

# ONCOLOGY NURSING SOCIETY 2003 RESEARCH AGENDA

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## I. EXECUTIVE SUMMARY

### A. Project background

The research agenda for the Oncology Nursing Society (ONS) is the product of a multi-method, stakeholder consensus-building effort. With the support of the National Cancer Institute and the National Institute of Nursing Research (1 R13 CA101305-01), the 2002-2005 Research Agenda has been updated and revised with regard to the original 6 priority research content areas. Two of the original 6 areas have been consolidated. As we seek to meet the mission of the ONS to promote excellence in oncology nursing and quality cancer care, we realize that new knowledge is needed to further define and expand the scope of excellence and quality. The agenda's focus is on areas where there are gaps in the knowledge base for oncology nursing practice. High priority topics are specified in the document.

### B. How to use this document

This document can be used to inform the Society's own planning for its research enterprise and to inform external individuals and groups regarding the scientific priorities of the ONS membership.

The ONS research agenda is submitted as a mechanism to achieve that mission with the goals: 1) to increase the knowledge base for oncology nursing practice through funding cutting edge/critical priority areas of oncology nursing research, 2) to prepare future oncology nurse researchers who will be well trained and prepared to implement ongoing programs of research and to seek support from major sponsors such as the National Institutes of Health and the American Cancer Society, and 3) to prepare clinical nurses as critical consumers of research findings that can be applied to practice.

### C. Common themes and fundamental strategies

As you read this research agenda, you will note particular commonalities among the recommendations of the experts. The recommendations tend to focus on resources needed and include the following strategies:

1. Collaborative networks of researchers and clinicians that provide incentive to partner scientists and clinical oncology nurses
2. Application of standardized approaches to research methods and procedures
- 3. Educational and interventional translation of scholarly evidence into nursing practice**

#### *A plan for bringing scholarly evidence-based interventions into clinical settings*

Because of the importance of providing realistic mechanisms to bring well-studied interventions into a clinical cancer care setting, the following exemplar area is offered as a way to systematically effect transformation of practice. Palliative, supportive and end of life (EOL) care are similar specialties in which well-founded interventions have been successfully evaluated and several are ready for wide spread implementation in practice. Since the IOM report on improving care and the end of life was issued in 1997, only gradual acceptance of the field of palliative care has occurred.

*The authors of this agenda highly recommend that ONS establish a group of members with diverse backgrounds to organize various efforts for disseminating scholarly evidence-based interventions, beginning with palliative/EOL care, throughout ONS. This group would develop strategies to sustain translation of evidence into practice that could be applied to other content areas.*

## **D. Content Areas with Rationales and Priority Topics**

### **1. Research in cancer symptoms and side effects to include new knowledge regarding successful relief strategies and identification of symptom clusters and their associated outcomes.**

Rationale. The number of people affected with the three understudied symptoms in section 1.1 is increasing due to shifting demographic trends, the increasing use of supportive care measures allowing for dose escalation, and improvements in survival rates. A growing body of evidence suggests that these three symptoms significantly impact quality of life in persons with cancer.

#### **Priority Topics**

- 1.1. Understudied Symptoms
  - 1.1.1. Hormonal disturbance
  - 1.1.2. Sleep disturbances/insomnia
  - 1.1.3. Peripheral neuropathy
- 1.2. Continued work in pain, fatigue, depression, cognitive impairment, anorexia, and neutropenia

### **2. Research in psychosocial and behavioral research including communications (both interpersonal and technological), strength based perspectives, ethics and decision-making**

Rationale. People with cancer are living longer after the diagnosis. The delivery of cancer treatment has shifted from acute care to ambulatory care and the home, necessitating the involvement of families and caregivers. Preliminary work and research for end-of life-care has been established. Yet the translation into the clinical and home settings has not proceeded. Known efficacious interventions must be adopted by providers in order to assure quality care.

#### **Priority Topics**

- 2.1. Strategies to develop self-management for patients and families.
- 2.2. Complete meta-analyses and meta-syntheses of studies on coping and related concepts and coping outcomes in the context of cancer.

### **3. Research in health systems issues, policy, quality of care and clinical outcomes**

Rationale. With the nursing shortage, we need to be able to clearly demonstrate the impact of nursing care. Nurses have a growing evidence base of effective symptom management – we should build upon that to understand the contribution of symptom management on patient lives beyond symptom relief. By using outcome methodology, this allows us to advance our knowledge across the care continuum to go beyond point of service and be patient centered.

#### **Priority Topic**

- 3.1. To evaluate the effectiveness of nursing care on cancer patient outcomes which should include symptom control, functional status, and access to and utilization of health services.

#### **4. Research in health promotion; primary and secondary prevention**

Rationale. Colorectal cancer (CRC) presents a unique opportunity for primary and secondary prevention. Regular screening facilitates early detection of CRC, which in turn leads to reduced mortality. Additionally, the removal of polyps contributes to decreasing the incidence of CRC. Early-stage diagnosis of CRC through regular screening can lead to survival rates of 90% for colon cancer and 80% for rectal cancer, indicating the need for research promoting increased screening. Although breast cancer prevalence and incidence are high, mortality has been decreasing due primarily to earlier detection through mammography. Current research with mammography screening adherence has demonstrated that interventions targeting both women and providers have significantly increased screening. New approaches include both targeted and tailored messages using phone counseling and interactive computer counseling. Our challenge for the future is to provide cost-effective approaches to delivering interventions while incorporating our new technology.

In the twentieth century, tobacco use emerged as the leading cause of preventable death in the United States, and a leading cause of death around the world. Tobacco use contributes to over 30% of cancer deaths. Almost ninety percent of lung cancers are attributed to tobacco use and could be prevented with interventions to eliminate tobacco uptake, support smoking cessation, and reduce exposure to second-hand smoke. Smoking cessation is the most cost-effective intervention for adults; more cost-effective than mammograms, pap smears, and screening for colorectal cancer or hypertension.

##### **Priority Topics**

- 4.1 Develop and test cost-effective interventions for breast and colorectal cancer risk and screening
- 4.2 Develop and test cost-effective interventions for prevention of tobacco uptake and use cessation

#### **5. Research that considers the late effects of cancer treatment and long-term survivorship issues for patients and their families.**

Rationale. Cancer has become a chronic illness. For the most part, even those individuals who ultimately die of their disease live years past the initial diagnosis. The use of intensive multi-modal treatment regimens also contributes to an increasing incidence, or perhaps awareness, of deleterious physiologic and psychosocial treatment complications called long-term or late effects. Appropriate medical, behavioral, educational, and psychosocial interventions for adult cancer survivors experiencing late effects of diagnosis and treatment, such as premature menopause, peripheral neuropathies, decline in sexual functioning, stress incontinence, cardiac damage related to anthracyclines, cognitive changes, and the effect of these issues on family functioning, must be researched and developed.

##### **Priority Topics**

- 5.1 Describe the physiological and psychosocial late effects of cancer and its treatment experienced by cancer survivors of all ages, and socioeconomic and ethnic groups.
- 5.2 Develop interventions that will reduce the risk and limit functional impairment related to the cancer diagnosis and treatment for cancer survivors of all ages, ethnic backgrounds, and socioeconomic groups. Develop interventions that will support optimal physiological and psychosocial functioning.

## **E. Mechanisms for funding**

The allocation goal should be \$500,000 for an individual priority topic. All of the research priority areas should be considered when the Foundation Board seeks research sponsorship, as some potential donors may be more interested in one priority than another priority. A variety of funding mechanisms should be utilized for each priority area to achieve the goals of building new science, developing new researchers and particularly, applying new knowledge to practice.

## **F. Relationship to Strategic Plan**

One of the 2003-2005 ONS Strategic Goals is: *Drive quality cancer care through education, research, leadership and advocacy.* In keeping with this ONS vision and strategic goal, the purpose of the research agenda is to identify key areas of science in which ONS can take a leadership role in supporting, through funding, the advancement of oncology nursing science. The knowledge acquired from this research can be integrated into practice to influence quality of cancer care.

## **G. Risk/Reward**

The major rewards possible through the effective use of this proposed agenda are the contributions that new knowledge can provide to the care of people with cancer, the development of oncology nurse researchers who can go on to obtain support from other funding agencies, the continued development of the evidence base for clinical practice, and creation of an infrastructure that will support and develop nurse researchers.

The major risk is that the agenda will not be used and/or that it will not be evaluated and revised on an ongoing basis. An additional risk may be that the selection of targeted areas of research funding needs will limit and possibly cause donors who are interested in other topics to fund research through research grants directly to investigators. The benefits of funding research through the ONS Foundation can far outweigh the potential risks.

## **II. INTERNAL/EXTERNAL ASSESSMENT**

### **A. Internal**

The 2000 ONS Research Priorities Survey results were used as the guide for the development of the Research Agenda Priority areas. Specific priority areas were selected based on the: 1) Research Priorities Survey; 2) feedback from the synthesis of the outcomes, neutropenia, biotherapy and symptom management expert panels of ONS; and 3) the Research Agenda Project Team member's assessment of cutting edge topics in cancer care. ONS has limited resources for oncology nursing research and thus should not duplicate what is available from large federal and other funding agencies but rather provide a "stepping stone" toward larger funding.

A systematic priority setting process involving various stakeholders was implemented in 2002/2003 after support was obtained from the National Institutes of Health. The updated priorities are included in this report. A group of 25 nursing research experts, members of the ONS Research Team and a consumer advocate participated in the priority setting process.

## B. External

The chosen content areas were also guided by a review of areas targeted for research by the NCI, NINR, Department of Defense (DOD), Komen and American Cancer Society (ACS).

## III. Agenda Design/Main Components

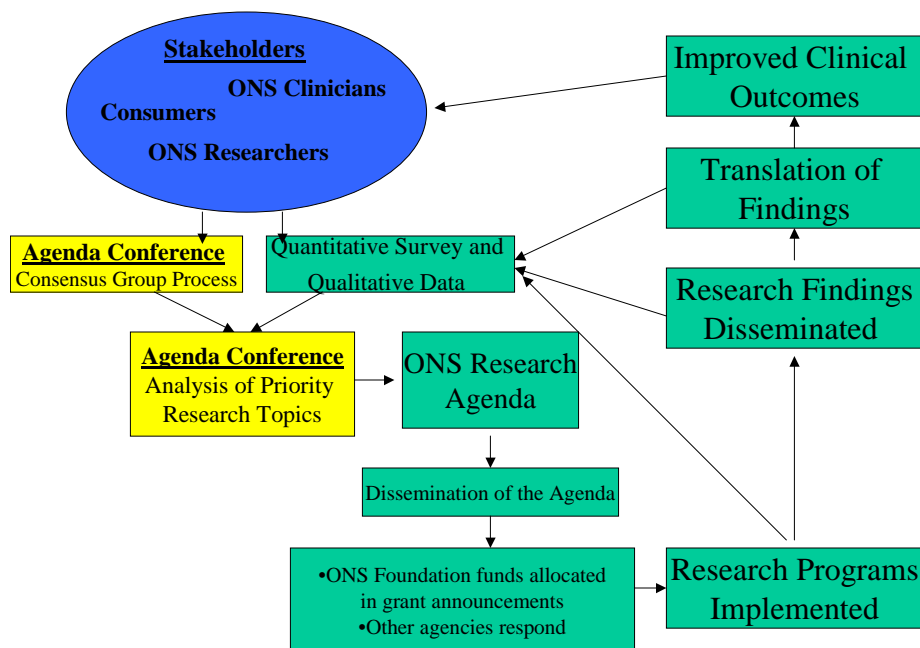


Figure 1. Framework for priority setting: The ONS Research Agenda

## A. Research agenda prioritization every 4 years

These priority areas will be identified through the results of the ONS Research Priorities Survey (conducted every 4 years), other funding agencies' priorities (National Institute of Nursing Research, National Cancer Institute, Department of Defense, American Cancer Society, other private foundations, etc.) and the state-of-the-science, determined via an assessment of current practice and research knowledge needs/gaps by oncology nursing research experts, clinical experts and consumer advocates (Figure 1). The input of oncology nursing research experts in the development of these priority areas is essential, as cutting edge, state-of-the science topics may not be identified through general survey methods. The perspectives of clinical experts and consumers are also essential as the issues and problems they experience in day-to-day living with cancer are the driving forces for this research agenda. All of these research priority areas should be considered when the Foundation Board seeks research support, as some potential sponsors may be more interested in one priority than another priority.

## B. Allocation of funds for each of the top priority areas should be \$500,000

This funding goal for major grants will enable the ONS Foundation to support a variety of mechanisms to facilitate all 3 goals of "building the science," "developing new researchers" and "creating critical clinician consumers". The fundraising goal should be \$500,000 for each priority area in addition to funding for the small grant awards.

## C. ONS Foundation Small Grants Program remains separate from the targeted priority areas for major grants. [unchanged from 2001]

The continuation of the ONS Foundation Small Grants and Fellowship Program as a separate program from the Major Grants Program will facilitate the generation of new areas of research and/or the development of new researchers. Even though the number and quality of applications for small grants has been variable in the recent past, small grants are an essential component of the ONS Research Agenda. Strategies to improve the quality and increase the number of applications need to be ongoing. The following recommendations are made for the Small Grants Program:

1. Small grant submission should not be targeted to the priority areas or areas of science but rather should reflect investigator initiated topics. This will provide opportunities for innovative research to be developed in all areas.
2. The funding level for Small Grants should be a minimum of \$10,000.
3. Detailed review and follow-up of the small grants recipients should be included in the program.
4. All applicants must include a specific plan for the submission of their supported research project for presentation and publication.
5. It is an expectation that all recipients of ONS Foundation Small Grants must present and publish from their work (acknowledging the ONS Foundation support) as an outcome of their research.
6. Funding should be for two years with a progress report submitted after one year.
7. All small grant applications must have an experienced researcher as a consultant or as a part of the research team.

#### **D. Review, Evaluation and Revision of Topics**

The review, evaluation, and revision of specific priority topics will occur at two-year intervals at the time of the Biennial Cancer Nursing Research Conference (next one is February 2005). The ONS Research Priorities Survey should be conducted every four years (next one should be conducted in 2004 to have the results available for the 2005 Cancer Nursing Research Conference). A full revision of this Agenda will take place in 2005 with the support of the Conference Grant from NIH.

#### **IV. Areas of Science for ONS Research 2001-2005**

The RFA (Request For Applications) mechanism is a process through which ONS/ONS Foundation issues a request for applications to study a given problem or topic. ONS is also open to ideas about the specific topic and the responding individuals or groups initiate their own research questions and methodology. Thus, “researcher initiated proposal” development within the identified priority area is the preferred method. In addition, the major research grants should consider the areas of science listed below. The driving force for funding will be based on scientific criteria and, through this approach, a range of models, including human and animal, will be considered. We expect that the majority of funding will support investigator-initiated research within the priority areas, areas of science, and populations. Content areas of science and priority populations should be appropriately integrated in to the calls for applications for each priority area.

The content areas of science listed in section IV C are those areas identified by the 2001 Research Agenda Project Team and then revised and updated by the 2003 ONS Research

Agenda Conference Group. These content areas reflect priorities for which more knowledge is currently needed.

#### **A. Common themes and fundamental strategies**

As you read this research agenda, you will note particular commonalities among the recommendations of the experts. The recommendations tend to focus on resources needed and include the following strategies:

- Collaborative networks of researchers and clinicians that provide incentive to partner scientists and clinical oncology nurses
- Application of standardized approaches to research methods and procedures
- Educational and interventional translation of scholarly evidence into nursing practice

#### **B. A plan for bringing scholarly evidence-based interventions into clinical settings: Palliative, supportive and end-of-life care**

Because of the importance of providing realistic mechanisms to bring well-studied interventions into a clinical cancer care setting, the following exemplar area is offered as a way to systematically effect transformation of practice. Palliative, supportive and end of life care are similar specialties in which well-founded interventions have been successfully evaluated and several are ready for wide spread implementation in practice. National initiatives are providing increased evidence of the support patients and families need to deal with symptoms, decisions and burdens associated with dying. However, the dissemination of this evidence through education of health care professionals is minimal. In 1997 the Institute of Medicine (IOM) issued a formal report addressing the status of the End of Life (EOL) care in the United States. In attempting to define the basic elements of a decent or good death, the IOM report stated that good death is "one that is free from affordable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards." The report emphasized that care for those approaching the EOL should become a very integral and important part of routine health care.

In the United States cancer remains second only to heart disease as a cause of death, and currently accounts for approximately 22 percent of all deaths. Cancer patients are unique in that the majority is likely to undergo a multitude of treatment options throughout the course of their illness. The care these patients receive is often interdisciplinary in nature, involving terms of physicians, nurses, social workers, and other health professionals such as psychologists, physical therapists, pharmacists, occupational therapists, and clergy. The nature of this disease looks at a wide variety of treatment modalities such as surgery, radiation therapy, and chemotherapy. Despite the best intentions for cure, these treatment modalities can all too often end with patients who are debilitated, weakened, financially strained and emotionally vulnerable. Illness can be prolonged and requirements for re-treatment can be multiply. Identifying points of futility in further treatment can be extremely difficulty for both the health professionals caring for these patients as well as the patients themselves and their families.

Since the IOM report on improving care and the end of life was issued in 1997, gradual acceptance of the field of palliative care has occurred. Nevertheless, increasing reports have been published about the slow expansion in educational efforts in the end of life care.

The need to address EOL care in cancer patients ideally needs to occur much earlier within our healthcare systems and major efforts need to be undertaken to translate evidence based practice into mainstream cancer care. To achieve this goal, however, a much broader acceptance of the

understanding of end-of-life issues needs to be achieved among health care providers. This is only likely to be achieved through demonstration projects that focus on quality of life issues in cancer care rather than survival endpoints, and widespread education of the healthcare professionals caring for cancer patients, as well as the patients themselves.

*The authors of this agenda highly recommend that ONS establish a committee of members with multiple backgrounds to work with the current R25 grant (approved, pending funding) for disseminating palliative/EOL care through local ONS chapters. This group would develop strategies to build on this foundation so content translated into practice could be sustained.*

### **C. Content Areas of Science**

- 1. Research in cancer symptoms and side effects; to include new knowledge regarding successful relief strategies and identification of symptom clusters and their associated outcomes.**

#### **Priority topics**

##### **1.1 Understudied Symptoms**

- 1.1.1 Hormonal disturbance
- 1.1.2 Sleep disturbances/insomnia
- 1.1.3 Peripheral neuropathy

##### **1.2 Continued work in pain, fatigue, depression, cognitive impairment, anorexia, and neutropenia**

#### **Rationale and background**

The number of people affected with these three understudied symptoms is increasing due to shifting demographic trends, the increasing use of supportive care measures allowing for dose escalation, and improvements in survival rates. A growing body of evidence suggests that these three symptoms significantly impact quality of life in persons with cancer. Assessment of concurrent, associated symptoms of each of the three understudied symptoms is important and will lead nurse scientists to the next generation of symptom work. For example, hormonal disturbances have been associated with the concurrent symptoms of sleep disturbances, cognitive changes, and affect changes. Additionally, persons who experience insomnia describe impairments in ability to concentrate, loss of memory, irritability and fatigue. There is a need to carefully characterize these symptom clusters linked to each of the three symptoms. This is imperative to the next step of intervention in building knowledge.

Hormonal disturbances. The symptom experience may include hot flashes/night sweats and affect in several groups of oncology patients. These groups include women who have been treated for breast cancer or ovarian cancer, or who have received hematopoietic stem cell transplantation, or men who have been treated for prostate cancer. The incidence ranges from 45-65% of postmenopausal women with breast cancer who experience daily hot flashes. Other incidences of hormonal disturbances are less well-known. Assessment of hormonal disturbances is challenging in that measurement of serum levels in healthy individuals do not transfer well to individuals who are being treated for cancer. For example, assessment of menopausal status is typically done in health women using serum estradiol and FSH levels. However, estradiol levels can be falsely elevated in women taking tamoxifen. Furthermore, prior research has shown that women who have breast cancer subjectively underestimate their hot flashes. Several hormonal disturbance symptoms can be measured objectively. For example, these could include measurement of hot flashes/night sweats with sternal skin conductance monitoring; loss of bone mineral density and measurement of body composition. There is very

little research focusing on interventions for hormonal disturbances, the exception is work on hot flashes. Limitations in even this work includes hot flashes as a sole outcome, hindering our understanding of the differential impact of interventions on multiple associated symptoms (e.g., affect, sleep, fatigue); and the use of uni-modal interventions, typically a botanical or drug.

Sleep disturbances/Insomnia. The symptom experience may include difficulty falling asleep, staying asleep, and early morning awakenings. The incidence ranges from 31-54% of patients during their first six months after the cancer diagnosis, and ranges from 23-44% of cancer survivors 2-6 years post diagnoses. Subjective reporting (self-report) of sleep disturbances has greatly benefited from the use of objective measures of wrist actigraphs and polysomnography). For example, self-report of nighttime awakenings tend to be under-reported by individuals but can be quantified more accurately with the actigraph. Interventions with these symptoms have benefited from studies of more than a dozen behavioral and nonpharmacologic techniques used successfully with persons with insomnia (e.g., stimulus control, sleep restriction, sleep hygiene, and relaxation therapy). Interventions with cancer patients have included sleep therapy programs with cancer survivors and use of drugs.

Peripheral neuropathy. The symptom experience involves a distal loss of function ascending from the toes up to the ankles, or from the fingertips back to the wrist. The sensation experienced by many patients is like wearing a tight stocking or glove, resulting in numbness and dysfunction. Peripheral neuropathy occurs in 10-20% of all cancer patients and is seen in patients with cancer cachexia, paraneoplastic sensorimotor disturbances, or receiving neurotoxic chemotherapy agents. Chemotherapy induced neuropathy is one of the most common neurological complications encountered, especially with cisplatin, vincristine, and paclitaxel agents. Assessing all components of the peripheral nervous system is essential so that any pre-existing neuropathy can be detected prior to therapy with a potentially neurotoxic agent. Recently, it has been reported that a rigorous clinical history was equivalent to a Somesthetic Evoked Potentials test in detecting clinically relevant peripheral neuropathy. Individuals may report the “stocking-glove” distribution of sensory and motor changes of numbness, pain and dysfunction. Many of the drugs including opioids, used in patients with neuropathy are used to treat pain rather than reversing the neuropathy itself. A number of complementary therapies have also met with some success in the management of neuropathic pain, including TENS, topical therapies, acupuncture and Chinese herbs.

## **Future research directions**

### Hormonal disturbances:

- Objective measurement of hot flashes/night sweats
- Varied patient populations- e.g., ovarian, breast, & prostate
- Descriptive research to characterize behavioral triggers and correlates of hot flashes, as these are factors which would be amenable to behavioral interventions
- Descriptive research to further delineate physiological mechanisms of hot flashes, particularly in terms of how they might differ from those of healthy women
- Evaluation of interventions to decrease frequency, severity, distress of multiple hormonal disturbances. There is a need to consider behavioral interventions in addition to pharmacological management
- Evaluation of interventions to educate patients and families regarding hormonal disturbance symptoms, in order to notify health care providers of their presence and the need for management strategies

- Important predictor and outcome variables: are many and could include mood, affect, sleep, concentration, sexuality, and quality of life
- Careful consideration of potential racial differences in hormonal disturbance symptoms.

#### Sleep disturbances/Insomnia

- Descriptive studies to characterize sleep patterns of patients with the most common cancers, undergoing various single and combination therapies
- Descriptive studies to characterize sleep patterns of patients at various stages of disease, and various ages.
- Descriptive studies to characterize sleep patterns in patients with clusters of other symptoms (pain, depression, anxiety, nausea, fatigue, loss of concentration, and their individual and combined effects on functioning (physical and mental/cognitive)
- Evidence based interventions are needed to address many of the sleep disturbances e.g., sleep latency, daytime sleepiness, hypersomnia, low sleep efficiency.

#### Peripheral neuropathy

- Descriptive studies to characterize the onset and natural course of peripheral neuropathies
- Descriptive studies to characterize the mechanism(s) of peripheral neuropathy and neuropathic pain
- Intervention research to evaluate primary and secondary prevention strategies
- Intervention research to test strategies of minimizing the disruption of existing peripheral neuropathy on activities of daily living
- Evaluate possible interventions to reverse the signs and symptoms of peripheral neuropathy

#### **Specific resources for this priority:**

- All three of these understudied symptoms need to be studied using subjective and objective measures. Therefore, funding levels need to be consistent with costs using objective measurement and other outcomes.
- Mentored research awards to train the next generation of nurse scientists in these objective measurements and to do research involving these three complex symptoms in general.
- Related to the above resource, there needs to be some type of funding mechanism to change practice in hospitals, clinics, and physician offices to include oncology nurses' assessment of these symptoms using objective measurement
- Funding partnerships with private foundations, ONS, pharmaceutical companies all need to occur for pilot work that will cost more than the existing small grants program of ONS.
- Establishment of collaborative networks among researchers and advanced practice nurses to develop our multi-site, and larger sample size capacity to move this important work along more rapidly.

## **2. *Research in psychosocial and behavioral research including communications (both interpersonal and technological), strength based perspectives, ethics and decision-making***

### **Priority topics**

- 2.1 Strategies to develop self-management for patients and families.

- 2.2 Complete meta-analyses and meta-syntheses of studies on coping and related concepts and coping outcomes in the context of cancer.
- 2.3 Understand the nature of the interaction between health care providers, patients, and families

### **Rationale and background**

Each year well over one million Americans die from chronic illnesses such as cancer. Further, people from minority groups are more likely to have higher mortality and morbidity from these conditions than whites (American Cancer Society, 2002). Countless individuals and families must cope with serious chronic illnesses such as cancer. For example, those who are at risk for conditions such as lung cancer associated with smoking, which have life-long consequences, are also a major public health concern. These conditions are responsible for tremendous health care expenditures as well as mortality and morbidity.

In recent years, changes in medical reimbursement and insurance coverage, including the widespread use of managed care, have moved care to community and home settings. In addition, shifting demographics toward an aging American population, a nationwide increase in prevalence of chronic diseases such as cancer and increased concerns over sedentary and unhealthy lifestyles, have demanded that the approach to supportive nursing interventions be reexamined. Primary, secondary, and tertiary prevention all require new modes of self and family management to prevent disease and disability. More focused examination must be undertaken to determine what interventions are effective for which populations and what outcomes are facilitated.

Self-Management. Although self-management has been associated with certain chronic diseases (e.g., diabetes) for some time, the concept of self-management and its practice is changing. Many individuals and families have access to a wide variety of health information on the Internet and in the lay press that was not available even a few years ago. Rather than relying on a more traditional model of a provider giving instructions with which a person is expected to comply, the public is being encouraged to take a more active role in management of their health (Anderson & Funnell, 2000). Self-management today encompasses a broad range of health, lifestyle, behavioral, and self-assessment and treatment activities practiced by an individual, in the context of the family and community, and with the support of others, often nurses. Self-management has been defined as the “cluster of daily behaviors that individuals (and their families) perform to manage (a condition)”. (Glasgow & Anderson, 1999, p. 2090). It is a dynamic means of maximizing health rather than the submission to prescribed orders implied by the term compliance (Ruggiero et al., 1997). Schilling, Grey, and Knafl (2002) noted that the concept of self-management, in contrast to the ideas of compliance and adherence, captures the complexity of living with an illness and suggests the need to manage the illness in the context of one’s everyday life.

Since self-management often takes place in a family context, it is important to develop knowledge that addresses how self-management is manifested as both an individual and family construct.

Nurses can target their interventions to working with individuals or families to develop or enhance their self-management capabilities. Self-management outcomes can also be the target of interventions. For example, nurses may develop new ways of interacting with patients and families based on their developing self-management abilities. In this case, the intervention may target ways to help a family adapt a health care regimen to their usual routine. Depending on the

situation, the intervention may be directed to the individual, to the family, or both. In intervention research, interventions are usually directed to the individual or family management of the risk or condition.

The main goal of self-management is to improve health status outcomes. To improve the illness or problem, to prevent complications, or to prevent complications from worsening is a key goal of nursing (Henderson & Nite, 1978). Key outcomes related to self and family management interventions include variables representing the illness or problem of concern.

As important as these problem-specific outcomes are, it is equally important to assess outcomes related to quality of life for both individuals and families. Another goal of self-management intervention is to achieve the highest possible quality of life for populations and their families as they live and work (Grey et al., 2000; Polonsky, 2000; Schilling et al., 2002; Stewart, 1992). Research has shown that quality of life is an important factor in morbidity and mortality outcomes, in particular patient perception of quality of life as it manifests itself in social, physical, spiritual, and psychological well-being (Grant, Padilla, & Greimel, 1996). The goal of treatment of a cancer is to help patients function and feel better. Traditional medical care, which focuses primarily on physical symptoms and signs, neglects other key components through which patients assess their own well-being, and families incorporate illness into ongoing family life. Other relevant outcomes include behavior change or enhancing self-efficacy.

Coping. Since 1995, thousands of articles that focus on or include coping with cancer as a variable were published across disciplines. Over a thousand articles that discussed coping and cancer were published in the nursing literature. Across these articles there is a general consensus that coping is an important phenomenon to consider in provision of care to oncology patients across the life span and at the individual and family level. These articles cover a wide range of situations such as coping in the context of specific cancer diagnoses and treatments, coping of individuals and families, and coping in relationship to quality of life outcomes. Despite the consensus that coping is important, the literature lacks consistent or adequate definitions of coping and related concepts; theories of coping are infrequently identified and rarely tested; and; there are inconsistent findings regarding the influence of coping on outcomes.

Much of the work on coping resembles a laundry list of psychosocial variables with little discussion of how specific variables were selected. The term “coping” often functions as an umbrella concept for many other concepts, resulting in conceptual overlap, a major concern in measurement. There is also much debate about whether there are differences in outcomes based on coping strategies used. It is imperative that the state of the science on coping and related concepts be analyzed and synthesized in order to both advance the science in this important area of oncology nursing research and guide development of effective interventions.

Only a few meta-analyses were found on coping in cancer patients [1-11]. These analyses were focused on specific questions or specific cancer populations. Examples of questions addressed include: the effect of psychological coping styles (including fighting spirit, helplessness/hopelessness, denial, and avoidance) on survival and recurrence in patients with cancer [2], the relationship between psychosocial factors and the development of breast cancer [5]; and the role that next of kin play in quality of life of patients coping with cancer [3]. Though these articles provide useful information, the scope of these analyses are narrow in terms of variables examined, definitions used, and samples studied. Few provide critique of theories or measures.

There are numerous related concepts that are inconsistently identified as antecedents, critical attributes, or outcomes of coping. The variables linked to or identified as components of coping are numerous and diverse. Examples include quality of life, hope and spirituality, fear, symptom distress, anxiety and uncertainty, substance use/abuse. These variables are frequently identified as strategies and classified as positive/adaptive or negative/maladaptive. There is disagreement about the roles that these strategies play and little consideration of the timing of when strategies are used during the cancer experience. In addition, there is little consideration of how these concepts may be different at different developmental or chronological ages.

The list of outcomes discussed in the literature in relationship to coping is long. Examples of terms that are used include quality of life, adjustment, adaptation, well-being and resilience. In few cases are these terms clearly defined or linked explicitly with a theory. Some meta-analytic studies of coping and outcomes have focused on the relationship of coping to incidence of cancer. For example, Pettigrew's meta-analysis of coping strategies in breast cancer found only a modest association between psychosocial factors and breast cancer and concluded the findings are contrary to the frequently held view that personality and stress influence the development of breast cancer [2]. Further studies are needed to link coping with cancer incidence, mortality and morbidity.

Interactions. Standards of practice and nursing policy statements identify the nurse-patient relationship as key to affecting desired outcomes. The nurse-patient relationship is at the heart of caring relationships. Interactions among patients, families, and providers influence the quality of care and health behavior and disease endpoint outcomes across the cancer continuum in many and diverse ways. Across the cancer continuum, the nature of the provider-patient interaction is a factor in decreasing barriers to screening [1]. At diagnosis and during treatment, effective communication is necessary to provide patients with a full understanding of their disease, treatment options, and potential adverse outcomes from treatment [2-5]. Interactions between health care providers and patients and families affect decision-making [6], symptom management and adherence[5], coping [7], satisfaction, and quality of life [8, 9] and suffering[10]. Discrepancies in treatment effectiveness is attributed in part to the cognitive dynamics in the provider-patient relationship [4]. Nurses play a significant role in support groups and ongoing interactions enhance opportunities for addressing survivorship issues and nurses[11, 12].

When patients move from curative to palliative cancer care, communication is of special importance. The things that nurses do not talk about or even understand as part of their important work have been referred to as "the silences of nursing practice"[13]. One study describes several subclasses of physician communication with patients transitioning to palliative care, very few of which would be considered helpful or satisfying. Effective relationships were described as building over time and very important to the patients' ability to handle the information and to cope. Little is known about how to help beginning practitioners learn effective ways to communicate with dying patients or their families [14].

The turmoil in health care delivery systems, including single provider, health maintenance organizations, and federally funded systems, impacts the longevity and nature of patient-provider relationships. Little is known about how the extent to which a patient knows or is known by a health care provider influences processes or outcomes of care for cancer patients. Preliminary study suggests that longer provider-patient ties improve cost outcomes and require less intensive medical care [15], but much more study is needed to understand how the length of relationships influences outcomes.

Interactive technology is identified as a way to more efficiently provide information and services to patients. The Internet is rapidly changing the way patients interact with providers. Patients obtain information from the Internet, bring that information to patient-provider interactions, and even receive care over the Internet. More information is needed about how the Internet and other similar interactive technologies affect patient education, patient outcomes, and nature of patient-provider interactions[6]. Interactive telephone technology also is being used for purposes such as to reduce barriers to screening, to triage patients with symptom management, and to provide prescriptive protocols to inform decision-making [16]. Yet little is known about how such technologies enhance or diminish the

caring nature of nurse-patient relationships, or whether such “caring” relationships are important for maintaining wellness.

Communication processes influence providers’ effectiveness, willingness, and ability to provide care. Interactions with patients are key to helping nurses find meaning in their roles and satisfaction in their jobs [17]. Providers’ willingness to risk or practice involvement with cancer patients are important considerations in job and patient satisfaction [18]. Nurses have a great deal of experience in communicating with patients about their questions and fears; the communication implications of pain control; and relationships with other professional groups. Yet, little research on nurses’ perception of communication problems or their suggestions for resolving them has been done. Further study of strategies nurses effectively use for communicating with patients and other professionals is needed.[19]. Providers view themselves as responsible for providing spiritual care, yet often feel inadequately prepared, may not have time, and may feel role uncertainty about interacting with patients’ about spiritual matters [20].

The amount of information, types of information, and timing of communication with patients, especially at key times such as diagnosis, relapse, or transition to palliative care are areas about which little is known, yet patients indicate the interactions around these times often influence them for years [7, 19, 21]. The psychological well-being of families, especially those dealing with a child with cancer is influenced by communication with professionals [22].

The role-stresses of caring for cancer patients influence patient and disease outcomes as well as nurse retention. Research indicates the nature of relationships is an important way nurses find meaning in their work [17]. Some work has been done on the nature of “special relationships” with cancer patients, but more work needs to be done. Research questions remain about when and how nurses and patients establish connectedness, if and how empathy can be taught, and what factors influence the phenomenon of emotional distancing from patients[18].

#### **Future research directions:**

- Descriptive studies to characterize patient and family self-management strategies
- Evidence based self and family management interventions to address treatment effects in high risk groups
- Clinical trials demonstrating the effects of patient and family management interventions on quality of life outcomes, survival, and cost
- Meta-analysis, meta-synthesis and meta-theorizing studies using literature and secondary analysis data should be conducted to:
  - Elucidate the boundaries of relevant and potentially related concepts
  - Examine relationships among these concepts
  - Describe how these relationships and outcomes change over time
  - Address issues of methods of inquiry and measurement
  - Identify interventions that effectively influence coping to improve outcomes.
  - Secondary analysis of existing data sets should also be used to examine alternatives
- Studies comparing provider/patient perspectives of interactions
- The effects of technology on the nature of the patient-provider interaction
- Evaluating patient-provider interaction and the influence on outcomes
  - Specifically, focus on symptoms, coping, and quality of life
- Testing interventions to improve provider-patient communication
- Studies of the influence of role stressors of providers on the provider-patient relationship and retention
- Studies to test the implementation of meta-analyses findings into clinical practice

#### **Specific resources for this priority:**

- Small grants (\$10-20,000)

- State-of-the-science summits
- Development of data repositories on coping with cancer
- A targeted call within the current grant mechanisms
- Multi-site trials for high risk groups, including Phase 1 and Phase 2 trials

### 3. *Research in health systems issues, policy, quality of care and clinical outcomes*

#### **Priority topic**

3.2 Evaluate the effectiveness of nursing care on cancer patient outcomes, including symptom control, functional status, and access to and utilization of health services.

#### **Rationale and background**

With the nursing shortage, we need to be able to clearly demonstrate the impact of nursing care. Nurses have a growing evidence base of effective symptom management – we should build upon that to understand the contribution of symptom management on patient lives beyond symptom relief. By using outcome methodology, this allows us to advance our knowledge across the care continuum to go beyond point of service and become patient-centered.

#### **Resources required**

- Consistent use of select standard instruments and measures to be used routinely where cancer care is delivered. (Ex. SF12, Brief Symptom Inventory, etc.)
- Establish a working group to select such measures to be used in practice and research.
- Educate researchers as to how and when to include outcomes in their research – especially the system related outcomes.
- ONS could provide leadership to encourage clinical and practice settings to adopt a data/information infrastructure to adopt and use common outcome measures.
- ONS should launch an educational campaign to educate nurses on the value and benefit for outcomes to be an integral component of their practice.
- ONS should continue to support outcomes research through targeted small and large grants.
- ONS should work with NCI, ACS, and AHRQ on targeting and promoting this priority area through agency funding mechanisms.

#### **Future research directions:**

- Studies to address gaps in determining adequacy, sensitivity, reliability and validity, respondent burden of current functional status, instruments appropriate for various cultures, languages, ages, genders, types of cancer, and stages of the cancer continuum
- Identification and inclusion of an instrument that is considered the gold standard for functional status in intervention studies
- Studies to characterize clinically significant change in functional status
- Describe patterns of access and utilization of health services within various cancer diagnosis, stages, and populations
- Examine disparities in supportive care to determine who gets treatment for which symptoms and performance, and who does not

- Develop methods to study “continuity” of nursing care for patients as they progress through the cancer continuum of care
- Determine the effectiveness of nursing interventions over and above pharmacological strategies to affect symptom control
- Descriptive studies are needed to describe the relationship between symptom change, functional status change, symptom change, and access to service utilization
- Develop or select and evaluate valid, reliable, and sensitive clinical assessment tools
- Broaden the scope of study of barriers to effective symptom control
- Conduct descriptive studies to determine clinically meaningful thresholds of symptom control

#### 4. *Research in health promotion, primary and secondary prevention*

##### **Priority Topics**

- 4.1 Develop and test cost-effective interventions for breast and colorectal cancer risk and screening
- 4.2 Develop and test cost-effective interventions for prevention of tobacco uptake and use cessation

##### **Rationale and background**

Prevention and early detection of cancer has great potential to decrease morbidity and mortality from cancer. Primary prevention is the prevention of disease through activities such as immunization, smoking cessation, and chemoprevention and genetic counseling. Secondary prevention is the early detection of cancer before signs or symptoms are apparent. This priority will focus on the two screening areas that have greatest potential to lower morbidity and mortality (breast and colorectal) and on the primary prevention areas of smoking cessation.

*Breast.* Although breast cancer prevalence and incidence are high, mortality has been decreasing due primarily to earlier detection through mammography. We have almost two decades of prospective data demonstrating a mortality benefit for screened populations of women 50 to 65 (Hendrick, Smith, Rutledge, & Smart, 1997; Smith, Osuch, & Linver, 1995; Smith, 1997).

The last decade has demonstrated significant increases in mammography screening in the United States, with over 70% of women age 50 or older reporting a mammogram in the last two years. African Americans, who historically have had lower rates, now report a rate of 76% vs. a white a rate of 74%. Hispanics are lowest in mammography adherence with a rate of 64% (Centers for Disease Control and Prevention, 2000). Behavioral research has produced interventions that have increased mammography screening significantly. These interventions have ranged from post card reminders to individual counseling to targeted and tailored strategies using print, telephone, and face-to-face interventions (Champion & Huster, 1995; Janz et al., 1997; Rimer, 1994; Skinner, Strecher, & Hospers, 1994). Researchers are now assessing interventions aimed at special populations such as Hispanics, who have a lower mammography rate, and African Americans, who have disease discovered at later stages. We also are exploring methods to increase interval screening and implement cost effective programs, such as a physician letter paired with telephone counseling in real clinical settings (Saywell et al., 1999).

Current research with mammography screening adherence has demonstrated that interventions targeting both women and providers have significantly increased screening. New approaches include both targeted and tailored messages using phone counseling and interactive computer counseling (Bonfill, Marzo, Pladevall, Arti, & Emparanza, 2001). Our challenge for the future is to provide cost-effective

approaches to delivering interventions while incorporating our new technology. We also need to pay particular attention to at-risk groups and older individuals and to adherence to periodic screening.

Colorectal. Colorectal cancer (CRC) occurs throughout the world, although the highest incidence rates are in developed countries. African Americans and men have a greater incidence of CRC, and African Americans have the highest mortality rate – 23 per 100,000 for African Americans compared to 17 per 100,000 for Caucasians.

CRC presents a unique opportunity for primary and secondary prevention. Regular screening facilitates early detection of CRC, which in turn leads to reduced mortality (Winawer et al., 1997). Additionally, the removal of polyps that may develop into cancer contributes to the decreased incidence of CRC itself. Early-stage diagnosis of CRC through regular screening can lead to survival rates of 90% for colon cancer and 80% for rectal cancer, indicating the need for research promoting increased screening (American Cancer Society, 2000).

There are three screening modalities recommended for CRC: fecal occult blood test (FOBT), flexible sigmoidoscopy (SIG), or colonoscopy. An FOBT detects the presence of hemoglobin in the stool from internal bleeding. The sensitivity and specificity of the test is affected by the fact that bleeding is intermittent and is not distributed evenly throughout the stool. Sensitivity for the most commonly used FOBT, the hemocult test, has variously been reported from 26% to 92%. Randomized trials using the FOBT began in Minnesota in 1975. Results from randomized trials with FOBT show a decrease in mortality from CRC ranging from 15% to 33% (Wagner, 1998). An FOBT, although relatively easy to use, is fraught with problems. FOBT alone is a poor test for CRC (Ahlquist, 1992). Of those screened, 2 to 10% will have positive results, but only 5 to 10% of these people will actually have cancer (Kronborg, Fenger, & Olsen, 1991). In other words, a large majority of those with positive FOBT results will actually have false-positive results.

A sigmoidoscopy is an invasive procedure that examines the lower third of the colon. Flexible sigmoidoscopy has been shown to decrease mortality, though the majority of studies to date have case-control designs. Three case-control studies have indicated, variously, 59%, 70%, and 79% reduction in CRC mortality (Muller & Sonnenberg, 1995 ; Newcomb, Norfleet, Storer, Surawicz, & Marcus, 1992; Shelby, Friedman, Quesenberry, & Weiss, 1992). One retrospective cohort study found an 85% reduction in mortality (Atkin, Cuzick, Northover, & Whynes, 1993). The only randomized trial reported to date found a 60% decrease in mortality (Friedman, Collen, & Fireman, 1996). There are, at present, two large randomized trials ongoing, one evaluating the use of every-3-year sigmoidoscopy in the US and the other evaluating the use of one-time sigmoidoscopy in the United Kingdom

A colonoscopy is also an invasive procedure, but it examines the entire colon. Colonoscopy is currently only recommended as a screening tool for certain high-risk groups and as a diagnostic test for those with a positive FOBT or sigmoidoscopy. Traditionally, there have been two major arguments for not using colonoscopy as the *screening* tool of choice – lack of randomized trial data and cost. Additionally, close to 60% of adenomatous lesions occur in the distal colon, and these can be detected by flexible sigmoidoscopy. New evidence, however, from two studies conducted with asymptomatic patients demonstrates some of the limitations of relying on a SIG alone. Lieberman and colleagues (2000) reported that 52% of the 128 patients found by colonoscopy to have advanced proximal neoplasms had no distal adenomas

Despite the benefits of early detection, use of colorectal cancer screening (CRCS) with any modality is low and has not increased substantially in recent years. BRFSS survey data show that in 1999 only

20.6% of those surveyed had had an FOBT in the preceding year compared with 19.6% in 1997; only 33.6% had had a SIG in the preceding five years in 1999 compared with 30.3% in 1997 (MMWR, 2001). These rates are well below the goals set in Healthy People 2010, which are to achieve screening rates of at least 50% for both screening behaviors (Center for Disease Control and Prevention, 2000). In 2000, the NCI Colorectal Cancer Progress Review Group summarized research on short- to medium-term (5 to 10 years) strategies for effective implementation of currently recommended methods of early detection at the population level (National Cancer Institute, 2000).

Few theoretically based intervention strategies have been tested. No intervention studies have addressed the issue of cost-effectiveness. We still need to identify cost-effective methods for delivering interventions to appropriate populations. Technology holds great promise for tailoring interventions that can be delivered via interactive computer programs or through the Internet. We need to increase screening among populations at risk for colorectal cancer, such as patients who have a history of polyps or a family history of CRC, and focus research efforts appropriately. Intervention research to increase CRC screening is an important frontier for behavioral oncology that holds great potential for decreasing colorectal morbidity and mortality.

Tobacco Prevention and Cessation. In the twentieth century, tobacco use emerged as the leading cause of preventable death in the United States, and a leading cause of death around the world (CDC, 1999). Currently 4 million people die every year from a tobacco attributable disease; 10 million annual deaths are projected for 2030 with the majority of these occurring in developing countries (Mackay & Eriksen, 2002). Half of all current smokers will die of a tobacco-attributable disease (National Cancer Institute, 1997). Tobacco use is attributed to over 75 billion in health care costs (CDC, 2002).

Tobacco use contributes to over 30% of cancer deaths (Wingo et al, 1999). Lung cancer continues to be the most common cause of cancer death for men and women, causing more deaths each year than deaths from breast, prostate, and colon cancer combined. Although lung cancer deaths among American women surpassed breast cancer deaths in the mid 1980's (USDHHS, 2001), and now constitute 40% more deaths than from breast cancer, only 13% of women in the US are aware of this fact (American Legacy, 2002). Other tobacco-attributable cancers include cancers of the lung, oral pharynx and larynx, esophagus, bladder, kidney, pancreas, and cervix among others.

Although tobacco use rates have declined, 1 out of 5 Americans continues to smoke (CDC, 2002a). Over 28% of high school seniors are current smokers (27.7% girls, 29.2% boys) (CDC, 2002b). Five million youths are projected to die of tobacco if tobacco use patterns are not changed (CDC, 1996). Other forms of tobacco use such as cigars and "spit" tobacco also are associated with increased risk of oral cancers among other cancers and diseases (NCI, 1997). Secondhand smoke is a carcinogen attributed to over 3000 deaths from lung cancer each year as well as other cancers and many other diseases such as heart disease (Hackshaw et al, 1997; California Protection Agency, 1999). As smoking patterns have changed, tobacco-attributable cancers such as lung cancer have increased in the impoverished, the poorly educated, and ethnic minority communities (Wingo et al, 1999; Wong et al, 2002).

Tobacco use is a chronic, relapsing condition (Fiore et al, 2000) Even after a diagnosis of cancer, some patients will still have difficulty quitting; and use during treatment has been linked to increased side effects (Gritz, 2000). Continued tobacco use among cancer survivors has been linked with increased risk of cancer recurrence, increased risk of second-tobacco attributable malignancies, increased risk of tobacco-attributable diseases such as cardiovascular disease, decreased overall survival, and diminished quality of life (Cinciripini et al, 1997; Gritz, 2000; Wong et al, 2002). Tobacco-attributable health effects such as those of cardiovascular disease and respiratory disease affect cancer treatment options. Smoking cessation for patients who have been diagnosed and treated for cancer has some received

attention (e.g. Gritz, 2000) but the nursing literature, in general, and the oncology nursing literature, in specific, is very limited in this area (Sarna & Lillington, 2002; Browning et al, 2000). Although a diagnosis for cancer may be a “teachable moment” for family members who smoke as well, few studies have examined this problem (Schilling et al, 1997). Of special concern to oncology nurses is smoking by childhood survivors of cancer (Emmons et al, 2003).

Almost ninety percent of lung cancers are attributed to tobacco use and could be prevented with interventions to eliminate tobacco uptake, support smoking cessation, and reduce exposure to second-hand smoke. Smoking cessation is the most cost-effective intervention for adults; more cost-effective than mammograms, pap smears, and screening for colorectal cancer or hypertension. Although the US Public Health Service has issued the scientifically-based Clinical Practice Guideline: Treating Tobacco Use and Dependence (Fiore et al, 2000)- which describes scientifically based tobacco cessation treatments - few nurses are aware of this guideline, and limited study has investigated the best strategies to incorporate this guideline into clinical practice. A number of barriers to nursing involvement in tobacco reduction exist including lack of knowledge and lack of skills (Sarna et 2000a, Sarna et al, 200b; Wewers et al, 1998).

A review of nursing interventions for smoking cessation found that the provision of cessation advice by nurses significantly increases the odds of quitting in a variety of health care settings (Rice, 2000; Rice & Stead, 2002). In a recent national survey of oncology nurses, few nurses actively engaged in smoking cessation interventions (Sarna et al, 2000a). Smoking by health professionals proves to be another key barrier to effective tobacco control. Nurses along with other health professionals are not immune to tobacco addiction, and their smoking affects their involvement in tobacco control (Sarna et al, 2001). Little research has focused on assisting nurses or nursing students with smoking cessation.

Few nursing research studies have included assessment of tobacco use in descriptions of patient samples, few have considered tobacco use as a variable potentially influencing outcome variables such as symptom distress among others, and few studies have tested smoking cessation interventions or interventions to decrease exposure to second-hand smoke (Sarna & Lillington, 2002).

The burden of tobacco-attributable diseases, including cancer, differs by communities. As demonstrated in California with the reduction of lung cancer, tobacco control policies can result in fewer cancer deaths (CDC, 2000). Research has supported the efforts of nurses in educating both adults and children about the tremendous health risks posed by tobacco use, improving their understanding of the benefits of smoking cessation, and increasing awareness of available local resources (Rice, 2000; Rice & Stead, 2002). More research is needed to examine and test strategies and policies for implementing tobacco control efforts.

With the decline in cigarette smoking in the larger population, tobacco companies have moved to target special segments of the population including women, young people, low-income, and other special populations (US Department of Health & Human Services, 1998; US Department of Health & Human Services, 2001). Research is needed to investigate the need for tailored strategies for prevention and cessation for these populations.

### **Future research directions - Breast Cancer**

**Now that descriptive work to increase mammography screening has been completed, we need research in evidence-based interventions to address:**

- Increasing repeat adherence to recommended guidelines (interval screening)
- Increasing screening in vulnerable populations or underserved populations (older, Hispanic, low-income)
- Increasing adherence in older women
- Cost effectiveness research to increase screening
- Interventions using of interactive technology and Web

### **Future research directions: Colorectal Cancer**

#### **Descriptive studies to characterize**

- Understanding the barriers to screening at individual, system and policy level.
- Disadvantaged or underserved populations including Hispanics, men, low literacy, rural, and low-income

#### **Evidence-based interventions to address colorectal screening:**

- Increasing screening in vulnerable populations or underserved populations (older, Hispanic, low-income)
- Cost effectiveness research to increase screening
- Use of interactive technology and Web
- Development of decision aids to help patients and care providers select appropriate screening recommendations.

#### **Dissemination and evaluation of criteria for implementing clinically significant changes in screening participation rates**

### **Future research directions- Tobacco:**

#### **Descriptive studies are still needed to:**

- Describe tobacco use and exposure to second-hand smoke among people diagnosed with cancer, undergoing treatment for cancer, and survivors of cancer
- Describe the relationship of a history of tobacco use with tobacco-attributable conditions that affect the experience and symptoms of cancer treatment
- Describe the relationship of continued smoking among patients diagnosed with cancer and variables of interest such as symptom distress, weight loss, and emotional distress
- Describe variables associated with smoking cessation/continued smoking after a cancer diagnosis
- Describe withdrawal symptoms from smoking among people undergoing treatment of cancer
- Describe the consequences of nicotine replacement among people undergoing treatment with cancer
- Investigate the use of pharmacotherapy for tobacco cessation and the relationship with symptoms, well-being, and other outcomes for people with cancer
- Explore cessation relapse among people following cancer treatment
- Explore the range of issues involved in smoking in the face of end-stage disease, including symptom distress and risk of fire-related injury
- Describe tobacco use and exposure to second-hand smoker among vulnerable populations (e.g. underserved populations, various racial/ethnic groups, low-income) at risk for cancer
- Describe and evaluate the efficacy of nursing involvement in current strategies for prevention of tobacco use, tobacco cessation, and exposure to second-hand smoke
- Describe the role of biochemical verification of tobacco use among people with cancer

***Evidence-based interventions are needed to address the role of nurses in tobacco prevention:***

- Prevent tobacco uptake use among youth
- Tailor tobacco prevention programs for vulnerable populations or underserved populations
- Examine the efficacy and cost effectiveness of nursing interventions in tobacco prevention programs
- Explore the use of new interactive technologies such as the Web
- Integrate tobacco use prevention into care and follow-up of survivors of childhood cancer
- Test programs specifically focused on “spit tobacco use”
- Evaluate methods to increase knowledge, enhance attitudes, and remove barriers to facilitate nursing involvement in tobacco prevention
- Explore the efficacy of nurse-led community-based interventions focused on policy changes

***Development and testing of evidence-based tobacco cessation interventions are needed for patients and families affected by cancer, in order to:***

- Explore variables associated with smoking cessation/continued smoking after a cancer diagnosis
- Assess and address nicotine addiction during cancer treatment, hospitalization, and follow-up care
- Address the types of social support and skills training for cessation that would be most important/successful in people with cancer
- Efficacy and cost effectiveness research of using oncology nurses for tobacco cessation
- Evaluate methods to increase knowledge, enhance attitudes, and remove barriers to facilitate nursing involvement in tobacco cessation
- Investigate recommended cessation strategies (social support, skills training, and pharmacotherapies) for use in cancer care
- Test the use of new interventions for cessation such as telephone *Quit-lines* and web-based support in the cancer population
- Disseminate and evaluate strategies to incorporate tobacco cessation services into all cancer care settings
- Test family-focused smoking cessation strategies among people with cancer
- Test best methods for increasing tobacco knowledge and skills among nursing professionals
- Test methods to assist nursing professionals with smoking cessation
- Evaluate strategies to reduce/eliminate exposure to second-hand smoke among people at risk for, or with cancer

***Important predictor and outcome variables***

- Biologic/physiologic: nicotine dependence, genetic differences, pharmacotherapeutics, comorbid tobacco-attributable conditions, symptom distress
- Psychologic: self efficacy, transtheoretical model of change, perceived risk
- Behavior: age, gender, education/literacy, access to intervention services, concurrent addictions (e.g. alcohol), impact on quality of life, history of use (age at initiation of tobacco use) and exposure to second-hand smoke
- Social: community norms, cultural norms, family use, school-based programs, community and work-place policies, income, insurance coverage, mass media
- System: quality of existing cessation services, knowledge and skills of providers, value of services
- Policy: role of the tobacco industry in promotion and advertisement of tobacco use, mass media, government regulations of tobacco products, smoke-free environments, tobacco excise tax, coverage for cessation services and pharmacotherapy

**Outcomes:**

- Prevention of tobacco uptake
- Prevention of exposure to second-hand smoke
- Increased quit attempts among patients, family members
- Increased number of former smokers
- Decreased relapse
- Inclusion of tobacco history and current use in sample descriptions in oncology nursing research
- Description of the prevalence of tobacco use among patients with cancer, undergoing cancer treatment, or dealing with survivorship issues
- Increased knowledge and attitudes about tobacco prevention and cessation among patients
- Increased knowledge, enhanced attitudes, and increased skills among tobacco prevention, cessation and decreased exposure to second-hand smoke among oncology nurses
- Increased assessment, delivery of cessation interventions and follow-up by oncology nurses
- Knowledge about the relationship of tobacco use to symptom distress and other oncology nursing variables of interest
- Effective health policies to prevent tobacco use and support cessation
- Decreased economic burden from tobacco-attributable disease
- Increased tobacco cessation programs in cancer care settings

**Specific Resources for this priority**

- Increasing visibility of prevention/early detection within ONS
- Increased nursing involvement in multidisciplinary tobacco control research and policy groups

**5. *Research that considers the late effects of cancer treatment and long-term survivorship issues for patients and their families.***

**Priority topics**

- 5.1 Describe the physiological and psychosocial late effects of cancer and its treatment experienced by cancer survivors of all ages, and socioeconomic and ethnic groups.
- 5.2 Develop interventions that will reduce the risk and limit functional impairment related to the cancer diagnosis and treatment for cancer survivors of all ages, ethnic backgrounds, and socioeconomic groups. Develop interventions that will support optimal physiological and psychosocial functioning.

**Rationale and background**

Issues related to cancer survivorship encompass both psychological and psychosocial complications with many of the complications directly related to treatment exposures. Cancer has become a chronic illness. For the most part, even those individuals who ultimately die of their disease live years past the initial diagnosis. The first inroads in cure rates were made in pediatrics. In 1960 only 1% of children diagnosed with leukemia were alive five years post diagnosis (Keith & Brown, 1971). The past 25 years has seen significant improvements in the five-year relative survival rate of many childhood cancers especially acute lymphocytic and acute myeloid leukemia, non-Hodgkin's lymphoma, and Wilms tumor. This is demonstrated by the five-year relative survival rate improvement among children for all cancer sites from 55.7% between the years 1974 and 1976 to 77.1% between 1992-1997 (Ries et al., 2001).

Adult cancer survival rates have also improved and it is predicted that of the 203,500 women who receive a diagnosis of breast cancer in 2002, 80% will survive at least 5 years (Ries et al., 2001). In addition, approximately 7,500 new cases of testicular cancer are predicted to occur in 2002; the overwhelming majority of these cases will be cured of their disease and become long-term survivors (Ries et al., 2001). The increases in survival rates are largely the result of the development of effective chemotherapeutic agents, and the widespread availability of intensive multi-agent and multi-modal treatment regimens and aggressive application of supportive care, including specialized oncology nursing care.

The use of intensive multi-modal treatment regimens also contributes to an increasing incidence, or perhaps awareness, of deleterious physiologic and psychosocial treatment complications called long-term or late effects. Late effects can be treatment side effects that persist beyond completion of therapy (i.e., premature menopause, impotence, fatigue, anxiety and depression) or cancer related difficulties that arise years after treatment has ended (i.e., premature cardiovascular disease, linear growth disturbances, difficulties obtaining employment or insurance, and worries about cancer in offspring). Children with cancer experience higher rates of physical late effects than adults do because children tolerate cancer treatment better than adults in the short term and thus receive more intensive treatments, and because children experience potentially toxic treatment exposures during periods of rapid organ growth and development. The most severe late effects occur in very young children who are exposed to treatments that damage tissues with low repair potential, for example, central nervous system tissue and myocardium (Dreyer, Blatt, & Bleyer, 2002). The identification of late effects of treatment and subsequent need for life-long expert comprehensive care for children that survived cancer began over 20 years ago (Schwartz, Constine, & Hobbie, 1994).

In adulthood, the process by which physical late effects develop is different and has been only recently recognized. Usual aging results in a decline of each organ that is influenced by an individual's diet, personal habits, and genetic factors; therefore, the older the individual, the more organ decline they have sustained. This decline in organ function may be accelerated for an adult or childhood cancer survivor depending on the type of cancer and treatment exposures (Harpham, 1998). Consequently, individuals that receive treatment during childhood or as older adults are at higher risk for developing physiological late effects of treatment than those that are treated during the young or middle-adult years.

Since cancer is experienced in the context of the family, psychosocial late effects including the impact on quality of life can occur in close family members and caregivers who experience the diagnosis and treatment with their loved one with cancer. Several nurse researchers have investigated quality of life in cancer survivors (Dow, 1996; Ferrans, 1994; Ferrell et al., 1996) but many of these studies were retrospective, cross sectional designs. The findings provided important data to begin to understand cancer survivorship but are limited by design and sampling.

Little is known regarding the incidence of late effects of cancer treatment for all cancer survivors and the independent effect of ethnicity on survival as well as socioeconomic status and race need to be examined (Aziz & Rowland, 2002). Minimal research has been done to explore the needs of the nearly 9 million cancer survivors in the United States today (Ries, 2001). These needs must be understood in order to develop optimal physiological and psychosocial interventions following cancer diagnosis and treatment (Priority #1). Research has demonstrated that the diagnosis and treatment for cancer can affect quality of life for

individuals diagnosed with cancer and their families, and that physiological and psychosocial outcomes of cancer treatment may be affected a number of things including age and treatment modality (surgery, radiation therapy, and chemotherapy).

Appropriate medical, behavioral, educational, and psychosocial interventions for adult cancer survivors experiencing late effects of diagnosis and treatment, such as premature menopause (Knobf, 2001), peripheral neuropathies, decline in sexual functioning, stress incontinence, cardiac damage related to anthracyclines, cognitive changes, and the effect of these issues on family functioning must be researched and developed.

Research is also needed to explore the physiological and psychosocial late effects of treatment experienced by young adult survivors of childhood cancers, for example, learning disabilities, restrictive pulmonary disease, premature cardiac and vascular disease, impaired linear growth and sexual development, infertility, alterations in weight, metabolic syndromes, early osteoporosis, and recurrent or second cancers experienced by this population (Dreyer, Blatt & Bleyer, 2002). Health promoting interventions such as those that offer education and practical advice concerning smoking cessation, and the adoption of a healthy diet and regular exercise regimens are needed to reduce the risks of cancer recurrence and the onset of other illnesses.

Models for late effects surveillance and the assessment of associated costs are sorely needed. Many long-term cancer survivors receive their follow-up care with oncologists and/or community primary care providers, and explicit guidelines for follow-up care and screening are limited. Screening and measurement tools are needed to identify individuals who are at risk for poor outcomes and for assessment of quality of life in survivors. Interventions for family members or significant others need to be developed to assist these individuals as they struggle with their family care-giving and other social roles (Rolland, 2002).

Individual, family, and cultural differences in coping with survivorship issues must be addressed across groups. Some data have been published on African American breast cancer survivors (Northouse et al., 1999; Knobf et al., 2003; Wilmoth & Sanders 2001). While other minority populations have been the targets of early detection interventions, very few investigators have described cancer survivorship in ethnic groups, such as Asians or Hispanics (Culver et al., 2003; Sun, 2002).

#### **Future research:**

- Well-controlled prospective longitudinal descriptive studies to identify and characterize specific physiological, psychosocial and economic late effects of cancer treatment.
- The development of valid sensitive and specific instruments to index the late effects experienced by cancer survivors and their family members or caregivers.
- Important *Predictor and Outcome Variables*:
  - Cancer diagnosis
  - Cancer treatment (e.g., nature, intensity, route, co-exposures)
  - Age (at treatment exposure and current age)
  - Gender
  - Family history
  - Ethnic background
  - Socioeconomic status
  - Quality of life
  - Development of late effects of treatment
  - Development of co-morbidities

- Health behaviors (e.g., diet, exercise, participation in recommended screening)
- Development of late effects surveillance guidelines for cancer survivors
- Development of algorithms for evaluating physiological late effects related to the cancer diagnosis and treatment
- Development of algorithms for evaluating psychosocial late effects of the cancer diagnosis and treatment exposures
- Population based studies of cancer survivors and their families that include quality of life endpoints
- Population based studies of cancer survivors and their families to explore the development of late effects of the cancer diagnosis and treatment
- Development and testing physiological and psychosocial support interventions
- Development of standardized yet tailored educational guidelines for health promotion and disease prevention for cancer survivors
- Evaluation of the cost-effectiveness of oncology advanced practice nurse in the prevention, detection and management of late effects of the cancer diagnosis and treatment for cancer survivors and their families.
- Development of interventions that focus on meeting the needs of families and/or significant others
- Development of culturally competent interventions across ethnic groups
- Development and evaluation of evidence-based interventions to address the physiological and psychosocial late effects of cancer diagnosis and treatment
- Development and dissemination of curricula and standards for delivery of physiological and psychosocial care for cancer survivors

### **Specific Resources for this priority**

- A centralized database system for recording the late effects of cancer treatment; this system will provide preliminary data that will drive research questions and intervention studies.
- Education of primary care and specialty physicians and nurses in the prevention, early detection and management of late effects of cancer diagnosis and treatment
- Linkages with acute oncology care providers so that what is learned about the late effects of cancer and its treatment from survivors can inform the care of people with cancer in the future
- An interdisciplinary group of individuals with interest and expertise in survivorship issues; this group would include clinicians, researchers, technicians, and support staff.
- A network of teams at various institutions to support the concept of multi-site clinical trials to test interventions
- Standardization of the diagnostic tests and laboratories used to evaluate physiological late effects related to the cancer diagnosis and treatment; this will allow researchers to develop interventions based on the outcomes of these tests on groups of cancer survivors

- Standardization of measurement techniques for evaluating psychosocial late effects of the cancer diagnosis and treatment

**C. Priority Populations for Study - All Priorities:**

- Research in the populations across the lifespan, particularly: pediatrics, young-to-middle-aged adults and the elderly
- Research in the area of family caregiving and the family group as a research participant across the cancer continuum
- Research in vulnerable populations including access to care and other factors related to health disparities

**V. Funding Mechanisms**

ONS’ strategies and priorities for funding (both small and major grants) should be the stepping stone for ONS researchers to use as pilot work in preliminary and exploratory scientific inquiry. The clinician should be involved in dissemination, translation and application to care and work in partnership with the researchers for the development and translation of research. A variety of mechanisms are needed for funding studies ranging from basic research to clinical intervention studies. We encourage ONS to fund research studies and projects using this full set of mechanisms when funds are available. The following types of funding mechanisms are proposed to both advance the development of new knowledge and to facilitate the development of new researchers and research partnerships.

**A. Partnership Funding Mechanisms:** [unchanged]

<b>Funding Type</b>	<b>Funding Amount</b>	<b>Funding Period</b>
Clinician –Researcher Project	\$15,000 - \$20,000	One year
APN/Researcher Partnership	\$50,000	Two years
Dissertation	\$15,000	One year
Postdoctoral Training Grant	\$20,000 including \$2,000 designated for the sponsor	One year
Senior/Junior Research Award	Maximum of \$100,000	One - Two years

All proposals submitted in this category must include the role and the support of the clinician/researcher, mentor/mentee or faculty/student.

1. Clinician – Researcher Project (\$15,000 - \$20,000)  
Applicant must be a beginning researcher who will work with a senior researcher in conducting a research project. The senior researcher will receive \$2,000 for support.
2. APN/Researcher Partnership (\$50,000)  
A partnership between the APN and researchers will apply for funds for APN release time (20% salary – up to \$13,000/yr), researcher honoraria (\$10,000), travel for partnership meetings (\$4,000) and project funds (\$10,000). A clinical research proposal will be developed and completed by this partnership within the 2-year funding period.

3. **Dissertation (\$15,000)**  
 Applicant must be at dissertation stage (eligible to submit a proposal) in their doctoral program and have a letter of support from the chair of the dissertation committee (faculty). The chair must document the availability of staff, research support and facilities to assist the applicant. The chair should be an active researcher who presents evidence of documented skill in one of the areas of the proposed research and will directly supervise the applicant's research.
4. **Postdoctoral Training Grant (\$20,000 including \$2,000 designated for the sponsor)**  
 A specific application form needs to be completed for this training grant. Before submitting, the applicant must identify a sponsoring institution and individual who will serve as a sponsor to supervise the training and research experience. The sponsor should be an active investigator who presents evidence of documented skill in one of the areas of the proposed research training program and who will directly supervise the applicant's research. The sponsor must document the availability of staff, research support and facilities to assist the applicant. Applicants must demonstrate how this grant will support new training experiences designed to broaden their scientific background and what significance this training will have in the area of oncology nursing research.
5. **Senior/Junior Research Award (maximum of \$100,000 for junior researcher with a senior researcher – the senior researcher's salary can be included up to 15%).**  
 The purpose of this award is to support the career development of investigators who have made a commitment to focus their research on specific issues of oncology nursing practice. Applicants must identify a mentor with extensive research experience who is willing to spend up to 15% of full time facilitating the research career development and clinical research project for the applicant. The application should reflect the collaborative pre-planning that has taken place between the applicant and the proposed mentor. The mentor must document the level of planned involvement and the availability of resources to allow for the success of the project.

**B. Individual Funding Mechanisms:**

<b>Funding Type</b>	<b>Funding Amount</b>	<b>Funding Period</b>
Pilot Work Funding	\$15,000 - \$20,000	One Year
New Investigator	Maximum of \$25,000	One Year
Supplemental	Maximum of \$100,000 Per Year	Two Years
Established Researcher	Maximum of \$100,000 Per Year	Two Years
Integrated Reviews of Research (synthesis)	\$5,000	One year
Evidence-Based Practice Change Projects	\$5,000	2 years

1. Pilot Work Funding (\$15,000 - \$20,000) for a one-time, one-year project. The applicant may be a new investigator, junior or senior researcher.
2. New Investigator (maximum of \$25,000) for a one-year project.

The principal investigator (PI) for this award should have a completed doctorate and no previous NIH funding.

3. Supplemental (maximum of \$100,000 per year for up to 2 years)  
The applicant will submit a supplemental study focused upon a specific issue/topic. The supplemental study will be attached to a major currently funded project already in progress with at least one year remaining in the original funding. The originally funded project does not need to be focused on a population or issue where the supplemental study focus is feasible, valid, and with scientific merit. It must be clear how the two studies will interface and that the supplemental grant will add to the original grant, not duplicate the objectives or aims of the original grant.
4. Funding for established researcher (maximum of \$100,000 per year for 2 years).
5. The synthesis of research literature regarding a specific topic area is very time consuming (up to 200 hours). Funding to support this time with the outcomes of a publication, presentation, and/or online resource is essential. A funding amount of \$5,000 is recommended for this mechanism.
6. Evidence-based practice change projects are an essential component of achieving the goal of preparing clinical nurses as consumers and implementers of research based practice changes. A funding amount of up to \$5,000 per project is recommended in order to provide support for clinician time, meetings, supplies, resource materials, evaluation, etc.

#### VI. Resources Needed for All Priority Areas

- A. At least \$500,000 per year is needed to fund fully across all funding mechanisms for **each** priority area. (See funding mechanisms - If these are used, new investigators and established researchers can both be funded for each mechanism).
- B. Recommendations should be made by Expert Panels (usually by conference call) when funding becomes available as to the focus of the call for proposals. The Expert Panel will review the current state of the science in the priority area, gaps in research, areas of science, populations, and specific funding mechanisms. The ONS Research Director will write and disseminate the calls for proposals.
- C. Resources will also be needed to support the ongoing review, evaluation, and revision of the ONS Research Agenda every two years at the Cancer Nursing Research Conference and to support the Research Priorities Survey every four years.

#### VII. Timeline

Activity	Date
Acceptance of plan by Foundation Board	Summer 2003
Fundraising by Foundation Board for priority areas	10/03 – 12/05
Expert Panels convened, calls for proposals, funding (as funding is received)	11/03 – 12/05
2004 ONS Research Priorities Survey conducted	Spring 2004
Review, Evaluation, Revision of Priority Areas (meeting during 2/05 at research conference)	6/04 – 3/05
Review of revised priority areas/agenda by Foundation Board	3/05

Fundraising by Board	5/05 – 12/06
Review, Evaluation, Revision of Priority Areas (meeting during 2/07 at research conference)	1/05 – 3/05

### **VIII. Budget**

- A. For each Priority, \$500,000
- B. Project start-up costs – Solicit funds for first one or two priority areas.
- C. Funding options –
  - Pharmaceutical Funds
  - Federal Funding/ACS/Foundation Funding
  - Contracts with Funding Agencies

### **IX. Benefits and Evaluation of Project**

#### **A. Benefits of Funding through the ONS Foundation**

The benefits of funding research through the ONS Foundation include:

1. The process of identifying knowledge gaps and practice needs, through the use of ONS Expert Panels, facilitates the funding of relevant, cutting edge cancer care issues.
2. Calls for proposals are disseminated to a wide variety of potential researchers.
3. Proposals are reviewed thoroughly by expert oncology nursing researchers in the area of the call.
4. Mechanisms are in place to monitor the progress of the grants.
5. The ONS structure provides several mechanisms to rapidly and efficiently disseminate the findings of funded research through education programs, online resources, publication, and the media.
6. Funding research through the ONS Foundation eliminates the perception of conflict of interest.
7. The Foundation’s relationship to the ONS membership provides a resource for dissemination studies that taps into the vast majority of cancer care settings across the country

#### **B. Expected Outcomes**

1. Increased knowledge base for oncology nursing practice.
2. Evidence based oncology nursing care in cancer care institutions
3. Improved quality of cancer care.
4. Forge ongoing partnerships between nurse clinicians and researchers.
5. ONS funds used as “seed” and “stepping stone” grants to facilitate researchers who will obtain federal dollars for larger amounts.
6. Increase in the number of junior cancer nurse researchers.
7. Contribution to the body of nurse researchers with knowledge, expertise and funding history to serve on NIH/NCI grant review teams.

#### **C. Monitoring of Grant Recipients**

1. Presentations, publications as outcomes
2. Future funding of all recipients and completion and success
3. Reviewed at 2, 3 and 5 years
4. Annual reports and 5 year update
5. Contract signed so expectations are clear
6. Report annually in the *Oncology Nursing Forum*

## **X. Impact Outcome**

### **A. Organization**

The ONS Research Agenda will have a major impact on the organization as it will enable ONS and the ONS Foundation to approach possible donors with priority areas based on the current state of the science in oncology nursing. The members of ONS will benefit directly from this through the availability of research funding to support the building of a scientific base for oncology nursing practice. The people cared for by ONS members will benefit through the application of new knowledge throughout the cancer care trajectory. These goals are directly related to the mission and strategic goals of ONS

### **B. Financial**

The Research Agenda will enable the ONS Foundation to seek funding in priority areas needing research to improve the care of people with cancer. Thus, the financial impact can be great as new sources of funding become available.

### **C. Professional Practice**

The new knowledge produced is the basis of what is needed to transform this knowledge to clinical practice for improved patient care and outcomes. The partnership/involvement of clinicians involved with research helps to ensure that the focus of the research is on key issues pertinent in practice. Knowledge gained will also transform the practice of all those involved as they gain new insights into clinical realities (for researchers) and into research realities (for clinicians).

### **D. Consumer**

The most important outcome of the ONS Foundation funding of oncology nursing research is the improvement of cancer care. The consumer will benefit from the improved care and the resulting improved outcomes of care that is based on the new discoveries made from the nursing research funded and from the nurse researchers whose career development is enhanced from this funding.

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