

What Do You Expect? *You've Got Cancer*

by Lillian M. Nail, PhD, RN, FAAN



ACCC presented its annual Clinical Research Award to Lillian M. Nail, PhD, RN, FAAN, at its 20th National Oncology Economics Conference held Oct. 8-11, 2003, in San Diego, Calif. The Rawlinson-endowed professor of nursing and senior scientist at the Oregon Health & Science University School of Nursing in Portland, Ore., Nail is internationally known for her research on coping with cancer treatments and their side effects. A three-time cancer survivor, Nail's acceptance speech brought home—from both the patient and provider perspective—the need for improved symptom management.

I became interested in fatigue as a side effect of cancer treatment when I was a doctoral student. I noticed that all the patients in the studies I was working on reported symptoms of fatigue. I went to the library—and let me say this is *before* the computer-based literature search system became available—and found only two studies on fatigue as a side effect of cancer treatment.

Today, hundreds of studies on fatigue and cancer are available. The problem now is that researchers keep doing the same study over and over again rather than moving forward. We need to understand the mechanisms behind cancer fatigue, and we really need to develop tested interventions.

In 1986 I was diagnosed with breast cancer and had local radiation treatment. I realized then that the fatigue I *thought* cancer patients were telling me about wasn't what they meant.

One day I was interviewing a woman from one of our studies and she said, "Give me a 4 out of 5 on that question about how tired I feel." Then she laughed. And I had the sense not to go on to the next question. And she said, "You know, people think sleep helps." And then she laughed again. She said, "It does. When you're asleep you don't know you're tired. But it's still there when you wake up." And that's one of the key differences between the fatigue that goes with cancer treatment and the fatigue that healthy people experience. Healthy people eventually feel like sleep and rest makes the fatigue go away. People getting cancer treatment don't. It's still there when they wake up.

In 1994 I was diagnosed with non-Hodgkin's lymphoma and was treated with CHOP [a chemotherapy treatment of Cytoxan® (cyclophosphamide), Adriamycin® (hydroxydoxorubicin), vincristine (Oncovin®), prednisone]. Then in 2000, I moved to Oregon, and was diagnosed with non-Hodgkin's lymphoma again. I was lucky enough to have chemo and radiation together this time.

From a research standpoint, I can tell you that being a three-time survivor of cancer has sensitized me to some of

the issues facing people with cancer. That's why today, I'd like to talk about advocacy challenges related to supportive care, and start with a question—Is simply feeling better an acceptable outcome for a cancer patient?

Challenge 1: I'd like to simply feel better.

You've been diagnosed with a life-threatening illness—would you want to feel bad or feel as good as you can? I'm going for *as good as you can*. But that thinking is a paradigm change for the healthcare industry and sometimes challenging for clinicians, researchers, and payers.

Following the "simply feeling better" philosophy means focusing on symptom *intensity* and reducing intensity of the symptoms experienced by cancer patients. Getting the healthcare industry and payers to accept the importance of this outcome, however, seems to depend somewhat on the symptom. Symptoms such as vomiting or pain are automatically perceived as bad. Symptoms such as fatigue or dry mouth seem somehow less important.

Back in the mid- to late-1980s, clinicians improved the treatment of acute chemotherapy-induced nausea and vomiting in their cancer patients using a new set of drugs. Today, it appears that the rates of delayed nausea and vomiting may be worsening. Over the years cancer treatment has moved to the outpatient setting and delayed symptoms occur in settings where clinicians cannot see them. This shift in setting has, in essence, weakened our understanding of the trajectory of symptoms for cancer patients.

Challenge 2: Most symptoms are invisible.

Many providers think they can tell how people feel by looking at them across the waiting room, and in the old days that method was used a lot. Invisibility is a big problem in symptom management. When I present education programs for people with cancer, I always tell patients, "I wanted to look good and feel better when I started getting chemotherapy in 1994. I spent \$400 on cosmetics and, of course, people told me I looked better than I ever had before. When I told them I didn't feel good, they'd say, no. It wasn't possible because I looked good."

Challenge 3: People don't want to complain.

Many cancer patients fear that complaining about something means they aren't doing well and that their treatment will stop. Clinicians may view such fears as irrational, but if you talk with your patients, they will tell you about this phenomenon.

Challenge 4: Attributional problems.

Again, research has not been carried out in this area. I recently reviewed a manuscript that mentioned aging as a cause of fatigue, but the manuscript did not include a single reference to support that conclusion. If you've ever heard a person with cancer say, "Well, I'm really tired, but I'm getting older," then you've experienced age attribution.

Challenge 5: Negative affectivity. It has been my experience that individuals with a “negative” view of the world report more symptoms or a higher intensity score. These individuals can and do have very real symptoms; however, their general world view does tend to affect their symptom reporting.

Challenge 6: Limited symptom knowledge. Cancer care providers *believe* they know what symptoms people experience, and they *believe* they know the pattern of the symptoms. The truth is that clinicians have a limited knowledge base about many of the symptoms experienced by people with cancer and the research base on many symptoms is extremely limited. This leads to some inconsistencies between what people are told about symptoms and the actual experience of symptoms.

For example, a radiation oncologist once told me, “Your taste will come back,” when I was complaining that I didn’t taste my food any more. Then she went on to tell me when it would come back and the order in which specific components of my taste would recover. I nodded my head and said, “You know, I missed that paper. Could you give me the reference? I haven’t seen any longitudinal studies of the experience of taste loss and recovery following head and neck radiation therapy.”

And that’s because there *were* no such studies. So why do some providers pass along such information? When I ask people to tell me why they held a specific belief about a symptom, they usually attribute it to a statement made by someone who was influential in their training. These assumptions present ongoing challenges, and if you’re in a community cancer center and looking for a research area—Symptoms “R” Us.

Challenge 7: What do you expect? You’ve got cancer. This attitude is often an excuse for a clinician not to provide care and/or a disguise for the clinician being poorly informed. The healthcare community needs practice guidelines on managing cancer symptoms. And we must use all levels of existing evidence—descriptive studies, correlational studies, and predictive studies—to develop these guidelines rather than waiting until we have a set of well-designed randomized trials.

As clinicians, we should be giving our patients permission to experience and tell us about the symptoms and side effects of cancer and cancer treatment. Oftentimes, providers are afraid if they talk to a patient about a symptom, they’ll be expected to do something about that symptom. You’d be surprised by how many patients with cancer are receptive to hearing, “It’s a good question, but I don’t know the answer.”

You can tell your patients: “This is what we know and this is what we don’t know. This is what researchers are pursuing right now.” Patients can deal with the idea that something’s not known. What they can’t deal with is having their concerns ignored by their care providers or feeling like they are the only ones who have ever experienced the symptom.

Challenge 8: Supportive care is nice but not necessary. This challenge is a little trickier than the others and requires an expansion of our basic values. When you’re diagnosed with cancer or any other illness, you really *do* want supportive care. Asking people what they would do in a hypothetical situation and finding out what they would prefer in a real situation are both very differ-

ent, and it is important to remember this when reading research on preferences for care.

Challenge 9: Using patient satisfaction ratings as an indicator of quality of care. Patient satisfaction as an indicator of quality of care is always a real issue for me. As a healthcare provider, I offer advice to people that I think *should* make them unhappy. I’m never happy when somebody tells me I should lose weight and exercise, but I recognize the appropriateness of the recommendation. For me, the quality of care relates to my personal outcomes, not satisfaction with processes.

Challenge 10: Adding care rather than changing care. We work under a reimbursement system that resists change. Quality cancer care means using problems you’ve encountered with other patients to *anticipate* problems with your current patients. By predicting and heading off a few of these symptom problems, we’ve helped our cancer patients, but this type of outcome is not well documented in the literature.

Challenge 11: Cost shifting. Much of the cost shifting that has occurred in cancer care has affected the patient and family. The care of marrow and stem cell transplant patients is an excellent example of such cost shifting. A family member may quit a job to provide care for this patient who can’t receive a transplant unless he or she has a care provider.

Challenge 12: A compartmentalized view of costs and benefits. Downstream outcomes aren’t well defined. If we do better with symptom management, what are the long-term effects? We don’t know because most symptom-management studies have been short-term. Clinicians have now identified persistent symptoms that do not end at the completion of cancer treatment. Fatigue is one of these symptoms.

Meeting These Challenges

So what actions can we take? We need to build a better economic impact model. We have to toss out the myths, especially the “what do you expect, you’ve got cancer” myth and the “there’s nothing you can do about it” myth.

We need public and provider education about each symptom and side effect of cancer. People experience symptoms in groups or clusters, and we’ve got to start looking at them that way in our research. Although we don’t have the statistical techniques in place to do cluster research, we’re starting to work on it.

We know our patients are experiencing pain, fatigue, and sleep problems at the same time. Did pain disrupt their sleep and now they’re tired? Do all three symptoms have the same underlying mechanism? Do the symptoms occur in some type of cascade? Answering these questions can show clinicians where to invest their symptom management efforts. If cancer symptoms occur in a linear cascade, of course we want to treat the initial symptom, because solving that first symptom may resolve the following two symptoms.

Demonstration projects for good supportive care—particularly symptom management—are needed. These long-term research efforts must demonstrate a measurable difference in patient outcomes. Finally, we need a long-term view of and acceptance of the benefits of good supportive care by the entire healthcare industry. 📌