The lived experience of women with cancer: Phenomenological findings expressed through poetry

by Lynne Duffy and Catherine Aquino-Russell

Abstract

Cancer rates for Canadian women between the ages of 22 and 44 are increasing. Improved survival times and more treatment choices, however, create new challenges. Little research has been done to uncover the lived experience of long-term survival. This pilot study describes the meaning of living with cancer for three Canadian women who were diagnosed more than four years ago. The process of inquiry was Giorgi’s descriptive phenomenological method for analysis-synthesis of a general structural description (the meaning of the experience). The findings have been interpreted creatively through poetry in an effort to enhance understanding of the experience of living with cancer. Each section of the poem is discussed in relation to the literature to encourage nurses and other health professionals to consider the importance of understanding patients’ lived experiences and the meanings they ascribe, in order to provide quality, holistic, and individualized care.

More women between the ages of 20 and 44 are diagnosed with cancer and survival rates are generally increasing (National Cancer Institute of Canada, 2003). While this apparent success in cancer outcomes is welcomed, longer life and more treatment choices bring new challenges to patients and care providers. Management and rehabilitation of cancer can entail complex and painful interventions that extend over time, often resulting in uncomfortable and undesirable side effects and complications that impact all areas of life (Hilton & Henderson, 2003; Kuo & Ma, 2002; Landmark & Wahl, 2002; Pasacreta, 1997; Rose-Ped et al., 2002). Izask and Medalie (1971, as cited in Pelusi, 2001) stated, “Survival rates, while justifiably important in themselves, cover only a portion of the total problem. These rates do not relate to how the patient survives” (p. 265).

While it appears that diagnosis and treatment options for Canadians are improving (National Cancer Institute of Canada, 2003), in epidemiological discussions of people living longer after a cancer diagnosis, quality of life issues are often ignored. This is where a qualitative approach to research can enhance statistical reports that fail to probe into the social and psychological factors that influence the experience of living with cancer. Each section of the poem is discussed in relation to the literature to encourage nurses and other health professionals to consider the importance of understanding patients’ lived experiences and the meanings they ascribe, in order to provide quality, holistic, and individualized care.

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Cancer has the ability to spread or metastasize in the body through various routes. The possibility of this occurring, and the continued focus on follow-up and testing brings a degree of uncertainty related to the healing process that is not necessarily a part of other disease trajectories. Howell, Fitch, and Deane (2003) qualitatively examined Toronto women’s experiences with recurrent ovarian cancer. Four themes that emerged were: waiting for recurrence, facing the diagnosis, managing treatment-related concerns, and attempting to gain control. The women in the study experienced considerable anxiety and anticipatory fear before checkups and felt shock and despair when faced with the news. Mahon and Casperson (1997) studied the meaning of recurrence among 20 persons living in the United States and found three emerging themes related to differences between the initial diagnosis and the recurrence. Some were similar to Howell et al.’s (2003) findings, but one theme focussed on both positive and negative changes in the health care system since the time of the first diagnosis.

Dirksen (1995) explored the search for meaning in survivors of malignant melanoma using the Search for Meaning scale. Dirksen (1995) found that 52% of the participants did search for meaning that was often related to finding a cause as they blamed themselves for their condition. This study was more prevalent in younger participants with Dirksen (1995) describing the search for meaning as “a thinking process related to why the cancer occurred and its impact on life” (p. 633). Utley (1999) reported that women over the age of 65 with breast cancer viewed cancer as sickness and death, as an obstacle, and as transforming. The lived experience of women who survived breast cancer longer than five years was captured by Carter (1993) in a qualitative descriptive study. Participants described “going through” a survival process that involved several evolving phases involving psychosocial issues that, Carter (1993) noted, are rarely focused on in long-term survival studies.

With few studies examining the meaning of the cancer experience from a female perspective, further qualitative studies are important. Zebrack (2000b) stressed that quality of life (QOL) questionnaires are “less sensitive than probing interviews” and, therefore, these tools “do not adequately capture the total essence of an individual’s QOL” (p. 1397). Understanding the experience of women who live with cancer, finding out what it is like for them, and illuminating their meaning will expand the knowledge base for nursing. Only the women themselves can begin to describe what it is like. In practice, “enhancing understanding…leads to an openness that can change the ways nurses interrelate with persons” (Mitchell & Heidt, 1994, p. 119).

Purpose

The purpose of this pilot study was to uncover the general structural description (also considered the meaning) of women’s experience of living with cancer for an extended period of time. The idea for the study developed after an acquaintance questioned whether there was any particular meaning for what she was experiencing in the aftermath of her cancer diagnosis and the difficult treatment. Since neither of us had faced such an event, we could not respond with any sense of familiarity and began wondering whether descriptions from other women might lead to a better understanding of the experience. This was the impetus for the study and for choosing a descriptive phenomenological method to assist in uncovering meaning.

Method

A study using descriptive phenomenological method was carried out (Giorgi, 1975; Giorgi & Giorgi, 2003). The method described by Giorgi was chosen because it is a discovery-oriented approach seeking to gain an in-depth understanding of the nature and meaning of phenomena as lived and experienced by humans. Giorgi’s method allows for participants’ descriptions to emerge in a natural setting with minimal interference; the researcher’s inevitable influence with the interpretation of the data and participants to be engaged rather than detached within the research framework (Santopinto, 1987). Giorgi (1970) stated that one can hold beliefs in abeyance (bracket them), but believed that, ultimately, one’s interpretation does come into play. He meant for researchers to refrain from jumping in and labelling something in a particular way the first time it is read or reviewed, based on their own point of view.
During the analysis-synthesis process the rhythmic flow of the general structural description was recognized, resulting in its presentation as a poem. Presenting the research findings in the form of a poem is an effort to enhance others’ understanding of the experience of living with cancer using an artistic medium.

Poetry, as an art form and expressive mode, articulates the experienced whole and provides an openness to perceptual sensibilities [which] can give meaning to the reality of knowing and being… Poetry and its images create accessibility to otherwise obscure, elusive yet deeply meaningful perceptive experiences. (Holmes & Gregory, 1998, p. 1191)

It has been written, “one attribute of poetry is how it emerges from lived experiences” (Hunter, 2002, p. 142). Since this research is about the meaning of a lived experience, the use of a poem to express the findings is very pertinent. The reader will understand, feel, and interpret the experience through the written words of the poets (i.e., researchers), which surfaced through analysis of participants’ words. Poetry may be utilized when researchers feel that traditional modes of presentation will not capture what they desire to show about their work and research participants, when they wish to write with more engagement, or when they desire to reach more diverse audiences (Faulkner, 2005)

Recruitment and participants

Colleagues with oncology connections and local cancer support groups (e.g. Run for the Cure and Bosom Buddies) were approached to assist us with recruitment through purposeful sampling. Four women residing in the Maritimes, between the ages of 40 and 48 years, and living with cancer for at least four years, agreed to participate. Two were from New Brunswick and two were from Nova Scotia with no one from Prince Edward Island contacting us. Participants’ diagnoses included breast cancer, thyroid cancer, and Hodgkin’s lymphoma. Selection was based on participants’ ability to describe in English their own personal experiences and feelings, as well as being willing to exchange with others using e-mail or regular mail. Selection criteria also included: age range of 20 to 50 years, having been diagnosed at least four years ago, and not receiving active treatment. We chose to focus on this age range since cancer rates are rising more quickly in this population while survival rates are improving. With considerable research done around the time of diagnosis, we wanted to explore the longer-term experience of living with cancer after initial interventions were completed.

Ethics and rigour

The study was approved through our university ethical review process. Participants signed an informed consent before being asked to write their descriptions. They could withdraw at any time without consequence. Measures were taken to ensure confidentiality and security of their documents. Sending documents as attachments in MS Word takes advantage of this program’s built-in encryption capability for security. Once received, the descriptions were saved and stored on personal computers with login required, and e-mails were deleted. Once analysis was complete the descriptions were saved on a CD ROM and removed from the computers. Print documents and CD ROM were locked and stored according to requirements of the ethical review board.

Scientific rigour of this study was enhanced through the consideration of four criteria commonly used to judge the trustworthiness of qualitative research: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Achieving credibility involved prolonged immersion with the participants’ descriptions, presenting the participants’ words in the discussion section, comparing our findings with other literature, noting many similarities, and hearing from at least one participant that the poem captured what she was trying to say. Following Giorgi’s (1975) method of analysis-synthesis and demonstrating its application through examples enhances dependability. Albaugh (2003) stated that Giorgi’s (1985) method “applies the concepts of rigour and precision to the study of human phenomena and ensures the capture of the phenomena according to the participant’s descriptions” (p. 594). Transferability has been shown through similarities to other research findings and from feedback at a research conference where members of the audience said they could relate to the findings. These three criteria, as well as providing an audit trail from the original descriptions to our synthesized findings, provide confirmability.

Data collection

Participants were requested to write a description in response to the following interrogatory statement: Please describe your experience of living with cancer. They took various amounts of time (four to six months) to write their descriptions and chose what and how much information they wished to share. While we did not expect it to take as long as it did, we also wanted participants to write at their own pace and to include what they thought was important. When completed, descriptions were delivered or sent as e-mail attachments. Three documents were received ranging in length from 10 to 20 typed pages. The fourth participant made several attempts at writing, but did not feel she had the right words to capture her experience in the way she wanted to and, therefore, did not submit. Two participants had considerable difficulty to begin writing, but once started found it a positive experience. One woman wrote, “Once I got going it just came out. I now have a document of my journey”. Another wrote, “I’m not sure if this is what you are looking for, but it’s what I wanted to say.” Writing their descriptions seemed to be a cathartic experience for all three participants.

Data analysis

Written descriptions were analyzed using Giorgi’s (1975) method, generating situated structural descriptions (SSDs) for each participant, as well as synthesis of a general structural description (GSD). Giorgi (1989) considers the GSD to be the meaning of the experience, of the phenomenon under study. The analysis-synthesis steps and processes of Giorgi’s method (Giorgi, 1975; Giorgi & Giorgi, 2003) are found in Figure One. Examples of two of the steps are provided in Tables One and Two. Spending time reading and rereading the GSD led us to transforming it into a poem.

Findings/Discussion

The Lived Experience of Cancer: A Poetic Interpretation

Living with cancer is fraught with disruption of life events, numerous and arduous choices amidst compassion-indifference of others. With fear of exacerbation, one remains vigilant. It is living in the moment tinged with hope for the future with appreciation and enhanced understanding amidst inspirational giving-receiving.

Each stanza of the poetic interpretation of the general structural description follows, with examples of the participants’ own words to demonstrate congruence and linkages to the literature in an effort to enhance understanding of the meaning of the experience. Pseudonyms have been used.

Living with cancer is fraught with disruption of life events

Ava: I was experiencing some cold-like symptoms…my doctor told me to check into the emergency room… I ended up missing my son’s birthday party.

Beth: I was accepted into the nursing assistant program... However, my life came to a crashing halt, four weeks before graduation. The cancer was back... My classmates were all applying for jobs, and I was fighting for my life.

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Chris: Three days before my surgery, the hospital called to cancel… I was devastated, because this meant I would not be around for my son’s first day of school.

With life-long monitoring and necessary interventions around prevention, wellness, or exacerbations that often follow initial treatment, disruptions continue to occur at various points along the survivor trajectory. These intrusions are reminders of what one is living with and they thwart attempts to maintain a degree of normalcy. Utley (1999) in her study of women survivors over 65 years of age, found cancer was described as an obstacle that women had to deal with before moving forward in their lives. These obstacles can occur at various points and may become life crises. Carter (1993) described

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<th>Figure One: Giorgi’s Analysis/Synthesis Process (Giorgi, 1975; Giorgi &amp; Giorgi, 2003)</th>
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<tr>
<td>1. Contemplative dwelling with the descriptions. The written texts of each participant were read several times for an overall sense of the description. A rigorous process of intuiting, and analyzing the raw data descriptions occurred.</td>
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<td>2. Returning to participants for elaboration on ambiguous areas of description. This step was not deemed necessary, as the participants’ descriptions were thorough and clear.</td>
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<td>3. Identifying meaning units. The raw data descriptions were examined for spontaneously occurring shifts in meaning or transition. Discrete passages of text, called meaning units (MUs) were identified and expressed in the participants’ own words.</td>
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<td>4. Identifying focal meanings. The MUs were raised to a higher level of discourse (to the abstract) and reformulated to become focal meanings (FMs) in the language of the researcher (see Table One).</td>
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<td>5. Synthesizing situated structural descriptions. Each set of FMs was then synthesized into a situated structural description (SSD) for each participant. It is the SSD that grasps the meaning from the perspective of the participant and is grounded in the setting of each participant (Giorgi, 1985) (see Table Two).</td>
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<td>6. Synthesizing a general structural description. This stage synthesized the most general significance of the phenomenon under study (Giorgi, 1985) and is aimed at capturing the meaning of the lived experience described by the participants in an insightful and focused way (Giorgi, 1975). The general structural description (GSD) was created by the researchers following contemplative dwelling with the FMs and SSDs of the participants.</td>
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| Table One. Meaning Units and Focal Meanings |
|---|---|
| Meaning Units (MU) | Focal Meanings (FM) |
| Ava-03 MU: It was my choice because all of the other tests, chest x-ray and bone scan came back negative. After some discussion and research, I decided to do the chemotherapy. This way, I had a better chance to continue working. I really needed to do that. I began my chemo the next week. | Ava-03 FM: Arduous decision-making was complemented by a search for new information and dialogue while choosing to live valued priorities. |
| Ava-05 MU: I was experiencing some cold-like symptoms. …my doctor told me to check into the emergency. I ended up missing my son’s birthday party. | Ava-05 FM: Fear of exacerbation leads to vigilance and disruption of life events. |
| Beth-08 MU: I have had the privilege of meeting women, over the years, to offer encouragement while they were undergoing treatment. …I received far more from them than I ever gave. …Then came the gruelling task of what to do next…He [oncologist] went through the results of the biopsy and made the recommendation that I do chemotherapy. It was my choice because all of the other tests…came back negative. | Beth-08 FM: The cancer experience leads to giving-receiving of support and inspiration towards enhanced understanding of self and others. |
| Chris-08 MU: My biggest battle with cancer was staying focused on the better times that lay ahead. I can tell you that I am experiencing these times now…Little things become “great joy” when you live life to its max! There is no doubt in my mind that the challenges I have experienced have made me a better person today. …I concentrate on helping others and living my life to the fullest. | Chris-08 FM: Living with cancer is living for the moment, going with the flow, being hopeful for the future while appreciating the little things in life. |

Numerous and arduous choices

Ava: …Then came the gruelling task of what to do next…He [oncologist] went through the results of the biopsy and made the recommendation that I do chemotherapy. It was my choice because all of the other tests…came back negative. Chris: After the surgery… I was faced with so many difficult decisions at a time when I felt the least capable of making them.

Nurses respect individual autonomy and attempt to support patients through offering care choices whenever possible. It is both important and ethical that patients receive all the necessary information in order to make informed decisions. Webb and Koch (1997) noted that information for some women with breast cancer in their study was very limited and they seemed “ill-informed” (p. 521). The literature is mixed on how people perceive having autonomy in treatment decisions (Brown et al., 2004; Degner & Aquino-Russell, 1988). In the Brown et al. (2004) study, the women expressed how many decisions are needed, appreciating having informed choices, and the importance of having the power to be active and respected members of their health care team.

Nurses, however, may need to become more cognizant of the burden all this can be for patients, many of whom may not be familiar with the medical and nursing context. As nurses, we can assist patients to explore the many options, to be there to help them make sense of these critical life-impacting decisions, and to work through a decision-making process that makes sense to them. Our skills in the art of nursing, along with nursing knowledge, can assist patients in making sense of the complex science of treatment.

Amidst compassion-indifference of others.

Ava: I believe I fared well with the chemo. My husband would take the day off… He picked up the kids and took them out for dinner and I just slept… Friends were there to help with the kids and make meals and my husband was my number one fan. Beth: The nursing staff was very kind to me… My family lived almost 100 miles from the hospital. This is one area… where I feel I was left completely on my own. There was no intervention, no one to talk to, to help me over this hurdle [infertility].
Chris: One nurse, who had stopped at the grocery store on her way to work, reached into her bag of groceries and made me the best ham sandwich I’ve ever had! I have never forgotten that kindness… One of the other doctors in charge was disappointing me… She was avoiding my room for days at a time, sending residents in her place. I felt like she couldn’t handle what was happening, so how was I supposed to? I felt so abandoned…

As a determinant of health the presence of social support is considered to have a beneficial influence on mastery, well-being, health status, and mortality (Public Health Agency of Canada, 2004). Dirksen (2000) examined several studies and concluded “social support impacts a woman’s ability to initiate skills of resourcefulness in successfully adapting to cancer survivorship” (p. 938). Pelusi (1997) found that the fears of newly diagnosed patients included abandonment by health care providers along with considerable reconciliation and adaptation in their relationships with significant others. Dirksen (2000) purported that when patients have low confidence in a provider they “may view disruptive events as even more stressful” (p. 938). Dirksen (2000) wrote that uncertainty may continue as longer survival often leads to less contact with the health care system.

Participants of the present study described how nurses went out of their way to connect and make a difference, stating some nurses will always remain in a special place in their hearts and minds. Unfortunately, the opposite is also true where health professionals were less than caring, which added to the stress of their diagnoses and treatments. While the physical tasks are important, going beyond usual emotional and supportive care with people in their search for meaning of the cancer experience is important for nurses to engage in. Quinn (2003) examined nurses who did provide such care. While some of these nurses did not always find the experience easy, they did value this role and recognized that the search for meaning is unique for each individual. Health care providers need to examine their own emotions around a cancer diagnosis and to truly be there for the patient and family when others close to them might be avoiding. “Viewing the world from the patient’s standpoint can provide useful insights into patient’s needs for information and support” (Luker, Beaver, Leinster, & Owens, 1996, p. 1200).

With fear of exacerbation, one remains vigilant

Ava: The other scare I had was the drainage problems… Mine was quite severe and after a few trips to the surgeon… he said that this is the last time and that it would settle in time. It did settle, but it was scary the first time it happened to me.
Beth: I was in remission. I applied for my first job…. But, within six months I had relapsed.
Chris: After my surgery, the doctors said everything had gone well. They said this was good news, but I didn’t feel the same way. I wanted them to take it all out. My instinct was telling me this was what I needed. Two weeks later, the post-surgery biopsy results came in. I was malignant and scheduled for more surgery.

Situations like these of the participants can occur at any time in the cancer experience. Zebrack (2000a) stressed that “cancer is not just a single event with a certain end, but an enduring condition characterized by ongoing uncertainty, potentially delayed or late effects of the disease or treatment, and concurrent psychosocial issues” (p. 238). Uncertainty is a common theme in the literature on living with cancer (Dirksen, 2000; Howell et al., 2003; Mahon & Casperson, 1997; Nelson, 1996).

Both fear and actual episodes of cancer symptoms may impact on quality of life. Pelusi (1997) found that the lived experience of breast cancer survivors included a theme of fear of recurrence. Pelusi (2001) later wrote about the importance of health care professionals focusing on psychological and social issues for long-term follow-up, including fears of recurrence; in other words helping prepare “for long-term survival” (p. 265). Nurses and others need to examine their own practices and how this is or is not considered, recognizing, as Zebrack (2000a) noted, that supports need to be available when each person is ready.

It is living in the moment tinged with hope for the future

Beth: [After hospitalization] When I was released… life continued… I led a pretty normal life for a teenage girl… boys, school, boys, clothes, boys, music.

Chris: Little things become “great joy” when you live life to its max!… In my case, my cancer is in remission… I concentrate on helping others and living my life to the fullest.

Ava: I also remember my surgeon prior to the diagnosis say to me that “If you do have cancer, you have won half the battle with your positive attitude.” I think that is why I have been able to deal with this disease with courage and hope.

Beth: Faith had become an important part of my life. Without it, I’m not sure how I would have managed to get through all of this.

Chris: My biggest battle with cancer was staying focused on the better times that lay ahead.

When faced with mortality and then able to move beyond that, life may take on new meaning with appreciation for each moment, each day, and hope for future possibilities. Utley (1999) found that some participants experienced cancer as life-transforming. This included benefiting from emerging possibilities from the experience, while gaining a new appreciation for things previously taken for granted. Carter’s (1993) participants described needing to “put things behind them” before they could move into the future (p. 359), while Bushkin (1995) depicted a later aspect of survivorship as one of endless possibilities. The uncertainty of survivorship can result in a reordering of priorities and values so that life has more meaning (Nelson, 1996). Each person’s cancer experience is unique and people will experience their present and future in different ways. Nurses need to listen to patients’ diverse meanings of daily experiences and their future hopes and plans.

Table Two. Abridged Situated Structural Descriptions (SSD)

**Ava SSD:** For this woman, living with cancer involved difficult, numerous, and arduous decision-making of treatment options that were enabled with support of family, friends, and available health professionals and complemented by a search for new information and dialogue. Time and support from one health professional led to her capacity to advance with self-care while lack of support from another led to cessation of that relationship… Fear of exacerbation led to continued vigilance and disruption of life events while in her quest for enhanced understanding, optimism surfaced, which she sees as a foundation for living with cancer.

**Beth SSD:** For this woman, the cancer experience began at an early age… While others were contemplating possibilities of employment, she was battling possibilities of demise… Moving with the rhythms of care provider-care receiver and remission-exacerbation, her relationships with God and others ensued… The cancer experience for this woman involves giving-receiving of support and inspiration towards enhanced understanding of self and others.

**Chris SSD:** …For this woman, living the experience of cancer brought feelings of confidence in health professionals’ process planning, mixed with profound distress when the plan changed. During the …treatment process taxing choices amidst exhaustion, discomfort, and desire for normalcy were facilitated through supportive significant others… Further, compassion from strangers was surprising and led to new strength… This woman’s personal and family perspectives of living with cancer have increased her empathy for others’ experiences. With gratitude for her own survival and from what she received from others, she performs acts of kindness to make a difference. She believes that living with cancer is living for the moment, going with the flow, being hopeful for the future, while appreciating the little things in life.
With appreciation and enhanced understanding amidst inspirational giving-receiving

Beth: As a cancer survivor, I feel it is a real privilege to grow older. Lots of people get really hung up on this age thing, but, I just tell them — “it sure beats the alternative.”

Chris: There is no doubt in my mind that the challenges I have experienced have made me a better person today.

Beth: I feel very blessed to have met some wonderful people during this cancer journey. People I would never have met, otherwise … I received far more from them than I ever gave.

Chris: I never felt as deeply loved as I did when I became sick. I am amazed at the way people came into my life and gave me love, even when they didn’t know me. I want to pass this power on to others in the same way, in honour of the angels I have encountered.

The women gained new insights about themselves and their relationships with others through the cancer experience. The memories they have of people who positively influenced their experience attests to the power of appropriate and caring support, further enlivening later connections and reaching out to others. Utle (1999) noted that with participants’ realization that time could be limited; they wanted to move outside of themselves. Howell et al. (2003) reported that some of their female participants “felt a desire and responsibility to give back in gratitude for the support they received” (p. 8).

It appears that the lived experience of cancer described by the participants concurs with findings in much of the available literature. Nurses reflecting on these findings, the words of the participants and the literature may find enhanced understanding of the lived experience and may alter their own practice to meet the needs of persons living with cancer. Frankl stressed that “the worst tragedies could be turned into triumph if individuals choose to make it so by taking the opportunity to grow beyond themselves and find meaning” (cited in Albaugh, 2003, p. 594).

Strengths and limitations

This research was a pilot study engaging three participants. Historically, studies using Giorgi’s method have involved one to seven participants (Giorgi, 1970, 1985; Giorgi & Giorgi, 2003). Maggs-Rapport (2001), in comparing several phenomenological methods, noted that Giorgi’s two criteria for deciding what is appropriate for sample size are “the depth of the dimension that is tapped” and “the time and effort needed to undertake a particular piece of research” (p. 374).

The process of eliciting written descriptions is one way to reduce the initial influence of a researcher in data collection and it has worked well in other studies (Aquino-Russell, 2006; Santopinto, 1987). However, we have seen that this is not a process for everyone (meaning the written descriptions). We sent a follow-up letter to the fourth participant asking about the experience and she replied:

I was very eager to participate. I attempted many times to put down on paper my thoughts about this whole experience, but always ended up deleting anything that was noted. I needed the right words to reflect what it was really like, so that it would make the impact needed to change some of the things that weren’t right. Somehow, it never happened. Emotionally this is so huge. For people like me, thoughts and feelings are better conveyed when you have a face to look at; when the raw emotion is right there in front of you.

For this woman, it appears a face-to-face interview would have been a better approach to data collection. While Catherine prefers written descriptions, Lynne prefers an interview format. We are not sure if combining these in one study would be feasible.

While there is a dearth of qualitative and phenomenological cancer research among Canadians, and none concerning the long-term lived experience of women living in the Maritime provinces, it is impossible to know if the experiences of Maritime women are different from women living in other geographical areas. It does appear from the literature that there are many similarities in the cancer experience of these women and those in other studies, especially regarding relationships with health care professionals. This study revealed the critical impact health professionals have on the quality of living the cancer experience.

Implications for practice and research

For nurses and other health professionals, it is important to know more about people’s lived experiences of cancer and the meaning they ascribe to these experiences in order to provide quality, holistic, and individualized care. Kleinman (1988) stated that even though illness behaviours are culturally and socially molded, they are also unique to each individual. He stressed the importance of understanding “the experience and meanings of illness … at the centre of clinical practice” (p. 253). Very often, however, the perspective of the person experiencing the illness is not the central focus of the care in medical practice. So, while the field of medicine focuses on the disease, Kleinman wrote that it is the patient, family, complementary therapists, and nurses who are left to care for the illness. Kleinman noted that it is critical to integrate both the treatment of disease and care of illness for a comprehensive practice, but that “does not happen easily” (p. 265). Zebrack (2000a) more recently suggested “understanding how persons who are long-term survivors manage the impact of cancer and experience the transformation of their lives is critical for health care professionals committed to assisting cancer survivors in their recovery” (p. 239). Nurses are educated to take a holistic approach to health and illness, yet those working within a biomedical system can find that a disease-focused approach is sustained in actual practice. Therefore, nurses and other health care professionals need to search for and listen to the meanings of personal lived experiences for greater sensitivity and understanding. Nurses who are open and ask people to share their experiences will make a difference in the lives of patients. As the participants in this study stated, having the opportunity to describe their experiences of living with cancer was meaningful to them.

Nursing educators could assist students in becoming more sensitive to lived experiences and demonstrate how to translate this understanding into practice. As well, students and nurses need to be cognizant of individual differences and needs regarding support and referral along the cancer journey.

Further studies of nurses’ experiences and their challenges in assisting others to search for understanding and meaning of their experiences would be beneficial, especially in light of increasing workloads and use of technology that can interfere with practicing the “art of nursing”. While the use of measurement scales can be beneficial in reaching a larger number of participants, more qualitative studies (or mixed method research) could provide the in-depth understanding that quantitative studies alone lack. Future studies could examine the influence of gender, age, socioeconomic status, or culture on meanings of the cancer experience. We also wonder about the experiences of lone parents and others without supportive partners, families, or workplaces and rural-urban comparisons. The lived experience and ascribed meanings of spouses and other family members are also important areas to consider. Further research that includes issues of spirituality and belief systems could also assist others living the cancer experience in finding meaning.

Concluding reflections

The interrogative statement was designed to be open to the participants’ interpretation. It is interesting that all three participants chose to detail their descriptions from the beginning of symptoms or from the time of diagnosis. This may be a natural starting point when describing what it is like to live with cancer since those events are life-changing ones and impact the rest of their lives. Breaden (1997) wrote
“survival for those diagnosed with cancer begins at the point of diagnosis and not at some pre-determined period in the future” (p. 979). It is also usually the period with the most intensive and lengthy interactions with health care professionals and participants seemed to want to describe those experiences. This study and others noted here have shown the importance of personal and compassionate connections between persons and health care professionals. It is hoped that the findings of this study, presented as a poem, will resonate with nurses and other readers, stimulating thoughts of possibilities of being with patients in creative, caring, and different ways. This includes spending time listening to patients’ descriptions of meaning and finding out what living with cancer is like for them.

References


