Report from the 2015 CANO/ACIO conference

Patient perspectives

CANCER TAKE TWO

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STUDY SUMMARY: Patient perspectives on second primary cancers
Krista Wilkins, PhD, RN. Unwanted encore 2.0: an update on the lived experience of having multiple cancer diagnoses. CANO/ACIO 2015, Session VII-03-A.

It is expected that the incidence of multiple primary cancer diagnoses (MPCD) will increase as the number of cancer survivors increases. In this qualitative study, 21 participants (including 8 men) with a mean age of 62 provided data from participant-generated photographs and audio-recorded interviews. Themes that captured the essence of this unwanted encore include: 1. From backdrop to centre stage; 2. It’s familiar but different; 3. There’s life after cancer (again); and 4. You gotta have faith. This study provided an avenue for cancer survivors to reflect upon and draw meaning from their lived experiences of MPCD.

COMMENTARY: This presentation described additional research and analysis by Wilkins since she first spoke on this topic at the 2014 CANO/ACIO conference. Multiple primary cancer diagnoses (MPCD), also referred to in the literature as second primary cancers or multiple primary neoplasms, applies when an individual develops more than one primary cancer, and the cancers are not extensions of each other, nor are they recurrences or metastases. The National Cancer Institute in the US reports that nearly 1 in 5 cancers will occur in an individual with a previous cancer diagnosis. A well-known monograph by the US Surveillance, Epidemiology, and End Results (SEER) Program retrospectively

LANDMARKS
analyzed data from 1973 to 2000 on over 2 million cancer survivors, revealing that 9.1% (n=186,000) developed a new malignancy.4 Travis (2006) estimated that the risk of a cancer survivor developing a subsequent primary cancer is as high as 50%.4 Additionally, MPCD can be devastating, leading to increased risk of morbidity and mortality as well as amplified stress, decreased general and mental health, and potential intensification of unhealthy behaviours.

Wilkins pointed out that, before this study, there was a shocking lack of qualitative research describing the lived experience of patients with MPCD. As a phenomenologic and existentially-driven research inquiry, lived experience is the meaning and value that people assign to this unique condition.5 Combining data from both participant-driven photography, as well as personal and focus group interviews, Wilkins’ overarching goal was to capture that which is unspeakable, including feelings of the body, lived space, relationships and temporal experience. Most of the 21 participants had 2 to 4 primary cancer diagnoses, with an average of 6 years between diagnoses.

These cancer survivors have a truly unusual perspective on the disease. Through analysis of her data, Wilkins identified 4 themes: 1. From backdrop to centre stage, whereby cancer moves from the past to present; 2. It’s familiar but different, describing how the experience of cancer is both new and old; 3. There’s life after cancer (again), capturing the notion that there is hope of going into remission or achieving cure another time; and 4. You gotta have faith. This final point, that spiritual grounding is important, is deeply tied to geography and cultural context, a point that Wilkins admits is specific to the lived experience of these participants.

This research illuminates some major care challenges for this unique patient population. First, cancer survivors are often not prepared, mentally or physically, for a second (or third or fourth) primary cancer diagnosis. Cancer survivors may find themselves questioning what they do and do not know about cancer, and in some cases healthcare providers take for granted that they “know” cancer already. This suggests that cancer survivors and healthcare providers both need information about MCPD. Personalized care plans are critical for this distinctive population, with heavy emphasis on mental and emotional care. The healthcare team should not make assumptions about these patients, nor take for granted their desire or need for more knowledge and teaching.

Montella et al (2009) noticed that not only has the absolute number of cases of cancer increased in recent years, but also the frequency of MPCD has kept pace.6 Speculating that this may be related to significant improvements in survival rates tied to technologic advancements in both diagnosis and treatment of the original disease, these authors conclude that the unfortunate situation of MPCD may actually be simply statistically due to people living longer. Quantitative studies like those by Thong and colleagues (2012) and Andrykowski (2012) confirm that cancer survivors who have to step back into the role of active cancer patient have poorer overall health status and a negative sense of wellbeing.7,8 Whether due to lingering influences of cancer treatments or arising from a unique etiology unrelat-ed to the previous cancer diagnosis, MPCD devastates in a way that calls for these patients to be cared for as an exclusive group, separate even from those with metastatic disease. As rates of occurrence are bound to continue trending upwards, the importance of preemptive and proper informed care planning for these patients demands further attention.

References