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Illuminating Problems, Defining Processes, and Improving Outcomes: The Essence of Oncology Nursing Research

Lillian M. Nail, RN, PhD, FAAN 2002 Oncology Nursing Society Distinguished Researcher

Introduction

by Kathi Mooney, RN, PhD, AOCN®, FAAN

Lillian M. Nail, RN, PhD, FAAN, became "hooked" on oncology nursing in the early 1980s while she was a student at the University of Rochester in New York. By this time, she was already on a trajectory to become a scientist and a researcher; a focus in oncology was the icing on the cake.

The Early Years

Growing up in a small farming village in the rural Hudson Valley of New York state, Lillian was recognized as bright and curious. This opened doors for her, including participation in a school enrichment program that unlocked the world of culture and ideas. Monthly field trips to New York City introduced her to opera, art, and the exchange of ideas on contemporary issues by prominent thinkers and scientists. One memorable evening was spent having dinner with Margaret Mead. These experiences lead Lillian to value inquiry and set her on her way to an education at the University of Rochester and a nursing degree.

As an undergraduate, she was exposed to research as a vehicle to build knowledge. Lillian made a lifelong connection between her curiosity and research as the means to explore and learn. As a staff nurse, Lillian sought positions where she could care for patients participating in clinical research trials. She eventually worked with a research team involved in the early development of the intra-aortic balloon pump. Out of this experience came her first publication, a coauthored article in *Heart & Lung* in 1973 about the device. Soon she returned to the University of Rochester for a master's degree in nursing; after she earned this degree, she took a teaching position in a nursing program at a small liberal arts college. Within a year she missed the excitement she felt in the university research environment, and she soon headed back to the University of Rochester to pursue a doctoral degree in nursing.

The Formative Years

Lillian began her doctoral study committed to research in cardiovascular nursing. She was interested particularly in studying how people evaluated symptoms, such as chest pain, and how they made decisions about what to do. Simultaneously, she began working for Jean Johnson, RN, PhD, FAAN, and later joined her research staff. As they say, "the rest is history." Intrigued by the symptom experience, Lillian decided to link her dissertation research with Johnson's work in coping with cancer. Johnson also encouraged Lillian to submit her dissertation proposal for critique to the Oncology Nursing Society (ONS)/National Cancer Institute Research Short Course, and the link was made to the professional society for oncology nursing—ONS. The circle was closed and Lillian became an oncology nurse, researcher, and scientist. The year was 1983.

Program of Research and Knowledge Generation

In the 19 years since her switch to oncology, Dr. Nail has built a progressive program of research that developed on her interest in the cancer symptom experience and the knowledge she gained about coping with cancer treatment from working with Johnson. She has woven these together to advance our understanding of how the symptom experience impacts psychosocial and functional well-being of people with cancer and how to more effectively support patients' coping processes. Her most recent focus has been on cancer-related fatigue. She is working now with a team of bench researchers and behavioral scientists to further identify the mechanisms, beyond anemia, that underlie cancer-related fatigue.

Dr. Nail's work is read and recognized widely and has been peer reviewed extensively. Of the more than 20 studies she has been involved with, 15 have been extramurally reviewed and funded. Her commitment to written dissemination of her work is evident with 40 peer-reviewed journal articles and 11 book chapters. These include traditional research reports and papers that are wonderful teaching tools, providing the application of her work for both future researchers and clinicians in practice.

From her research and writing, oncology nurses have a heightened appreciation for cancer and the symptom experience from patients' perspectives. This has helped oncology nurses to see how patients endeavor to deal with their cancer experience beyond the limited encounter with them at the bedside

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or in the clinic. Some of the important insights from this work include finding that the use of many coping strategies is a signal that coping strategies may not be helping an individual and, in fact, are correlated with a higher negative mood. This has helped correct a misconception held by researchers in interpreting coping studies and clinicians in determining how patients are doing. Dr. Nail's work also has demonstrated clearly that side effects and symptoms resulting from treatment drive the functional and emotional responses of patients with cancer. To support coping and improve outcomes, symptoms must be addressed. Knowing this and recognizing the demands of the clinical environment, Dr. Nail has worked systematically to provide nurses with the tools needed to rapidly assess coping and symptoms. The results of her research have been directed toward helping oncology nurses understand the impact and importance of their care, particularly the importance of the selfcare suggestions nurses give to patients.

Contributions to the Profession

Throughout her career, Dr. Nail has been a talented teacher and mentor to others. She has a growing list of students, postdoctoral students, and young faculty eager to join her research team and gain her consultation. She has supported these efforts with two federal training and mentor grants. She is generous with her time and research knowledge. Everyone who has had the opportunity to participate with her on research projects is a better researcher because of the experience. She is nurturing and supportive and willing to read endless drafts of grants and papers, giving thoughtful feedback. She understands the importance of creating an intellectual community to explore and advance the knowledge base of oncology research.

Dr. Nail has been a long-term and active member of ONS, joining in 1983 when she first turned to oncology nursing research. She understands the importance of the local network of oncology nurses and has extensively visited ONS chapter meetings to disseminate her research.

Dr. Nail has provided sustained leadership at the national level of ONS, beginning in 1987 as a member of the Education Committee. Among other assignments, she was a member of the Research Committee and helped guide and develop the research grant review process of the ONS Foundation. After assisting with the Research Committee and grant review Study Section, she went on to a term on the Congress Committee and played a strategic role in helping to integrate a variety of formats for providing research findings in a largely

clinical conference. Later, in 1995, she was called on to provide the leadership for the Fatigue Initiative Planning Group that spawned the Fatigue Initiative through Research and Education project. This project was so successful that it has served as a prototype for other symptom initiatives.

Dr. Nail has provided service that has helped to integrate oncology or nursing expertise in other research review groups. For example, she served a five-year term as a reviewer for the National Institutes of Health's Nursing Study Section; she currently is serving a term as a member of the Human Genome Project Ethical, Legal, and Social Implications Study Section; and she is finishing a term as a member of the American Cancer Society's Psychosocial, Behavioral, and Health Policy Research Study Section. This work is time consuming but adds significantly to nursing's visibility in the research community.

Advocacy

Dr. Nail knows the power of research to change the every-day care of patients with cancer. But she also recognizes that coping and symptom improvement often are overpowered by the national research and public policy drive to cure cancer. Thus, she pours enormous energy into getting the message of her research out to practicing nurses, physicians, the media, and patients themselves. She feels that she has come to appreciate that research skills include "clinical marketing, media relations, lobbying, and being a spokesperson."

Besides her advocacy with policy makers and healthcare providers, Dr. Nail frequently provides public lectures and forums to talk about coping with cancer and the symptom experience. Few clinical researchers take their research directly to patients, but Dr. Nail realizes that patients and their family members need to be empowered to talk about their coping and symptom management needs with their healthcare providers. This allows her research to make a full circle, grounding her to where she began, by understanding the patient's perspective and then working to improve care.

Conclusion

Dr. Nail has a profound passion for improving the lives of people experiencing cancer. Her own experiences with cancer have only deepened this passion. Her vehicle is research and education combined with a strong dose of humor and humility. Her curiosity, enthusiasm, and talent have combined to make a world-class researcher. We are lucky she made that detour to oncology in 1983.

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his award recognizes the work and contributions of a large number of investigators and collaborators who have contributed to our collective understanding of the experience of cancer treatment and post-treatment survivorship. The distinguished researchers recognized from 1992– 2001 epitomize both the depth and the diversity of scholarship required to push the boundaries of knowledge in a clinical discipline. Despite the marked differences among them in research topics and preferred methodologies, the first 10 recipients of this award have emphasized the same three concepts in their lectures: collaboration, building on prior work conducted by themselves and by others, and fostering the development of the next generation. This article addresses those same concepts from the perspective of the third generation of oncology nurse researchers and discusses some of the challenges that we face in illuminating problems relevant to oncology nursing practice, defining the processes that drive human responses to cancer, and improving outcomes.

Background

Nurse Scientists

Research preparation at the doctoral level was just beginning during the late 1960s. As an undergraduate student, I recall being surprised when I learned that one of our basic science faculty was prepared as a nurse but did not view herself as such. She felt that her basic science doctorate mandated identifying herself solely with that field. I remember thinking that this was a loss because it eliminated the link between basic science and clinical practice. Fortunately, the federal nurse-scientist program was funding doctoral preparation for nurses in a variety of disciplines and provided an identity that crossed disciplinary boundaries to maintain the link to nursing as a clinical discipline (Grace, 1978). The nurse-scientist program and other mechanisms of support for those seeking doctoral degrees attracted nurses with a great deal of experience, many of whom held leadership positions within the profession prior to entering doctoral study. It is this cohort of highly motivated, experienced, and influential leaders, such as Jean Johnson, Jeanne Quint Benoliel, Ruth McCorkle, Barbara Given, Marylin Dodd, Frances Marcus Lewis, and Victoria Champion, who represent the first generation (see Table 1). They launched their doctoral studies prior to the rapid increase in the number of doctoral programs in nursing that occurred around 1980, and they all established programs of research organized around a specific clinical problem. Marcia Grant is an honorary member of the first generation because her national influence and research mentorship activities preceded the award of her doctoral degree.

Betty Ferrell and Christine Miaskowski both migrated to the West Coast after completing their doctoral studies, obtained mentorship from established clinical oncology researchers, and rapidly established themselves as rising stars. Ferrell and Miaskowski represent the second generation. They benefited from the work of the first generation in building the infrastructure, and they are making major contributions to knowledge and to the continued expansion and refinement of the infrastructure that supports the development of oncology nurse researchers.

I think I am the first representative of the third generation. Most of the members of this generation have doctoral preparation in nursing and have studied with established oncology nurse researchers. My cohort benefited from the vision and service activities of the first and second generations in many ways. We had access to scholarship support, individual mentorship, experience working on funded research, coursework, opportunities for research skill development (see Table 2), and an affinity group all engineered by the first generation. I was selected to participate in the first Oncology Nursing Society (ONS)/National Cancer Institute (NCI) Research Short Course in 1984, shortly after I was recruited into oncology nursing. My doctoral dissertation, which was supervised by Johnson, was funded by the local chapter of the American Cancer Society under a program designed specifically to support dissertations in oncology nursing. My present position was created as a direct result of observations made by an NCI Cancer Center Site Visit Team. I am confident that those observations were influenced by the work of Grant and others with the Cancer Centers Committee. The second generation provided role models for me in promoting interdisciplinary collaboration, providing leadership within ONS and other national organizations, and maintaining a focused program of scholarship. These selected examples illustrate the impact of the first and second generations as they opened doors to oncology nursing research, worked to build recognition and identity, and lobbied to make the voices of nursing and nurse researchers heard in formulating national cancer policy and national research policy.

Challenges

The challenges faced by the second and third generations include maintaining the gains achieved to date and pushing for more in a regulatory, legislative, and economic environment that is raising new barriers to clinical research; recruiting and preparing the next generation when changes in the educational system and the demographics of the profession will influence doctoral education; and shifting effort from promoting acceptance and recognition of oncology nursing research to establishing a firm identity based on our unique scientific strengths.



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Table 1. Doctoral Preparation and Affiliation of Distinguished Researcher Award Recipients (1992-2001)

Award Year	Name	Discipline (Year degree awarded)	Institution	Affiliation
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1992	Jean E. Johnson, RN, PhD, FAAN	Social psychology (1971)	University of Wisconsin- Madison	University of Rochester
1993	Jeanne Quint Benoliel, RN	Nursing (1969)	University of California, San Francisco	University of Washington
1994	Ruth McCorkle, PhD, FAAN	Mass communication (1975)	University of Iowa	University of Pennsylvania
1995	Barbara A. Given, RN, PhD, FAAN	Higher education (1976)	Michigan State University	Michigan State University
1996	Betty R. Ferrell, RN, PhD, FAAN	Nursing (1984)	Texas Woman's University	City of Hope
1997	Marylin J. Dodd, RN, PhD	Nursing (1981)	Wayne State University	University of California, San Francisco
1998	Frances Marcus Lewis, RN, PhD	Sociology of education (1977)	Stanford University	University of Washington
1999	Marcia M. Grant, RN, DNSc, FAAN	Nursing (1987)	University of California, San Francisco	City of Hope
2000	Christine A. Miaskowski, RN, PhD, FAAN	Physiology (1987)	St. John's University	University of California, San Francisco
2001	Victoria L. Champion, DNS, RN, FAAN	Nursing (1981)	Indiana University	Indiana University

Barriers to clinical research: Increasing regulatory requirements have the potential to slow research review processes, increase resources invested in documenting compliance, and demand increased levels of institutional service from established investigators. Specific legislation, such as the Health Insurance Portability and Accountability Act of 1996, could eliminate the use of successful procedures for identifying and screening potential research subjects during critical, brief time frames if research staff cannot access clinical information (Annas, 2002). This means that some studies will be more difficult to conduct because the percentage of those eligible for the studies who are accessible to investigators in the appropriate time frame will decline, and some research may be feasible only if one of the investigators is providing the clinical care to the target population. This regulatory issue has implications for the resources needed for specific studies, the type of collaborative relationships that may need to be developed, and the direction and feasibility of specific programs of clinical research.

Recruiting and preparing the next generation: The tradition of recruiting doctoral students from the ranks of experienced oncology clinical nurse specialists with strong clinical backgrounds, solid systems orientations, and a focus on addressing the needs of groups of clients is no longer viable. We now are recruiting applicants for doctoral programs from among the best and brightest of those completing undergraduate programs. Those who enter doctoral study after obtaining a master's degree in nursing may be prepared as primary care nurse practitioners or nurse informaticists rather than in advanced practice roles in oncology. These changes have implications for the way we market oncology nursing to novice researchers and the design of the plans of study for doctoral students planning roles as oncology nurse researchers. Emerging resources are available to doctoral students, including

Table 2. Selected Examples of Formal and Informal Research Skill Development Experiences Provided Through the Oncology Nursing Society

Year	Type and Source of Experience			
1984	Proposal development and critique of dissertation proposal through Oncology Nursing Society (ONS)/National Cancer Institute Research Short Course			
1984+	Presentation experience and networking (advice, consultants, investigators for multisite studies, etc.)			
1988+	Proposal review experience through ONS Foundation study section			
1989+	Abstract review experience through ONS Congress Abstract Review Group			
1989+	Research policy experience through ONS Research Committee			
1992+	Study section chair experience			
1993+	Research policy experience through ONS Congress Committee and providing ONS testimony at Department of Defense Breast Cancer Research Program Meeting			
1994	Proposal development and project implementation through ONS Foundation small grant funding			
1995	Synthesis and clinical translation of evidence base on cancer treatment-related fatigue for Fatigue Initiative through Research and Education (FIRE) Project professional education course			
1996	Proposal development and multisite research project implementation through FIRE Project pilot study funding			
1997+	Research education experience—AOCN® Review Course			
2000+	Research policy, knowledge synthesis, and "request for proposal" development through Neutropenia Expert Panel			

access to multiple oncology nurse researchers at a single site as the research groups at individual institutions grow and long-term, multi-institutional relationships develop.

The potential for multigenerational development of oncology nurse researchers now is being realized (see Figure 1). It has been very rewarding for me to have an opportunity to pass on a fraction of the encouragement, support, and intellectual stimulation I received from Johnson, Madeline Schmitt, and Josephine Craytor as a doctoral student at the University of Rochester to Anna Schwartz as the supervisor of her dissertation work at the University of Utah and to Deborah Eldredge in my role as faculty mentor at Oregon Health and Science University. The infrastructure provided by the specialty organization is important in developing this generation as well. Both Schwartz and Eldredge received funding from the ONS Foundation, participated in the ONS/NCI Research Short Course, and have received support and advice from senior oncology nurse researchers through networking opportunities provided by ONS.

Unique Strengths of Oncology Nurse Researchers

The unique strengths of oncology nurse researchers reflect our focus on understanding the human experience and commitment to making that experience as good as it can become. Our ability to recognize and describe problems that are being ignored by others, place problems within a clinical context, define processes that drive human responses, and focus on outcomes are the areas that have been most relevant to my career.

Recognizing and describing problems: Recognizing gaps in knowledge is the critical foundation skill of knowledge building. My most compelling example of this is my experience working on Johnson's descriptive study of patients receiving radiation therapy (King, Nail, Kreamer, Strohl, & Johnson, 1985). During this study, I noticed that fatigue was reported by most of the subjects and realized that

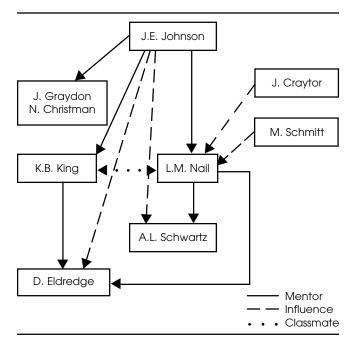


Figure 1. Multigenerational Mentorship

only two published studies addressed fatigue as a side effect of cancer treatment. The finding of high incidence and prevalence of fatigue was replicated in research with women undergoing radiation implant procedures for the treatment of gynecologic cancer (Nail, 1993). Spontaneous comments from women in this study raised questions about the usefulness of self-care strategies suggested to relieve fatigue. A subsequent study with patients receiving chemotherapy revealed that most of the self-care activities suggested for preventing or treating fatigue either were not used by patients or did not completely relieve fatigue when they were used (Greene, Nail, Fieler, Dudgeon, & Jones, 1994; Nail, Jones, Greene, Schipper, & Jensen, 1991). It also was clear that other oncology nurse researchers were reaching similar conclusions around the same time. It was the aggregation of the results of studies conducted by different investigators that eventually characterized fatigue as a high-incidence, highprevalence, high-impact side effect of cancer treatment (Winningham et al., 1994). Since that point in time, many new investigators have been recruited to define the patterns of fatigue associated with specific types of cancer treatment, examine the correlates of fatigue, explore the contribution of other symptoms (e.g., pain, sleep disruption) to fatigue, and test approaches to preventing and managing fatigue.

As each study is completed, new questions develop. This incremental knowledge building can be both frustrating and challenging. The process is frustrating because many of the new questions that arise seem very limited in scope, and the answer to each individual question is unlikely to make a big difference in practice when viewed in isolation. The process is challenging because each assumption made about the way the world works must be dismantled to fully articulate the questions. For example, results of the research on the effects of treating chemotherapy-induced anemia with recombinant human erythropoietin often are interpreted as demonstrating that improving the hemoglobin level relieves fatigue. However, subjects actually were asked to rate energy level instead of fatigue (Demetri, Kris, Wade, Degos, & Cella, 1998; Glaspy, 1997). The unstated assumption in interpreting the results was that energy was the polar opposite of fatigue. So, the logical question is, "What is the relationship between perceptions of energy and fatigue?" We concluded that patients' ratings of the two words on multiple adjective checklists were inversely related (r = -0.61), but the relationship was not strong enough to conclude that energy and fatigue represent opposite ends of a continuum (Schwartz et al., 2000).

Assumptions about the symptoms people experience at varying levels of hemoglobin, the practice of basing recommendation for the treatment of anemia on hemoglobin cutpoints without considering starting hemoglobin levels or current symptoms, and concern about possible differences in the process of symptom monitoring when symptoms are worsening versus improving all contributed to the rationale for studying symptoms experienced as hemoglobin declines. The question about symptom monitoring raised concern about the practice of generalizing from the results of studies of patients being treated for anemia to conclude that the mirror image represented the experience of symptoms during the period of decline in hemoglobin level. Changes in symptoms while hemoglobin levels decline are being examined in a study that currently is under way.

Placing problems within a clinical context: One of the major contributions of oncology nurse researchers is placing the understanding of human responses within the context of clinical practice. I think our strengths in applying knowledge combined with our ability to define important clinical considerations in conceptualization, study design, and interpretation of results drive this contribution. An example of a clinical consideration in conceptualizing a research project is understanding the importance of addressing the type of treatment and time elapsed since the completion of treatment in making decisions about sample selection. Linking points of measurement to clinical landmarks rather than elapsed time since diagnosis is a critical study design issue in research with people undergoing cancer treatment. Interpreting results obtained from specific research instruments depends on a careful assessment of the strengths and weaknesses of the measurement approach in the context of cancer care (e.g., symptom-based measures of depression may capture treatment side effects rather than affect, the word "shaky" is used often as an indicator of anxiety but can be a result of dehydration or a drug side effect). All of these issues are important to the validity of studies of people with cancer and represent common concerns of research grant proposal reviewers, manuscript reviewers, and clinicians seeking answers to practice prob-

Understanding and accounting for the clinical context is critical in generating clinically relevant knowledge. This is the knowledge that allows us to question the wisdom of designing and testing a face-to-face psychosocial intervention when the target population is not available in the clinical setting, except for brief cancer treatment visits during which patients receive medications that cause amnesia. Understanding the pattern of treatments and side effects allows selection of appropriate points of measurement, reasonable scheduling of study procedures, and suitable clinical populations for a given project. Understanding the natural trajectory of human response to a diagnosis of cancer and cancer treatment allows nurses to time interventions appropriately, develop study designs that address the right issue at the right time, and construct plans that incorporate adequate control of potential confounding variables.

Defining processes and targets for interventions: Much of the work done by oncology nurse researchers reflects a strong commitment to the idea of process. This is not surprising because process is a foundational concept in the life sciences and social sciences (e.g., recovering, caregiving, coping, managing symptoms, learning, communicating, adapting, decision making, providing information, modifying, skills training). This focus on process reflects our understanding of the human experience as one that changes over time. Prospective longitudinal research designs are needed in descriptive studies aimed at capturing the natural history of a process, as well as in most experimental studies designed to influence components of processes. Cross-sectional designs are useful in the early exploration of a problem, but the results will not reflect the element of change over time, which is essential to studying processes. It is important to recognize that a crosssectional approach may produce an average midrange score for a variable that actually is high early in the process and low three weeks later if 50% of the subjects were recruited from the early phase and 50% were recruited at the three-week point. To build knowledge about the human experience of cancer or cancer risk efficiently, the decision to use a crosssectional approach needs to be justified given the state-ofknowledge on the problem, an assessment of the nature of the problem to determine if critical process elements must be assessed over time, and the potential for producing valid, interpretable results.

In addition, process studies have to address the impact of feedback on the way specific problems are managed. For example, pain management interventions are adjusted depending on the results they achieve (i.e., feedback), so changes in pain management strategies must be part of the data collection. Side effects of treatment change over time and should be addressed in studies of people undergoing treatment. Patients who are extremely unsure of what to expect prior to the first chemotherapy treatment will have gained experience and filled in some of the information about what treatment is like between the first and second treatments.

Improving outcomes: Understanding the process leads to the development of interventions that target specific aspects of that process and can be tested with the goal of improving outcomes. The description of the process provides clues about what targets are appropriate for intervention, guides the selection of the point in time when the intervention should be used, and provides information about the timing of postintervention data collection on outcomes. At times, interventions are designed to accelerate a naturally occurring progression to a desired outcome (e.g., providing a roadmap rather than expecting each person to go through a procedure once to find out what it is like, coaching people about questions to ask during a visit, providing a memory aid to prompt questions). In other situations, interventions may be used to limit exposure to a stimulus that is associated fairly consistently with negative outcomes (e.g., using neuroprotective drugs, teaching thought-stopping techniques to manage troubling or intrusive thoughts).

Oncology nurse researchers address a variety of outcomes. Among the most common are various aspects of comfort, function, emotional response, and the umbrella concept of quality of life. At times, we predict different patterns of results for different outcomes when comparing different intervention approaches, or we may predict different short- and long-term effects for a single experimental intervention. These outcomes provide much more information about the human experience than the classic cancer-treatment-trial approach of examining mortality, extent of tumor response, and morbidity, and they reflect nursing's allegiance to comfort and optimum function as key outcomes. High priority areas for further development include refining approaches for measuring function to improve the measures' sensitivity so they address the changes that occur early in the trajectory of illness, developing methodologies for capturing the indirect costs of care absorbed by people with cancer and other segments of the community, and developing methodologies to analyze data on symptom clusters.

Conclusions

The unique strengths of oncology nurse researchers and the areas of emphasis in the programs of research that have been recognized since the inception of the Distinguished Researcher Award reflect the philosophic link of nursing to the human experience and human responses. My own research addresses

coping and symptom management at the level of individual clients. Other investigators are including family issues and family-level outcomes. Person- and family-centered outcomes like comfort, function, and mood remain important to nurse researchers and reflect the key elements of human response. Oncology nursing research is well established in the area of supportive care. Continued development of the research base for practice requires careful attention to encouraging critical review of existing knowledge and assessment of gaps in knowledge to ensure that resources are devoted to filling the most important gaps. We are at the point where collaborative efforts are needed to develop new methodologies for addressing increasingly complex issues, such as the identification and management of symptom clusters, developing and promulgating standards and techniques for considering the clinical context of cancer and cancer treatment or management in research, and encouraging synthesis of what we know and what we need to know to bring clinical practice to the next level.

This paper addresses a few of the things I have learned from valued collaborators, colleagues, students, study subjects, people with cancer, and my family. The contributions of Jean Johnson, RN, PhD, FAAN, Anna Schwartz, PhD, ARNP, Kathi Mooney, RN, PhD, AOCN®, FAAN, Susan Beck, PhD, APRN, AOCN®, B. Lee Walker, PhD, RN, Deborah Eldredge, PhD, RN, Lee Ellington, PhD, Madeline Schmitt, PhD, RN, FAAN, Barbara Given, RN, PhD, FAAN, C.W. Given, PhD, Robert Croyle, PhD, Andrea Barsevick, DNSc, RN, AOCN®, Marcia Grant, DNSc, RN, FAAN, Motomi Mori, PhD, Betty Ferrell, PhD, RN, FAAN, Mel Haberman, PhD, RN, FAAN, Kathleen King, RN, PhD, FAAN, Marylin Dodd, RN, PhD, Pearl Moore, RN, MN, FAAN, and many others are gratefully acknowledged.

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References

- Annas, G.J. (2002). Medical privacy and medical research—Judging the new federal regulations. New England Journal of Medicine, 346, 216– 220.
- Demetri, G.D., Kris, M., Wade, J., Degos, L., & Cella, D. (1998). Quality-of-life benefit in chemotherapy patients treated with epoetin alfa is independent of disease response or tumor type: Results from a prospective community oncology study. *Journal of Clinical Oncology*, 16, 3412–3425.
- Glaspy, J. (1997). The impact of epoetin alfa on quality of life during cancer chemotherapy: A fresh look at an old problem. *Seminars in Hematology*, 34(Suppl. 2), 20–26.
- Grace, H.K. (1978). The development of doctoral education in nursing: A historical perspective. In N.L. Chaska (Ed.), *The nursing profession: Views through the mist* (pp. 112–123). New York: McGraw-Hill.
- Greene, D., Nail, L.M., Fieler, V.K., Dudgeon, D., & Jones, L.S. (1994). A comparison of patient-reported side effects among three chemotherapy

- regimens for breast cancer. Cancer Practice, 2, 57-62.
- King, K.B., Nail, L.M., Kreamer, K., Strohl, R.A., & Johnson, J.E. (1985).Patients' descriptions of the experience of receiving radiation therapy.Oncology Nursing Forum, 12(4), 55–61.
- Nail, L.M. (1993). Coping with intracavitary radiation treatment for gynecological cancer. *Cancer Practice*, 1, 218–224.
- Nail, L.M., Jones, L.S., Greene, D., Schipper, D., & Jensen, R. (1991). Use and perceived efficacy of self-care activities in patients receiving chemotherapy. *Oncology Nursing Forum*, 18, 883–887.
- Schwartz, A.L., Nail, L.M., Chen, S., Meek, P., Barsevick, A.M., King, M.E., et al. (2000). Fatigue patterns observed in patients receiving chemotherapy and radiotherapy. *Cancer Investigation*, 18, 11–19.
- Winningham, M.L., Nail, L.M., Burke, M.B., Brophy, L., Cimprich, B., Jones, L.S., et al. (1994). Fatigue and the cancer experience: The state of the knowledge. *Oncology Nursing Forum*, 21, 23–36.