Preliminary data on the lived experience of having multiple primary cancer diagnoses

by Krista L. Wilkins

ABSTRACT
Approximately one in two Canadians will develop some form of cancer, and some will develop long enough to be diagnosed with multiple primary cancers. There is some indication that multiple primary cancer diagnoses negatively impact survivors’ mental and physical status, and quality of life. Existing research studies do not fully capture the complexity of what it is like to have multiple primary cancer diagnoses. Accordingly, a qualitative study was conducted to elicit detailed descriptions of the lived experiences of having multiple primary cancer diagnoses. Participants included 10 individuals from Atlantic Canada with a history of two or more cancer diagnoses. Data were captured through semi-structured interviews and participant-generated photographs. Interviews were transcribed and reviewed for common meanings. Preliminary data analyses suggest that the essential meaning of having cancer multiple times is that cancer is “unwanted encore”. This study yields findings that can provide empirically-based guidance to healthcare providers to help support cancer survivors in a more holistic way throughout the extended continuum of care and ultimately improve the health of individuals who have had multiple primary cancers.

Cancer has been transformed from an almost uniformly fatal disease to one that is now frequently curable. Whereas survival from cancer was the exception 40 years ago, the five-year relative survival rate has risen steadily to 63% for all cancers combined from 1992–1994 to 2000–2004 (Canadian Cancer Society’s Advisory Committee, 2014). Cancer survival is a fundamental existential issue. It raises questions about life and death, and calls for both descriptive and ontological reflection on the nature of being (Pascal, Endacott & Lehmann, 2009).

MULTIPLE PRIMARY CANCERS
The growth in the number of cancer survivors has been accompanied by a corresponding increase in the number of individuals diagnosed with multiple primary cancers. Multiple primary cancers are defined as “two or more primary cancers occurring in an individual that originate in a primary site or tissue and that are neither an extension, nor a recurrence or metastasis” (Soerjomataram & Coebergh, 2009, p. 86). It is expected that at least one in nine people will develop two or more cancers in his or her lifetime (Mariotto, Rowland, Ries, Scoppa, & Feuer, 2007). Further, when all ages are considered, cancer survivors have a 14–20% higher risk of developing a new primary cancer compared with the general population (Curtis et al., 2006; Soerjomataram & Coebergh, 2009).

IMPACT OF MULTIPLE PRIMARY CANCERS
Multiple primary cancer diagnoses predispose cancer survivors to morbidity and early mortality through their effects on general health, quality of life, and long-term survival. Compared with survivors of a single cancer and individuals with no cancer history, survivors of multiple primary cancers report having lower global quality of life, higher cancer-specific stress, greater lifetime prevalence of medical conditions and more health-related disability (Andrykowski, 2011; Gotya, Ransom, & Pagano, 2007). With only one exception (physical inactivity), survivors of multiple primary cancers engaged in unhealthy behaviours to a greater extent than did survivors of a single cancer yet the behaviours were healthier than those of the control group (Burris & Andrykowski, 2011). All of these effects of a cancer diagnosis on psychosocial well-being were still detectable years later, suggesting that time does not lessen these effects (Thong et al., 2011).

Together, these research studies suggest that the illness burden of multiple primary cancer diagnoses is cumulative and exceeds that of survivors of a single diagnosis. Although important, they do not fully capture the multidimensionality of having cancer multiple times. There is a need for research approaches that access and give voice to cancer survivors to understand what it is like to have multiple primary cancer diagnoses.

RESEARCH QUESTION
Because of its focus on revealing the nature of human experiences in the world, phenomenological research can be used effectively to delve deeply into cancer survivors’ lived experiences (van Manen, 1990). For this two-year research study, a phenomenological approach was used to develop a rich understanding of how it feels to have cancer multiple times and the meaning for individuals in the context of their everyday lives. The research question for this study is: What meanings do individuals assign to the lived experience of having multiple primary cancer diagnoses?

LIVED EXPERIENCES CAPTURED IN PHOTOGRAPHS
Capturing lived experiences in photograph-elicited data allows for a different way of “seeing” a lived experience, revealing the “unspeakable” in an experience (Pain, 2012). This includes shared understandings of: (1) lived body (bodily presence in the world), (2)
lived time (temporal way of being in the world), (3) lived space (space that affects how a person feels), and (4) lived relations (established in the space shared with others) (van Manen, 1990).

For this study, people who have had two or more cancers (see Table 1 for inclusion criteria; Table 2 for recruitment strategies) were asked to:
1. Provide demographic information (e.g., age, education) and cancer history
2. Talk about what it has been like to have had cancer multiple times (about 60-minute, digitally recorded interview);
3. Complete a photo assignment that involved:
   - Taking photographs with a digital camera of whatever represents their experiences (e.g., bodily changes, experience of time from one cancer to the next);
   - Focusing on inanimate objects when possible and seeking written consent from people who appeared in their photographs; and
   - Writing notes about the photographs they took; and
4. Talk about the photographs they took (about 90-minute, digitally recorded interview).

In 2015, a photo-sharing session and public display of participants’ photographs will be hosted. Participants will decide which photographs they want to share, how to share them and with whom they will be shared.

Thematic statements were isolated using van Manen’s (1990) selective highlighting approach, which involved selecting and highlighting sentences or sentence clusters that stood out as thematic of participants’ lived experience of having multiple primary cancers. Using all the phrases and sentence clusters, textual data were reduced until essential themes emerged. Writing and re-writing the themes helped to develop the interpretation. Participants provided the first contextualization of the photographic data by identifying the most important issues that emerged from them. The researcher’s task was to generate the overall interpretation of the photographic data (Guillemin & Drew, 2010).

**FINDINGS**

**Demographics/Disease characteristics**

There were 10 participants, including seven women and three men (see Table 3 for participant characteristics), who provided data for the preliminary analysis. Recruitment efforts will be ongoing to achieve a sample size of 20 (see Table 2 for recruitment strategies). All participants have completed the first interview, and six have completed the photo assignment and second interview.

Participants were, on average, 61 years of age (range 27–75 years) when they enrolled in the study. Most participants had cancer twice. There were 23 cancer diagnoses reported by the participants. This cancer diagnosis count does not include cancers that had metastasized or recurred within six months. The cancer diagnoses included breast, colon/bowel, lymphoma, melanoma, cervical, and prostate cancers. There was an average of nine years between cancer diagnoses (range 2–27 years). At the time of cancer diagnosis, participants were, on average, 50 years of age (range 7–70 years). A variety of cancer treatments were reported for each cancer diagnosis, including chemotherapy, surgery, radiation or some combination of these treatments.

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<th>Table 1: Inclusion criteria for participants</th>
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<td><strong>Criteria</strong></td>
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| Cancer diagnosis | 2 or more cancer diagnoses  
Minimum interval of 6 months between the diagnoses  
Any type of cancer  
At least 6 months post most recent cancer diagnosis |
| Age at interview | 19 years of age or older |
| Residence | Atlantic Canada |

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<th>Table 2: Recruitment strategies</th>
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<td><strong>Strategies</strong></td>
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| Social media  
facebook.com/SMCUNB  
Follow us on Twitter @CancerRsrchUNB |
| Public service announcements |
| Online classifieds |
| Support groups |
| Local chapters of the Canadian Cancer Society |
| Interviews broadcast on radio and published in newspapers |
| Cancer survivors excluded from previous studies but are eligible for this study |

<table>
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<th>Table 3: Participant characteristics (n = 10)</th>
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<td><strong>Demographics/Disease Characteristics</strong></td>
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| Gender | Male  
Female |
| Age at interview | 61 (27–75) |
| Number of cancer diagnoses | 23 (2–4 per participant) |
| Number of years between diagnoses | 9 (2–17) |
| Age at time of cancer diagnosis | 50 (7–70) |
The essence: Unwanted encore script

Preliminary analyses suggest that the essence of having cancer multiple times is best described as an “unwanted encore”. Simply put, this is a script that study participants wish had not been written. Common to all participants was the perspective that having cancer again was not something in demand or wanted like the encores at plays, concerts, or lectures. The reality for these individuals is that cancer is not a one-time deal. Having cancer multiple times frames a part of their life, sometimes with burdens and sometimes with blessings. Nonetheless, participants concluded that there was a lot of good that comes from having cancer multiple times, including a different perspective on life.

Themes

Three themes communicate the essence of this experience: (1) From Backdrop to Centre Stage, (2) It’s Familiar But Different, and (3) Feeling Blessed... “I would like to thank...”

From backdrop to centre stage

The time between cancer diagnoses was a period of recovery in which participants sought to re-establish themselves. Some got married. Some witnessed their children growing up. Some got new jobs or entered retirement. Participants shared that they felt strong and healthy. For some women who lost a breast, it was a time for surgical reconstruction of their breast. When cancer takes centre stage, this means that cancer has returned. For the participants, it meant they had just done a 180-degree turn, ending where they started with another cancer diagnosis.

Participants felt disappointed and discouraged that they were not able “dodge” subsequent cancers for two reasons. First, participants explained that their first cancer diagnosis seemed insignificant or unimportant to participants in the context of their lives; it was a “blip” on their lifeline. It was something that happened in the past. As one participant (2 lymphomas) said: “It just kind of becomes part of the backdrop. Somebody says ‘cancer’ and you just go, ‘Oh, I’ve been there, done that.’ It’s like the chicken pox or something that only happens once. It never occurred to me that it might happen again.”

Second, participants placed a lot of trust in the opinion of health care providers and were disappointed when health care providers were wrong about subsequent cancer diagnoses. For example, some participants believed they were not going to get cancer again because they had been cancer-free for, on average, nine years. Being past the five-year “cure” mark when they were diagnosed with another cancer was particularly troublesome for participants who felt they were “misled” by health care providers to believe they were “cured of cancer”.

Most importantly, having cancer multiple times provided participants with evidence that cancer can happen again. It seems like there is no sense of closure; there is no clear end to the cancer experience. It is a blurry future, as is depicted in Mike’s photograph of a blurred construction zone end sign (see Figure 1). Speaking about his chances of developing a third cancer, Mike said: “I feel like it’s a reality, that it’s possible, because the first two (cancers) were unrelated and out-of-the-blue and I wasn’t old then, I’m still not old to have another cancer.”

For some, a subsequent cancer diagnosis made them feel insecure and threatened. They started to worry about every pain, ache or bump, and asked themselves, “Is this normal pain or cancer pain?” For example, in speaking about a photograph of scarves, Deborah (cervical cancer followed by breast cancer) shared that she was keeping the scarves she wore when she lost her hair from chemotherapy treatments because she might need them again if she has cancer a third time.

It’s familiar but different

There is a pervasive assumption by both cancer survivors and health care providers that having cancer once automatically prepares individuals for subsequent cancers. In this sense, a person who has cancer multiple times is considered to be a “veteran” cancer patient who knows what to expect with regards to their cancer diagnosis, treatment, and both immediate and long-term effects because they went through the cancer experience before. The problem is that having one cancer does not necessarily prepare even the “veteran” cancer patient for subsequent cancer diagnoses. Indeed, this assumption may actually interfere with the patient’s care when they have cancer again, as illustrated in the following quote from Sarah when she had breast cancer the second time:

“I kept making wrong assumptions because I was making assumptions about the way things were done 14 years ago. It’s all changed so much. I almost would have been better off, if it was the first time. I kept thinking this will happen this way...and this way, and this way. I would end up not asking a question that would get me certain information. People (health care providers) would assume that I knew the answer because I had gone through the system before and so little things would get missed.”

When participants compared their cancer experience of their first cancer to subsequent cancers, they spoke about the similarities and differences they observed with respect to cancer characteristics, cancer treatment, life stage tasks, and future outlook. The cancer characteristic of most concern for the participants was the extent of tumour invasion. Most participants were diagnosed with non-invasive, localized cancers for their initial cancer, whereas their subsequent cancers were often more invasive with some metastases.
Participants were astounded with the progress made thus far with respect to cancer treatments. They observed that radiation treatments are better targeted to cancer cells, with less damage to surrounding healthy organs and tissue (e.g., photon beams versus cobalt 60 for radiation). Participants also spoke about the importance of receiving cancer treatments in the same facility for each cancer diagnosis. This was particularly helpful for one participant whose care returned directly to her previous medical team when she developed a second breast cancer because she was “still in the system.”

Participants described the impact of their cancer treatments on the body from one cancer to the next. For some, the cancer treatments impacted them in similar ways—“tearing up emotions and body.” Others recognized differences in preparing for their cancer treatment. Referring to a photograph of a kayak, Deborah (cervical cancer followed by breast cancer) said:

“The difference is my first cancer (compared with my second cancer)... I wasn’t as physically fit going into it. I wasn’t emotionally as stable. And spiritually I wasn’t ready... so it took me a lot longer to get through the first one.”

Participants were in different life stages when they were diagnosed with different cancers. Those who were single when they had their first cancer were normally married by the time they had their second cancer. Some had young children when they had cancer the first time. When they had cancer again, they had adult children and grandchildren. As Lillian illustrated with a photograph of her family:

“By the time second breast cancer occurred, I was in a different stage of life... I knew my children didn’t need me like they did before... we had just reached the time where it was “our (couple) time” again because our kids were gone.”

Participants’ needs varied according to their life stages. Nelda, who was a single parent when she diagnosed with breast cancer the first time at the age of 32, was diagnosed with a second breast cancer. This time, she needed life insurance, reduced workload from her job, and ability to give her husband a child.

Participants’ outlook on their future selves changed over time. Most reported feeling afraid of dying when they were first diagnosed with cancer. This fear of dying is captured in Nelda’s photograph entitled, “Scared to the Bone” (see Figure 2). When first diagnosed with cancer, the fear of dying was so intense that two participants felt compelled to have guardianship papers prepared because they did not think they were going to be alive to care for their children. For subsequent cancers, most participants did not seem as concerned about dying because having “beat” cancer once meant they could “beat” it again. Only one participant, Sheila, a four-time cancer survivor, expressed an enduring sense of fear that transferred from one cancer diagnosis to the next. She said, “It was the same feeling (fear). Doesn’t matter how many times I think you’re told (you have cancer), it’s the same.”

Figure 2. “Scared to the bone” by Nelda (2 breast cancers).

Feeling blessed...“I would like to thank...”

Having cancer multiple times is part of the participants’ lives that is not going to change. This does not mean they are victims of their circumstances. Participant’s attitude and perception were something they created. They were not dictated by their circumstances. Participants chose to look for the blessings in their cancer experiences. The blessings were something that helped them or brought them happiness and prosperity. For some participants, blessings were obvious. For others, blessings were disguised such that they seemed bad at first, but later turned out to be beneficial.

First and foremost, participants were thankful for the blessing of life. They were alive. They survived having cancer multiple times. They were regaining their health and strength. One very important blessing bestowed onto a participant was a second daughter. Reflecting on a photograph of a baby doll, Nelda shared that she conceived and raised her second daughter despite being told that she could not and should not have a baby. It was suggested to her that having breast cancer twice meant she would likely develop another cancer and not live long enough to see a second daughter grow up.

Having cancer multiple times offered participants an opportunity to discuss cancer with their family members and encourage them to engage in cancer screening practices. While passing cancer genes to their children was seen as troublesome, there were some benefits that came from being aware of what participants referred to as a “cancer legacy.” As Lillian (two breast cancers) said:

“It’s horrible legacy to leave my daughters because for their entire life they will have to just be on top of this all the time. But that might put them in a better position than a lot of other people. They will be seen by lots of doctors and won’t be allowed to forget their mammograms. If they were not followed closely, they might miss something.”

Another blessing that participants spoke about was the opportunity to be an ambassador charged with creating awareness of the ongoing fight against cancer. They are passionate, tenacious, action-oriented, change makers. They have taken action on cancer
Prevention, cancer support and fundraising activities like the Canadian Cancer Society’s Relay for Life.

Seeking opportunities for the blessing of comfort/solace was also important for the participants. Participants were often comforted by their faith in a higher power (God). As Lillian (two breast cancers) said, “I just believe that He’s in control and whatever happens, happens. There’s nothing we can change anyway.” Captured in her photograph entitled, ‘spiritual care’, Deborah (cervical cancer followed by breast cancer) shared that she was thankful for both of her cancer experiences. She would “do them all over again” because they led her to a relationship with her Creator. She spoke about her struggles to get to know Him when she had cancer the first time because she “had religion, but not a relationship with Him.” By the time she had cancer the second time, she had secured this sacred relationship with God. It was this relationship that helped her find peace and joy in her cancer experiences.

Places of sanctuary were important for quiet moments of meditation and reflection. For Deborah (cervical cancer followed by breast cancer), any place near or on the water had a soothing effect on her body. With the photograph entitled, “Quiet moments of meditation” (see Figure 3), she recounted, “There’s a sound being near water... there’s birds flying, there’s birds chirping, there’s the sounds of sailboats. All of these sounds have a quieting place in my body.”

Figure 3. “Quiet moments of meditation” by Deborah (cervical cancer followed by breast cancer).

IMPLICATIONS FOR ONCOLOGY NURSING PRACTICE

One of the most important things oncology nurses can do when caring for someone who has had cancer multiple times is to avoid assuming that having one cancer is the same as having cancer multiple times. It is important to recognize that there may be differences in how cancers present and how they are treated. Don’t assume that patients who do not ask questions know what is going on with their cancer treatment. Oncology nurses need to demystify cancer and its treatment based on what patients know and what they do not know. It is especially helpful to review side effects of cancer treatment and what to do about them because the information is often given when people cannot process it. Patients may be in different life stages from one cancer to the next. This means their supportive care needs may also change. Oncology nurses need to provide supportive care that fits with the patient’s life stage.

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REFERENCES


