Survivorship pioneers

First of its kind NP-led primary care clinic for colorectal cancer survivors another big step forward for a rapidly growing profession. Is this the survivorship model of the future?

By Brett Ruffell

(At the grand opening from left to right): Jennifer Tiberio, Nurse Practitioner, Colorectal Cancer Survivorship Program, North York Family Health Team; Clea Lang, Nurse Practitioner, Colorectal Cancer Survivorship Program, North York Family Health Team; the Honourable Deb Matthews, Minister of Health and Long-Term Care; Michael Coteau, MPP, Don Valley East

Both Clea Lang and Jennifer Tiberio became nurse practitioners out of an aspiration for more. Tiberio, for example, had previously sharpened her expertise as an RN at the North York Family Health Team (NYFHT) in Toronto. There, she worked closely with a physician taking patients' medical histories and conducting physical exams.

The nurse learned so much from her colleague that she was confident she could diagnose and prescribe in some cases—though her scope of practice kept her from doing so. "I was ready to take that next step," she says. And in the

NP role she also saw an opportunity to play a greater part in health promotion, self-empowerment, and mental health care.

Hence, Tiberio obtained her master of nursing from the University of Toronto in 2008, and then her primary health care nurse practitioner (PHCNP) certificate from Ryerson two years later.

Now in her new role, Tiberio is certainly getting her wish for more responsibility, partnering with Lang as pioneers in uncharted territory. In May, they started accepting colorectal cancer survivors from the North York General Hospital into a new community-based follow-up program based out of the NYFHT.

After patients have completed active cancer treatment and are proclaimed disease-free, the NPs guide survivors through a holistic approach to follow-up care for five years.

The clinic, which received funding under Cancer Care Ontario (CCO)'s new survivorship program, isn't the first program for survivors to be led by a nurse. Nor is it the first to provide survivorship care in the community. What's unique is that it's the first model to combine those two factors.

Indeed, a 2009 systematic review published in Nursing Times found nurse-led clinics for survivors have traditionally involved either consultations at cancer centres or telephone-based reviews. What's more, nurses in the study were never responsible for diagnosis or prescribing.

In contrast, Lang and Tiberio combine the physical monitoring specialists at the hospital used to perform with a new psychosocial component—all from the convenience of a primary care setting.

Not only do they interpret blood tests, CAT scan results, and conduct physical assessments, they also screen patients for anxiety and depression. What's more, the NPs collaborate with an in-house caseworker to assess patients' social functions, and to connect patients with community resources.

Survivors can also attend group sessions by the Colorectal Cancer Association of Canada, and consult with a psychiatrist. All the while, the NPs keep patients' broader healthcare team in the loop to ensure nothing falls through the cracks.

Undeniably, leading patients through such a vulnerable period is a step up in responsibility for both nurses. For instance, Lang says that while she gained some management experience in the past leading such things as a hospital bed-flow initiative, her role with the cancer clinic is an entirely new test of her leadership abilities.

But the NP, who was previously working in a remote northern Ontario community, is confident the program will be a success. She feels that way because she says NPs like herself and Tiberio have the ideal combination of medical knowledge and nursing skills to provide a holistic form of care for survivors.

“The NP role is not just the physical part of monitoring cancer,” says Lang. “It’s also about assessing their emotional and functional needs.”

Should that assessment prove accurate, experts believe these nurses could impact post-cancer care on a broad scale. Could Lang and Tiberio be setting the template for the survivorship model of the future?

Part of a broader rethink

The North York program is indicative of a broader review happening across North America of how cancer survivorship care is delivered. A combination of factors is driving this rethink.

For one, the survival rate has increased sharply in recent years. At the same time, the number of new cancer cases has risen. As a result, cancer centres are struggling for resources to treat new cases.

Certainly, addressing a capacity problem was a driving factor behind the North York model. In fact, it was the hospital’s oncologists and surgeons who proposed offloading survivorship care to primary care providers.

“What if you were diagnosed with colon cancer and were told to you could get in to see a surgeon six weeks from now—what would that be like?” says Dr. Kimberly Wintemute, NYFHT’s medical director. “If we offload some of this follow-up care, we free them up to act as consultants.”

North York’s goal of freeing up specialists to treat new cancer was one of the reasons CCO decided to fund the model.

The agency also liked that the team was using its new evidence-based guidelines for colorectal cancer survivors as a basis for the clinic. The team even integrated those protocols into its electronic medical record (EMR).

What’s more, CCO is committed to supporting innovative new models that consider the broader spectrum of caring for survivors.

“We need to pay attention to not just detecting recurrent but the long-term side effects of treatment,” says Dr. Carol Sawka, VP, clinical programs and quality initiatives with the agency, adding that primary care is the ideal setting for this approach.

Experts like Denise Bryant-Lukosius, an associate member, department of oncology at McMaster, agree with CCO's direction. She says due to capacity problems, cancer centres have traditionally focused on monitoring for recurrence.

While Bryant-Lukosius feels hospitals have done that well, she says that system has largely ignored other important aspects of caring for survivors such as chronic disease prevention, managing side effects, overall wellness and helping patients reintegrate back into society.

"That's where primary care can really have a stronger focus," she says.

Sharing this view is Margaret Fitch, head of oncology nursing at Sunnybrook Health Science Centre, who says that cancer centres need to pay more attention to how they're treating survivors.

However, while she acknowledges some pioneering initiatives, overall she describes survivorship care in Canada as "spotty".

"I think that because the fact that we actually have survivors is still new, there hasn't been the full recognition of all of the issues folks might deal with," says Fitch, who's also co-director of the integrated psychosocial, supportive and palliative care program at Sunnybrook's Odette Cancer Centre.

That's why the nurse, as chair of the Canadian Partnership Against Cancer's Cancer Journey Advisory Group, helped develop a new set of survivorship guidelines.

In developing the document, a pan-Canadian, multi-disciplinary group conducted a systematic review of research literature. Fitch says the guidelines provide evidence-based insights into what works and what doesn't when caring for survivors.

She adds that if there's one key takeaway from the guidelines, it should be the fact that survivorship exists. "First and foremost, we want health professionals to acknowledge that even though their cancer has been treated and eradicated, patients still face ongoing issues," she says.

Overcoming barriers

Bryant-Lukosius learned firsthand how difficult it could be to introduce innovative new nursing roles. She previously advised on the creation of an NP position meant to provide post-cancer treatment follow-up care.

While it was to be an autonomous role, the NP would work collaboratively with a family doctor and be situated in their office. However, the plan fell through due to resistance from physicians.

Such opposition is common, she says, citing a 2010 report published in the Canadian Journal of Nursing Leadership that identified several barriers to integrating new NP roles. For one, doctors on a fee-for service model fear offloading tasks to nurses could negatively impact their income.

What's more, physicians and administrators often don't understand the NP role, frequently due to a lack of exposure. Sometimes other providers are simply resistant to new ways of working. And, in the case of caring for cancer survivors, some don't see a need for care beyond monitoring for recurrence.

However, Bryant-Lukosius believes the North York model will succeed where others have come up short. Her primary reason for making that assessment is the leadership provided by Dr. Wintemute. "In every study I have read, and in some of our own research, administrative commitment is a predictor of successful NP role development and implementation," she says.

And Lang and Tiberio certainly have that support with Dr. Wintemute. As a medical director, the physician feels she has a responsibility to ensure everyone is working to full scope. In that regard, however, she says that too often decision makers are failing NPs.

The physician points to a 2010 descriptive qualitative study published in Canadian Family Physician showing several factors have complicated NP role transitions in the past.

Because of various organizational and interprofessional challenges, 40% of the PHCNPs in the study either changed or planned to change positions within their first 12 months on the job.

"The message I took from that research is NPs need focused, meaningful roles where they're the primary provider for the appropriate work and are utilizing their skills," she says, adding that leading survivorship care is one such role where NPs can thrive.

To ensure a successful rollout, Dr. Wintemute worked to truly integrate the nurses into the cancer care team. For instance, to get specialists to buy-in to the NP-led model she had them personally train the nurses.

What's more, the NPs sit in on the hospital's bi-weekly tumour board reviews where a multidisciplinary team discusses the most complex cancer cases. This step made sense, says Dr. Wintemute, given that many of those cases will end up in the survivorship clinic.

But the physician still encountered several obstacles such as legislative restrictions to NP practice—though that area keeps improving. And Dr.

Wintemute says the strongest resistance came from her physician colleagues. “For me, it’s taken a lot of inner strength to meet those barriers and not back down,” she says.

One expert understands why doctors are anxious about nurse-led survivorship care in the community. Dr. Eva Grunfeld, a clinician scientist with the Ontario Institute for Cancer Research, is a strong advocate for transferring survivorship to primary care practices.

And she’s conducted research showing family physicians can take on this responsibility effectively. What’s more, studies have shown they’re quite willing to do so. However, she fears adding another provider to the patient’s healthcare team could fragment patient care.

“Especially at a different location, the family doctor will be out of the loop,” she suggests. “There could be confusion about who’s responsible for what, and a risk of things falling through the cracks.”

But the clinic has taken steps to ensure that disconnect doesn’t happen. For one, the family doctor receives a copy of the care plan at the beginning of the program, as well as a summary of the clinical encounter after each visit. What’s more, the clinic’s electronic pathways can be easily transferred to a doctor on the same EMR.

What the research shows

Dr. John Sussman, a researcher at McMaster University’s Juravinski Cancer Centre, can attest to the uniqueness of the North York approach. Dr. Sussman recently took part in a yet-to-be published review of survivorship models and found no literature documenting a similar clinic.

To the physician, the North York model is an exciting step forward in cancer care. “It’s innovative—I’m glad to see someone’s trying it,” he says. “Now, they need to rigorously evaluate health system, patient, and provider-level outcomes to make sure they’re achieving what they’d hoped.”

But while experts like Dr. Sussman agree the North York model needs to be thoroughly evaluated, strong evidence supporting a doctor-led model has existed for several years. Dr. Grunfeld led many of those studies.

For instance, in 1996 she co-authored a report published in the British Medical Journal comparing follow-up care delivered by hospital-based specialists with care delivered by general practitioners (GPs). That randomized controlled trial (RCT) was based in England and involved 300 women whose breast cancer was in remission.

The study, which assessed the effect on time to diagnosis of recurrence and on quality of life, found no differences in clinical outcomes when transferring primary responsibility to GPs. What's more, those patients receiving care in the community setting reported being more satisfied than those being cared for in hospital outpatient departments.

Then, in 2006 the clinician scientist led an Ontario-based study published in the Journal of Clinical Oncology that once again compared the breast cancer follow-up care of family physicians and hospital-based specialists. This time, the RCT involved 1,000 patients and measured the rate of recurrence-related serous clinical events (SCEs).

And, once again she found follow-up care could be safely transferred to the primary care setting. In fact, the study found the rate of SCEs was slightly higher in the hospital setting. Furthermore, the research detected no statistically significant differences between groups on any health-related quality of life factors.

But while there is a strong body of research measuring hard clinical outcomes of doctor-led follow-up, Dr. Grunfeld says this isn't the case with nurse-led care. "There are studies that have found patients were satisfied and that their quality of life improved, but they haven't looked at hard clinical outcomes—which I'm most concerned about," she says.

The Nursing Times review cited earlier supports her observation. That research found only a handful of quality studies exist that measure the impact of survivorship care delivered by nurses.

Most of those studies involved specialist nurses working on collaborative teams at cancer centres and often involved phone follow-up. None of the nurses involved were responsible for diagnosis or prescribing.

Despite the limitations of published literature, the paper suggests nurse-led care could possibly improve continuity of care, psychosocial support, and the delivery of information.

However, it concludes that future research should incorporate an evaluation of patient outcomes. Only then could experts accurately compare nurse-led care with follow-up by doctors, the paper says.

The outlook

Both the North York partners and CCO are considering using the NP-led model as a template to move forward with. Given their intentions, both parties are rigorously evaluating the approach.

The primary care team is tracking statistics, such as whether or not a physician consultation was required at any given visit, whether there was abnormal imaging or CEA value, and whether the visit resulted in re-entry into active cancer care or palliative care.

At the same time, CCO is conducting its own research to assess its investment in the clinic. The agency will be tracking the number of referrals and patient satisfaction. “Their model is interesting to us so we look forward to evaluating it,” says CCO’s Dr. Sawka. “We hope it’s a success so that we can disseminate it across the province.”

Regardless of their findings, Sunnybrook’s Fitch says the North York model is only appropriate for following certain types of cancer. Fitch believes specialists will likely still handle survivorship for patients requiring more complex care, such as those recovering from treatments for head and neck cancers.

But she says NPs in the community setting are the logical choice for less complex follow-up, such as caring for colorectal cancer survivors.

Bryant-Lukosius agrees, adding that these nurses provide a comprehensive form of care that is particularly important with colorectal cancer patients, as they’ve often had colostomies. Following the surgery, patients must be wary of potential problem-causing foods that may lead to blockage and cause complications.

That’s where nurses can have a strong impact, she says. “Primary care NPs have much more education than other healthcare providers around health promotion and healthy living.”

And Tiberio says colorectal cancer survivors she’s seen have been particularly responsive to that health promotion piece, which in turn has made her job especially gratifying.

“In regular primary care, you can talk diet and exercise to prevent illness all you want, but if the person feels well and hasn’t had any major illnesses it oftentimes goes unheard,” she says. “With this population, however, they’re very motivated to do what they can to stay healthy.”

Indeed, if the nurses’ early interactions with patients are any indication, patients are quite satisfied with the model. The NPs says survivors have expressed a sense of peace knowing they had a reliable place to go and didn’t have to worry about getting in with their oncologist or surgeon. “One gentleman even called us to wish us a Happy Easter,” says Lang.

What's more, several survivors who've been redirected to the nurses midway through their follow-up said they wished Lang and Tiberio had been caring for them from the start of their survivorship.

The nurses are excited about setting the foundation for a new way of caring for cancer survivors. Says Lang: "It's wonderful for nursing, it's wonderful for the NP role, and it's wonderful for the patients because of the kind of care we can deliver."