

Fear of recurrence affects the well-being and relationships of breast cancer patients and their partners

May 13 2020, by Karen B. Roberts

To recur means to take place again. It is a word that can generate positive feelings when used in connection with any number of events, such as a favorite social gathering or regular vacation spot.

But when used with the word cancer, it takes on a whole new connotation.

Breast cancer is the most commonly diagnosed cancer in women in the United States. Increased screening, early detection and improved treatment have contributed to a large population of [breast cancer](#) survivors, estimated at 3.8 million in 2019. This number is expected to grow to approximately 4.5 million survivors over the next decade.

Many breast cancer survivors worry about [cancer recurrence](#). Often, their spouses or partners do, too.

With \$3.25 million in new funding from the National Institutes of Health (NIH), an interdisciplinary team of researchers from University of Delaware and the Helen F. Graham Cancer Center and Research Institute at ChristianaCare will examine how the fear of cancer [recurrence](#) affects the well-being and relationships of breast [cancer patients](#) and their spouses or partners.

Led by Jean-Philippe Laurenceau, Unidel A. Gilchrist Sparks III Chair

in the Social Sciences and professor in the Department of Psychological and Brain Sciences, the research team will focus on three main health behaviors that can be influenced by recurrence fears but also can potentially protect survivors against future recurrence. These behaviors include taking therapeutic hormonal medicines, physical activity and quality sleep. The team will study the physical activity and sleep quality of the patient's spouse or partner, too, since they also experience disruption when a loved one has cancer.

According to Laurenceau, fear of recurrence is a top concern for cancer patients and arguably the most commonly shared adverse psychosocial effect of cancer and its treatment.

"It is not just [physical symptoms](#) they have to live with. Fear of cancer recurrence is a psychological symptom that is a consequence of having cancer and can persist for months or years," said Laurenceau.

"If this symptom becomes chronic and interferes with an individual's ability to engage in recommended health behaviors that actually might protect them, it will affect their long-term ability to reach their treatment goals and to reduce their chance for recurrence. We're interested in understanding what breast cancer patients and their spouses or partners are experiencing from the couple's perspective, not just the patient alone."

Underscoring the need for this work is that cardiovascular and metabolic disease have been directly linked to long-term outcomes of recurrence in breast cancer patients, as well as morbidity and mortality for both patients and spouses.

The work is a collaborative project with ChristianaCare's Helen F. Graham Cancer Center and Research Institute.

"Cancer treatment extends beyond surgery, chemotherapy and radiation. We know it's important to address the psychosocial needs for our patients and their loved ones," said Dr. Nicholas J. Petrelli, medical director for the Graham Cancer Center and Research Institute. "This important study, forged from a robust partnership between UD and the Graham Cancer Center at ChristianaCare, has the strong potential to help us improve the delivery of cancer care for our community and inform best practices nationally."

Understanding the role of worry

Shortly after arriving at UD in 2005, Laurenceau began collaborating with Scott Siegel, a clinical health psychologist who practices in the cancer center and director of Population Health Research at ChristianaCare's Value Institute. Laurenceau and Siegel noticed that fear of cancer recurrence was a common clinical problem reported by cancer patients.

This new NIH-funded project represents the culmination of several peer-reviewed publications and other grant projects funded by the National Cancer Institute. It builds on preliminary data from previous NIH-funded projects suggesting that fear of cancer recurrence may be linked to greater sedentary behavior and weight gain, less adherence to doctor-recommended medication regimens, and increased sleep disruption.

In a recent study, the research team further found that when patients—or their significant others—felt they couldn't share their fears of recurrence with a partner, they typically experienced greater levels of fear, even on a daily basis. The couples tended to feel a less intimate connection on days when they felt more inhibited about disclosing cancer-related concerns, too.

"Human beings aren't as rational as we like to think, and our decisions

are often dictated by our emotions," Laurenceau said. "When fear gets to a certain level and we can't process it with our significant others, we can't think straight, so we're going to do unexplainable things."

What makes fear of cancer recurrence different from other fears is that there is a possibility that the cancer actually may recur and lead to death, even if the probability is small.

The research team plans to follow approximately 300 early-stage breast cancer patients and their partners for two years following surgery, to explore the couple's everyday habits and reactions in terms of fear of recurrence.

"We want to see if the fear of cancer recurrence gets better after the first or second mammogram when results come back okay, which will be the case for the vast majority of these patients," said Laurenceau.

Both the patients and their partners will complete daily electronic diaries of their activity, interactions and relevant thoughts, feelings and behaviors, including any worries. The approach, developed by Laurenceau and a colleague, leverages what Laurenceau calls "intensive longitudinal methods," to track patients rigorously over multiple weeks to gain a sense of their everyday life and communications. The couples also will wear research-grade continuous activity trackers, similar to the common Fitbit, to allow the researchers to correlate the participant's diary entries with objective measures of sleep quality and physical activity.

"People are not the best reporters of their own behavior," said Laurenceau. "For example, while you might have a general sense of how many hours you slept last night, that doesn't always map onto the data that are recorded if you wore an activity tracker overnight."

UD graduate students involved in the project will collect additional health data, such as cholesterol, blood sugar levels and body composition, all of which are considered indicators for long-term health and wellness. In addition to research experience, students gain valuable clinical training as psychotherapists alongside psycho-oncologists at ChristianaCare and learn ways to help patients relieve worry and stress to promote healing and recovery.

"Students are integral to this work. They are involved in everything from helping design the study and collect the data to recruiting and monitoring patients' well-being to publishing study results," Laurenceau said.

Adherence to oral hormonal medication, for example, is one of the biggest predictors of longer life for breast cancer patients and lowers the chances of actual cancer recurrence. Yet some survivors struggle with taking their medication regularly, said Laurenceau. He suspects there may be a number of reasons for this, from potential side effects that the medicine may cause to the fact that the physical act of taking medication is a constant reminder that a person has cancer.

Poor sleep is associated with greater risk of cardiometabolic disease and shortened lifespan, even without a cancer diagnosis. Laurenceau explained it is well-documented that breast cancer patients, in particular, experience a lot of sleep disturbance, but his research team also has preliminary evidence that sleep disturbance affects spouses/partners, too.

Laurenceau said he hopes this research will produce a better understanding of how this fear can help drive interventions to improve health behaviors and increase well-being among patients and their spouses. This aligns with the recent Cancer Moonshot Blue Ribbon Panel report, which calls for symptom management research related to cancer.

Research challenges during a pandemic

For scientists across the world, including Laurenceau, conducting research during a global pandemic brings many new challenges. For example, Laurenceau's research team typically recruits patients to their studies soon after surgery for early-stage breast [cancer](#), but these processes have been disrupted under current best practices during the COVID-19 pandemic.

The UD research team does not expect to begin recruiting study participants until the pandemic threat has passed. While disappointing, Laurenceau is mindful of the greater toll to patients undergoing any number of treatments.

"It's amazing to me how this pandemic is affecting so many people across all walks of life, many of whom are in the middle of managing significant medical conditions," said Laurenceau.

More information: Christine Perndorfer et al. Everyday protective buffering predicts intimacy and fear of cancer recurrence in couples coping with early-stage breast cancer, *Psycho-Oncology* (2018). [DOI: 10.1002/pon.4942](https://doi.org/10.1002/pon.4942)

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