



Comfort in the face of discomfort

Bloomberg Faculty of Nursing researchers and alumni are breaking new ground in the growing field of symptom management. For cancer patients, it can't come soon enough

By Luciana Ciccocioppo

For those living with cancer, the sting of treatment effects can add to their pain, anxieties and fears. Nausea, vomiting, fatigue and breathlessness are part of the bewildering cancer journey some patients have to endure. Some take comfort in their Internet blogs. Shin Na (shinscancerblog.blogspot.com) from Singapore writes: "I'm having the worst breathing problems I've had so far and can't spend time with the kids for fear of having an anxiety attack that would scare them." As her cancer progresses, her friend and "chemo buddy" takes over the writing: "She mentioned anxiety and panic attacks in her last blog. These continue. In fact, her breathlessness now has turned in to a feeling of suffocation. This in turn creates anxiety, adding further to the suffocation. She feels claustrophobic when this circle begins."

It's painful to read; imagine suffering through it, or watching a loved one experience it.

But there is hope. New research at the Bloomberg Faculty of Nursing is investigating ways of minimizing such distress by first understanding exactly what the patients are experiencing—and not just from a biological perspective.

"There's very little understanding of all the other psychosocial and contextual life circumstances that actually play into the patient experience of cancer," says Dr. Doris Howell, RN, MScN 8T3, PhD 0T3. "People who have a sense of personal control may actually perceive a symptom differently," says Howell, RBC chair in oncology nursing research at University of Toronto and University Health Network. Her research focuses on understanding how patients process symptoms, and has found psychological variables, such as depression and anxiety, can influence the severity of one's symptoms.

While most of the current interventions for symptom management are pharmacologically based, Howell says it's time to look at better self-management techniques of symptom relief, to give patients a sense of control once again. "Most times, patients don't take on self-management because they don't feel there's anything they can do about the symptoms, such as fatigue. So they feel very helpless about their fatigue right from the start."

Fatigue affects about 90 per cent of cancer patients in treatment. In fact, studies have shown exercise, proper diet and prioritizing daily activities are effective ways of managing fatigue and energy levels. "It's much more than giving patients a self-care educational package, and saying 'Here's something that might work.' We don't give them a lot of tools with tips about how to manage their symptoms, and how to actually integrate these tips in their day-to-day life at home. How do you organize new pain medications, now that the patient is up every four hours at night, and integrate this into a new way of living with managing a symptom?" Howell likens it to learning to live with a

chronic illness, for example diabetes or arthritis. "You have to learn new ways of moving, exercising and functioning. It's a new lifestyle integration around a cancer diagnosis and the symptoms related to that."

Symptoms such as dyspnea, or shortness of breath, have significant meaning for lung cancer patients who interpret this problem as a sign of how advanced their disease is, says Howell. And it triggers all the emotional feelings related to it, such as cancer being a potentially life-threatening illness, which prompts more fear, which could influence the severity of the problem and worsen the symptom. Adds Howell: "What we're trying to do in our research is understand what those trigger factors are so we can line up supportive care and interventions."

We don't have to look too far for a Bloomberg Faculty of Nursing connection to an intervention that is turning heads across the province. Over at Credit Valley Hospital in Mississauga, clinical nurse specialist Cathy Kiteley, RN, MScN 9T7 worked on an evidence-based intervention in partnership with Cancer Care Ontario, developing a program of assessment and management of dyspnea, which included an educational toolkit for nurses. New lung cancer patients make up the majority at the Carlo Fidani Peel Regional Cancer Palliative Care Clinic and breathlessness was identified as a significant symptom to manage, after fatigue, says Kiteley. "We knew right there that, although it's not the number one symptom on the Edmonton symptom assessment system (ESAS), it's a high priority because it's often an underreported symptom as well as under-assessed symptom, that can be as difficult or perhaps more distressing than the pain," she adds.

The program was promoted to every nursing agency in the Mississauga, Halton and central west health regions, and a nurse leader took charge to continue rolling out the intervention, explains Kiteley. The nursing toolkit includes a guideline to assess if medical intervention is needed, and advice on breathing and relaxation techniques to help reduce the breathlessness symptoms. What was missing was the patient's tip sheet—and that's what Irina Nistor, RN, MN (ACNP) 0T9 created. During her clinical placement with Kiteley, Nistor, now at Mount Sinai Hospital, produced a brochure aid dealing with managing breathlessness around daily activities, including rest breaks. It also taught breathing exercises. "I know how scary it can be for patients when they're having difficulty breathing. I can imagine being in the community and not having any information about what to expect in this type of situation or how to manage it," she says.

There's a whole field of work unfolding in this area of interventions, says Dr. Margaret Fitch, RN, MScN 7T7, PhD 8T6. The associate professor (status only) at the Bloomberg Faculty of Nursing and associate scientist at Sunnybrook Research Institute researches the challenges not

only of symptom management but also the patient's whole experience with cancer.

Fitch has developed a measurement tool called the fatigue pictogram. "It's a clinically useful tool for a practitioner to identify and monitor people struggling with fatigue. Cancer patients can tell you how much fatigue they are experiencing and how much it interferes with their lives." The rating scale substitutes numbers with pictures and colours, which makes it relevant for people whose first language may not be English, or who find a numbered scale difficult to apply. Used at Sunnybrook Hospital in Toronto, Fitch says a colleague in Brazil asked for a copy and had it translated into Portuguese for use there. Through her leadership role in the Cancer Action Journey, Fitch hopes to foster changes in the cancer system to make it more "person-focused. At the moment, it's predominantly a 'tumour-focused' system," she says. "What we need is a little bit of balance. Cancer is more than a

Cancer is more than a physical disease. It has emotional, social, psychological and spiritual impacts and consequences. If we don't pay attention to those as well, then it can be a very difficult experience for people

physical disease. It has emotional, social, psychological and spiritual impacts and consequences. If we don't pay attention to those as well, then it can be a very difficult experience for people."

The same goes for health-care providers as well. That's where the palliative care and symptom management consultation service (www.ppsmctoronto.com) comes into play. It's a program that exists across the province but was only recently launched in Toronto, where nurse practitioner Cindy Shobbrook, RN (EC), MN oTo, provides one-on-one consultation to health-care providers. She's the 'go-to' nurse for practitioners struggling with complex pain situations, such as medication titrations and conversions, or resource searches. "It can be an information exchange on best practices, a mentoring moment," says Shobbrook. "It can also be more challenging, such as working with a nurse on multifaceted cancer cases, those with complications."

She's contacted regularly for consults by long-term care nurses, agencies and homecare nurses. "A hospice nurse from Perram House asked for support for patients who were high risk for substance abuse—how to respect their autonomy and still support them. Another nurse in an acute care setting called about relieving constipation," says Shobbrook, who advises physicians and allied health professionals as well. "You can hear their sigh of relief when they get the assistance to address real problems in real time for their patients." And with the increasing number of cancer patients and survivors living with the after-effects of treatment, there's a growing need for her advanced nursing skills and expertise in this unique service.

That's because advanced practice nurses have the time and clinical abilities to do a better job at the holistic assessment of each patient, says Dr. Robert Sauls, palliative care program director at Credit Valley Hospital. "Our program is more productive because we have an APN in

that role, which allows us to manage more patients more productively. And keep them out of the hospital. The APN can do consults in our unit and adjust medications over the phone. Without that, some patients would end up in the emergency department for unmanaged symptoms." Sauls says the breathlessness intervention program has become a model for other settings in Ontario, through the Cancer Care Ontario network. "We've had positive reactions from other places."

For Credit Valley Hospital nurse Cathy Kiteley, the success of the program is two-fold. "I had one patient tell me 'This saved my life!' But it also really identifies the nurse as a knowledge worker, not a task-based individual, and as someone who cognitively uses the literature to help assess, plan, manage, intervene and evaluate care." Nobody wants to spend any more time in a cancer centre than they have to, says Kiteley, and this nurse-led intervention gives patients control in their own home. While Sauls says they don't have the hard data to measure

the impact, the 10-point ESAS scores of patients suffering from breathlessness fell to '2', down from '3-4', over the same time period last year, when the intervention program was rolled out.

All this means a better quality of life for patients, and an improved, efficient health-care system for society. Emergency admissions are reduced, as are unnecessary or inappropriate dispensation of drugs. Says nursing professor (status only) Doris Howell: "If we know how to target the symptom experience problem more effectively, then we're not going to keep trying different agents, when it's not the pharmaceutical agent that's the issue. It's a supportive care issue."

This support is crucial. Patients have told Howell in an earlier study that having an oncology nurse who understood their cancer experience and supported them in their symptom management was a "transformative" moment for them, since they no longer felt "lost" in their cancer journey but could put their coping techniques to work.

Howell's expertise will help shape practice change for clinicians to be more comprehensive in their assessment of symptoms, and more inclusive in all the psychosocial factors surrounding these issues. Her research will help pinpoint realistic goals to deliver in high volume cancer clinics. "Nurses will play an increasingly vital role in educating patients and preparing them for self-management of their symptoms," she says.

Half a world away, breathlessness is no longer an issue for Shin Na. She lost her fight with cancer on Jan. 29, 2009.

But for the increasing number of cancer patients and survivors, their battle continues, empowered more and more each day with this innovative and critical new knowledge in symptom self-management.

Researchers and alumni from the Bloomberg Faculty of Nursing take comfort in that. ♣