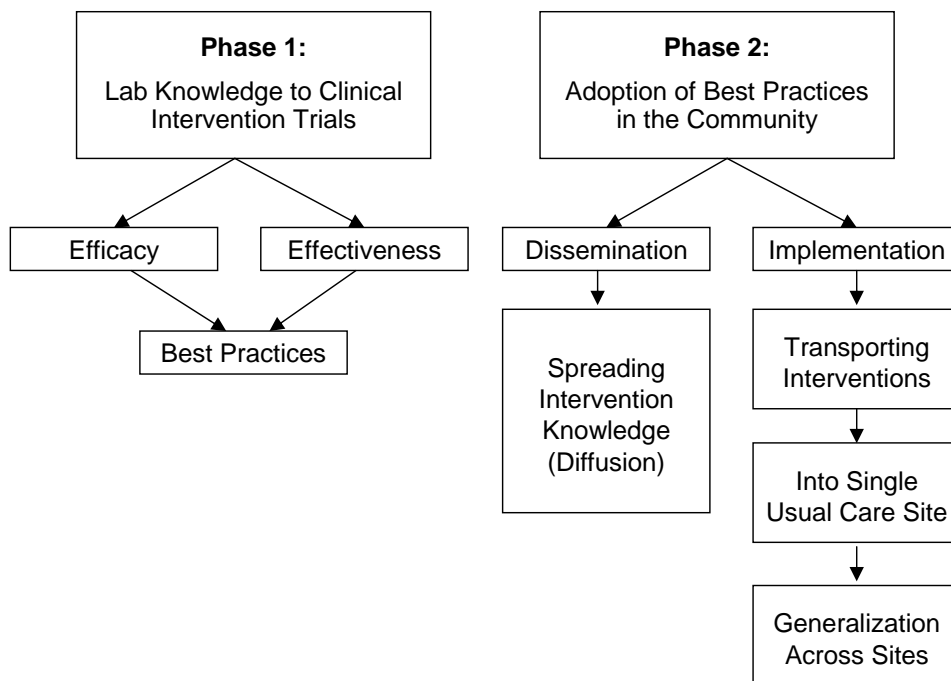


Figure 1: Conceptual Model for Translational Research (reprinted with permission)

This priority encompasses strategies to (a) promote the adoption of cost-effective interventions by clinicians (e.g., audit and feedback, capacity building), (b) integrate cost-effective interventions into service systems (e.g., clinician reminder systems), (c) tailor tested interventions to ensure compatibility with a wide variety of service delivery models while preserving efficacy, (d) promote research-practice partnerships that increase the likelihood that cost-effective interventions can be embedded within care delivery processes, (e) enhance organizational capacity for sustained delivery of evidence-based interventions, (f) exploit informatics and technology for dissemination and sustained adoption, and (g) test systemwide efforts to routinely achieve evidence-based care, including the development, implementation, and evaluation of point-of-care information collection and clinical decision support.

### Progress 2004–2008

Clinical practice guidelines for selecting an intervention to manage cancer symptoms are available for 16 symptoms via ONS PEP<sup>®</sup> cards. The ONS PEP<sup>®</sup> resources have become the first targeted topics for translational research in oncology nursing. In addition, ONS has recommended that continued work be supported for pain, fatigue, dyspnea, cognitive impairment, anorexia, and neutropenia. This priority builds on the work done in the symptoms and NSPOs content areas. Three competitive practice grants were funded in 2005; results are not yet available. No studies were funded in this topic area in 2007.

G.2. Identify cognitive-behavioral, psychoeducational, rehabilitative, and self-management interventions (individual and multilevel) with demonstrated effectiveness in

targeted populations, and refine, manualize, and evaluate those interventions for use by clinicians to address multiple outcomes. Based on feedback from a survey of ONS members, interventions that address pain, sleep, fatigue, and mood disturbances should be prioritized for funding

G.2.1. Conduct exploratory analyses and test resultant hypotheses in experimental designs to develop new knowledge that allows interventions to be targeted effectively (i.e., develop knowledge that contributes to identifying which interventions work best for whom, under what conditions or contexts, at what costs, and to achieve what outcomes)

G.2.2. Modify interventions for use by clinicians to target multiple outcomes simultaneously (e.g., symptom distress and functional status) and examine implementation, service, and client outcomes

### **Rationale and Background**

The body of evidence is accumulating concerning effective strategies to improve specific clinical outcomes such as pain, fatigue, mood, sleep disturbances, and caregiver strain; however, few efforts have translated these research-tested interventions into programs that can be adopted and delivered by staff nurses. Examples include ECAM (Barsevick, Dudley, & Beck, 2006), SMaRT (Strong et al., 2008), CBT for sleep quality (Berger et al., 2008), CBT for symptom management (Doorenbos et al., 2005; Doorenbos, Given, Given, & Verbitsky, 2006; Given et al., 2008; Sherwood et al., 2005), uncertainty management intervention (Mishel et al., 2005), family-based interventions (Northouse et al., 2007), and APN case management (McCorkle et al., 2009). Symptom clusters have been an important focus of descriptive or correlation studies in oncology nursing, and evidence suggests that symptoms including pain, sleep disturbance, fatigue, mood, and functional losses commonly co-occur. Also, overlap in the intervention categories (e.g., CBT, exercise) targets multiple symptoms.

The development, dissemination, and testing in naturalistic settings of interventions that target multiple symptoms and that have been packaged for delivery by clinical oncology nurses would accelerate the adoption of effective interventions into clinical practice, promote greater system efficiency by simultaneously addressing multiple symptoms, and lead to improved patient and caregiver outcomes. Knowledge also is needed to promote the matching of subpopulations of individuals to specific interventions and intervention contexts (e.g., content, delivery source, dose, location, timing) based on demographic, behavioral, psychosocial, biologic, or genetic factors.

In addition to testing implementation, service, and client outcomes (Proctor et al., 2008) that result when interventions are used in heterogeneous populations, empiric work is needed to identify the most appropriate measures for screening and outcomes evaluation, including quality indicators. In addition, these research-tested interventions should be linked with screening measures that identify patients in need of intervention and with real-time clinical monitoring and outcomes evaluation measures that establish,

in a diverse sample, the relationship between the intervention and improvements in multiple outcomes. In addressing the need for screening and evaluation measures, approaches should capitalize on efforts such as the Patient-Reported Outcomes Measurement Information System ([www.nihpromis.org](http://www.nihpromis.org)) and other recent initiatives designed to strengthen and streamline the evaluation and interpretation of symptoms, functional status, and other health outcomes.

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## **E. Psychosocial and Family Issues**

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## **F. Nursing–Sensitive Patient Outcomes (NSPOs)**

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## **G. Translation Science**

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