

# Doctoral dream team

Bloomberg graduate students are at the forefront of nursing scholarship with their innovative studies in cancer care. And people are paying attention

By Lucianna Ciccocioppo

## Clearing up the ‘fog’

**Samantha Mayo, RN, BScN oT4, MN oT6**, hopes to reduce stress and anxiety among recipients of bone marrow transplants when they start to worry about misplacing their keys one too many times, can't concentrate on reading, or even forget to pick up their children from school.

“We know there are neuropsychological tests that measure functions and tasks; what we don't know is the impact of treatment on day-to-day activities,” says Mayo. And after hearing these concerns from her patients at Princess Margaret Hospital, Mayo decided to delve further. Her doctoral research will survey people after bone marrow transplant treatment of blood cancers and disorders, such as leukemia and aplastic anemia. These transplants are accompanied by high doses of chemotherapy, radiation and immuno-suppressants. Patients complain of “being in a fog,” says Mayo, and worry about life after treatment, particularly handling responsibilities at home or at work.

“By understanding what contributes to these issues patients are experiencing on a daily basis, we can try to address them, and hopefully alleviate their concerns by creating some interventions for them,” says Mayo. Patients gain back a sense of control in their life when their concerns are validated, adds Mayo. The new knowledge from her research will help create resources required to help patients get on with their lives. It's an important issue, as cancer survivor rates increase and patients strive for an optimal quality of life.

Mayo says it's unclear when these symptoms first appear, whether they are immediate or part of the late effects. “So we need to find out when interventions should start,” she says. There are several interventions for people with significant memory impairments, but not for those with subtle issues. “That's where we need more general interventions because these minor, cognitive changes can be very distressing as well.”

## The deconstruction of decision-making

It's a far cry from finance, but **Shan Mohammed, RN, BScN oT4, MN oT6** wouldn't have it any other way. After five years in investment banking, Mohammed turned to oncology nursing. “Being a nurse is very meaningful for me; it's a continuation of my mother's spirit. She was a nurse, and cancer is part of my family experience.”

Mohammed is investigating the complexities of decision-making among cancer patients with advanced illness. “We don't know a lot about this issue from the patients' perspective,” he says. “How do some patients come to the decision to continue with certain treatments when they're very ill? Is it how we structure our care, or are there other factors involved?”

He hopes his doctoral project will shed new light on the ongoing discussion about end-of-life treatment and how to balance patient choice with responsible care. “I want my research to contribute to the

wider body of knowledge on this issue, and examine how patients make sense of their care. There are very good reasons why very ill patients choose to continue treatment,” says Mohammed.

He'll explore the options and alternatives to treatment, the role of supportive care or counseling, and the impact the patients' family has on decision-making. Mohammed says his clinical expertise in oncology care positions him to conduct his research from a unique perspective.

“Nursing and supporting patients on a daily basis informs my research. I appreciate what the patients are actually experiencing, what their symptoms and fears are. It's a complex issue, and I want to understand the complexities.” He would like physicians, nurses and health-care practitioners, in addition to policymakers, patient groups and advocacy groups to understand the issue better as well, and hopes to disseminate his findings broadly to initiate a more effective process of offering treatment at the very end of the cancer journey.

## The costs of cancer

When a family hears their child has cancer, a myriad of emotions, coupled with a dizzying amount of new information, can overwhelm them. But there's one more thing **Argerie Tsimicalis, PhD (C)** would like them to think about: the economic impact. In her doctoral study of the costs incurred by families with children with cancer, Tsimicalis found families eager to talk, contrary to previously raised concerns that it was an inappropriate topic to broach after a diagnosis. “But I had a very high participation rate in my study, which suggests this is appropriate to talk about,” she says. Families need to know that a child's cancer diagnosis will cost them “X” amount of dollars per month, “so they are better informed, and prepared about their cancer experience, and hopefully reduce some of the anxieties,” she says.

Tsimicalis tracked 111 families at Sick Kids' Hospital in Toronto and McMaster Children's Hospital in Hamilton on their expenditures in and out of hospital, such as meals, mileage, parking, medications, supplies, childcare for siblings at home, and lost time at work or school. She's currently writing her thesis but can say the costs incurred do add to stress levels.

“What happens to benefit plans if parents lose their jobs due to lost time? Who pays the rent or mortgage?” It's a significant issue, she says, one that's not visible in the public realm—but should be. “We need to engage the public and ask ourselves how do we as a society support a child and family with cancer?”

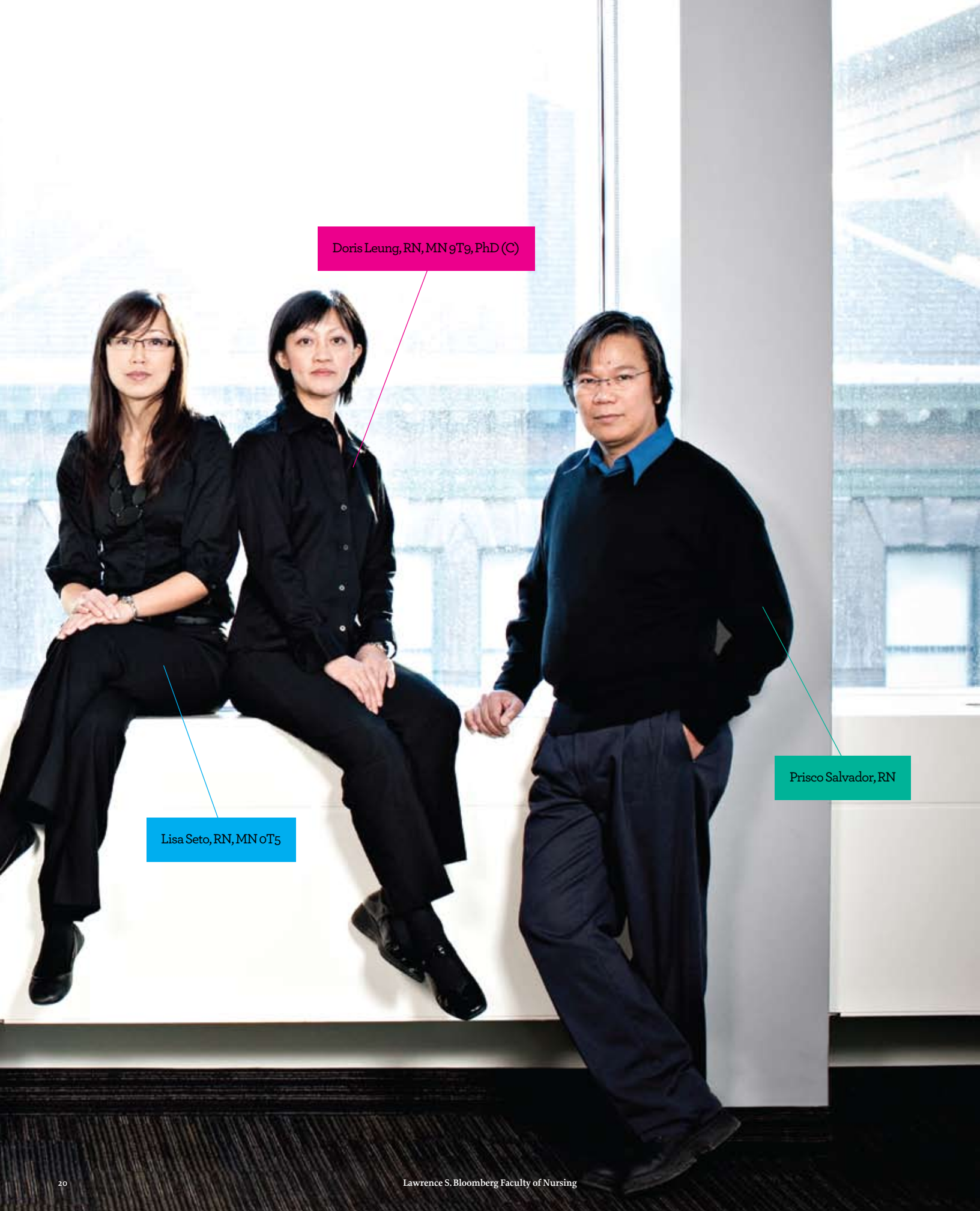
She'd like to effect change at the policy level and argues for a universal prescription plan. She'd also like to see increased resources for families after diagnosis, such as access to a financial counselor, to nip potential problems before they deteriorate. “We need to support families so they can be where they want to be—at their child's bedside,” says Tsimicalis.

A photograph of three nursing professionals in a modern office setting. On the left, a woman with long dark hair is sitting on a white ledge, wearing a black top and leggings. In the center, a man with short dark hair is standing, wearing a black cardigan and pants. On the right, a woman with dark curly hair is standing, wearing a black blazer and pants. The background is a large window with a view of a city skyline. Three colored callout boxes with lines pointing to each person contain their names and credentials.

Shan Mohammed, RN, BScN oT4, MN oT6

Samantha Mayo, RN, BScN oT4, MN oT6

Argerie Tsimicalis, PhD (C)



Doris Leung, RN, MN 9T9, PhD (C)

Lisa Seto, RN, MN oT5

Prisco Salvador, RN

## Tackling taboos

**Lisa Seto, RN, MN oT5** is researching end-of-life care and experiences in Chinese-Canadian families—not an easy subject matter to tackle in a cultural group thought to be superstitious about death.

“It can be a taboo topic; if you talk about death, you’re reinforcing bad luck,” says Seto. But when she did some field work with a nurse colleague from Princess Margaret Hospital in Toronto, Seto found this may not necessarily be the case. She went into the homes of Chinese patients with advanced cancer and discovered their families were open to discussion.

“I went to two homes, one of a recent immigrant, the other who had been here 20 years. So possibly we are stereotyping. Instead of assuming Asians don’t want to talk about death, we might discover better ways to approach the topic that would be more sensitive and allow people to discuss their experiences,” say Seto.

Her doctoral project will focus on the meanings of “home” for the participants and outside homecare providers, and “how this meaning shifts when it becomes a place of death.” Through interviews and observations, Seto will document and analyze daily activities and “how the meaning of home can structure, constrain or facilitate their abilities to negotiate end-of-life care. I hope the study will really speak to individual experiences and the diversity within cultural groups—how different experiences of migration, settlement, and socio-economic status play into a sense of belonging in their own home, and in this country.”

New knowledge on current nursing practice and assumptions about cultural groups can impact care, says Seto. She’d like to increase awareness among health-care providers during end-of-life discussions with immigrant families, and point nurses in the right direction for appropriate resources in order to provide more effective palliative care in the home for these groups.

## The end-of-life discussion

When **Doris Leung, RN, MN oT9, PhD (C)** was first exposed to death as a young nurse at Toronto General Hospital, she found it to be a stressful experience. “I wasn’t taught how to deal with death and dying,” says Leung. But today, the PhD candidate will soon be lecturing on this issue at the Bloomberg Faculty of Nursing. That’s because what she experienced long ago was still occurring among nurses in 2003, a year she faced several deaths in her extended family. She saw nurses struggling with death and dying, but this time from a family’s perspective.

“I thought: this is a real problem. Nurses are uncomfortable about this issue, and didn’t know quite how to support families during this time.” She decided to investigate and started her PhD researching nurses working in bone marrow transplant services, a patient population with significant risk of death and complications. “These nurses have experienced the complexities of providing care for transplant patients, where, at any given moment, patients may be ‘teetering on death’s door,’” says Leung. She found the nurses were struggling with high stress and uncertainties about the ethics of the right course of action for their patients. Nurses were struggling when patients began confiding in them, says Leung, and sought advice about another bone marrow transplant. “This is one option that nurses might disagree is best for particular patients at that moment. And, as a result, nurses may not know how to respond,” says Leung. “This kind of patient experience hasn’t been examined before, and it does cause a lot of distress for nurses.”

# One research project will focus on the meanings of ‘home,’ and how this shifts when it becomes a place of death

Leung wants communication skills about death and dying to be taught in schools for all front-line health-care providers. She’d like to see better support in place for nurses, such as improved debriefing skills, to engage in these issues and improve the transition from acute to palliative care when patients are in distress. When health-care providers communicate better with patients and their families, there is less stress all around, and a seamless continuity of end-of-life care with no delays or possible emergency readmissions, says Leung.

## Back to basics with baking soda

In his 18 years of oncology nursing, PhD student **Prisco Salvador, RN** has seen up close the suffering of cancer patients, not only from their disease but also from treatment effects. His doctoral study is investigating preventative measures to eliminate or reduce the severity of oral mucositis, characterized by swelling, inflammation, and ulceration of the mouth after chemotherapy.

“Just imagine how painful it is,” says Salvador. “Patients are unable to swallow or eat.” Salvador works in an inpatient malignant hematology unit at Princess Margaret Hospital in Toronto and witnessing such effects led him to go back to school. A retrospective study he did for his master’s degree in the US prompted him to continue his research on preventative oral care. This study found mucositis was more severe when oral care began after treatment.

“This changed how we manage mucositis at Princess Margaret; we now advise patients starting chemotherapy to start their mouth care right away, not one or two days later,” says Salvador. The rinse of choice? Water with baking soda, one teaspoon for one cup of water, just the right amount. Too much baking soda meant patients risked burning their mouths or becoming nauseous. Patients found their mucositis more tolerable, but Salvador was not satisfied with the outcomes because there wasn’t enough evidence of efficacy.

His doctoral research is an expanded, multi-site study looking at the use of ice chips and baking soda rinse, and patients’ behavioral change as a predictor of symptom severity. In a hospital pilot study, sucking on ice chips before, during and after chemotherapy, together with the oral rinse, decreased the severity of mucositis, says Salvador. More importantly, it decreased reliance on painkillers and patients were discharged one day earlier. “This may not be statistically significant, but it’s clinically significant,” says Salvador. “It certainly increased patient satisfaction, and decreased hospital costs.” ♣