

Quality of Living Among Ovarian Germ Cell Cancer Survivors: A Narrative Analysis

Melinda M. Swenson, RN, PhD, Jessica S. MacLeod, RN, BSN, Stephen D. Williams, MD, Anna M. Miller, RN, DNS, and Victoria L. Champion, RN, DNS

Purpose/Objectives: To describe and interpret the meaning of experiences that are important to the quality of living of ovarian germ cell cancer survivors.

Research Approach: Qualitative description within a constructivist paradigm.

Setting: 32 member sites of the Gynecologic Oncology Group and the University of Texas M.D. Anderson Cancer Center in Houston.

Participants: 109 women between the ages of 19–64 (median age = 36) who were enrolled on prospective clinical trials of cisplatin-based chemotherapy after surgery and disease-free for at least two years.

Methodologic Approach: As part of a larger study, narrative responses to four semistructured questions were collected at the end of a telephone interview. Using naturalistic inquiry and qualitative description techniques, content labels were assigned to units of text that seemed to encapsulate one complete thought or idea. The labeled groups were collapsed into interpreted subthemes. Finally, four general themes were constructed as representations of shared narrative responses and meanings.

Findings: The four constructed themes are celebrating illness, experiencing empathetic affirmation, mourning losses, and valuing illness.

Interpretation: In addition to measuring physical, psychological, and sexual functioning in women surviving ovarian germ cell cancer, nurses also must understand how these issues fit into their everyday lived experiences. The four themes may help clinicians and researchers to understand issues that are important to the quality of living of ovarian germ cell cancer survivors.

The treatment of ovarian germ cell cancer has advanced significantly since the 1980s. Researchers and clinicians have made impressive progress in the treatment of this very curable cancer. As recently as the 1960s, this rapidly growing malignancy often was associated with very poor prognoses, with only 5%–20% of patients with stage I disease surviving after surgical treatment (Gershenson, 1993). The relatively recent introduction of combination chemotherapy, including bleomycin, etoposide, and cisplatin, into standard treatment protocols for ovarian germ cell cancer has significantly improved the outlook for those diagnosed with this disease (Williams, Blessing, Liao, Ball, & Hanjani, 1994). Overall cure rates for this cancer have improved to 75% or better in patients with metastatic cancer and 95% in patients with stage I disease (Gershenson, 1993, 1994; Gershenson et al., 1990; Mitchell et al., 1999).

Key Points . . .

- ▶ Although ovarian germ cell cancer is a very curable disease, girls and women who are diagnosed with this rare cancer still experience physical and psychological sequelae from the cancer itself or the treatment.
- ▶ Using qualitative methods to explore the experiences of women with ovarian germ cell cancer may help researchers and clinicians gain a deeper understanding of what patients experience when surviving this cancer, beyond the information that traditional quality-of-life measures can provide.
- ▶ Four themes are important to the quality of living of ovarian germ cell cancer survivors: celebrating illness, experiencing empathetic affirmation, mourning losses, and valuing illness.

Ovarian germ cell cancer usually is diagnosed in girls or young women, with the median age of 16–20 at diagnosis (Sagae & Kudo, 2000). The young age of women and girls diagnosed with this cancer, coupled with the high survival rates, presents an obligation to investigate the occurrence of possible long-term physical or psychological sequelae of the cancer itself or the mechanisms used to treat it. As noted by Williams, Gershenson, Champion, and Cella (2001), little research is available on long-term physical sequelae in women treated for ovarian germ cell cancer and subsequent quality of life (QOL) after treatment.

Survivors of this cancer may face site-specific or more generalized physical or psychological problems as a result of the

Melinda M. Swenson, RN, PhD, is an associate professor of nursing and Jessica S. MacLeod, RN, BSN, is a doctoral student, both in the School of Nursing at Indiana University in Indianapolis; Stephen D. Williams, MD, is director of the Indiana University Cancer Center; and Anna M. Miller, RN, DNS, is a research scientist and Victoria L. Champion, RN, DNS, is a professor and associate dean for research, both in the School of Nursing at Indiana University. This project was supported, in part, by the National Cancer Institute (R01 CA77470) and the Gynecologic Oncology Group. (Submitted November 2001. Accepted for publication January 15, 2003.)

Digital Object Identifier: 10.1188/03.ONF.E48-E54

treatment or the disease itself (Andersen, 1993, 1995; Cella, 1987; Gobel et al., 2000; Mitchell et al., 1999; Sagae & Kudo, 2000). Potential problems identified in the literature include fertility concerns, sexual function issues, neuropathy, secondary malignancy from chemotherapy, decreases in psychological well-being, and disruptions in social support (Lackner, Goldenberg, Arrizza, & Tjosvold, 1994; Mitchell et al.; Zeltzer, 1993).

The National Cancer Institute-funded study (Williams et al., 2001) is the first attempt to measure and understand QOL indicators and their predictors in ovarian germ cell cancer survivors. The researchers hypothesized that cancer diagnosis and treatment, sociodemographic characteristics, other life stressors, and social network variables would affect three components of QOL: sexual, physical, and psychological functioning. Quantitative measures and predictors of QOL are important in understanding how these specific variables may affect an ovarian germ cell cancer survivor at the time of the interview. However, in asking about specific variables that are meant to quantitatively measure a predetermined conception of QOL, researchers may obtain only a single point-in-time measure, as well as inadvertently miss crucial questions that may evoke rich data about the quality of living^a as an ovarian germ cell cancer survivor.

Anticipating this possibility, Williams et al. (2001) added four semistructured interview questions at the end of their quantitative measures. This design strategy intended to capture data not previously available, because these researchers were aware that the previous questionnaire items could influence the qualitative responses and were interested in asking these questions to strengthen the questionnaire data. These are the data considered in this present qualitative study. Taken along with the quantitative data generated by Williams et al. (2001), the qualitative inquiry and analysis may help to more fully capture important issues previously undefined. Specifically, the current analysis sought to answer two questions: (a) How do female survivors of this cancer describe their experiences? and (b) How do these responses help healthcare professionals understand the idea of “quality of living” as shared among women surviving ovarian germ cell cancer?

Background

In the present study, a preliminary literature review was undertaken to survey survivorship issues of cancer survivors. Specifically, gynecologic cancer survivors and survivors of ovarian cancer (not necessarily of germ cell histology) were targeted. This literature review was not exhaustive but rather was used to provide a context in which to compare and contrast findings and themes from a qualitative description of narrative data. Conventional quantitative research and clinical journal articles were included in this literature review, along with other writings (e.g., fiction, poetry, biographic and autobiographic works) that provided more narratively eloquent descriptions of chronic illness experiences.

Many of the research and clinical articles specifically addressed usual QOL categories, including sexual, physical, and

psychological functioning. For example, Auchincloss (1995) called for practitioners to be aware of infertility and sexuality issues that might arise in this population, such as decreased desire, pressure from a partner to resume sexual activity, and fearing or experiencing pain. Cella (1987) included infertility concerns and satisfaction with sex life as a measure of sexual adjustment and possible interpersonal disruption in cancer survivors. He proposed that the category of marital and sexual adjustment might be difficult to quantify: “It is possible that this reduced desire for intimacy is not adequately measured by a gross, subjective measure such as marital satisfaction” (p. 63). Therefore, qualitative, narrative data analysis may be better situated to uncover the sexual issues that cancer survivors, especially ovarian germ cell cancer survivors, may face in the years after their cancer treatment.

The articles reviewed also supported the Williams et al. (2001) QOL category of physical functioning as a pertinent issue in cancer survival. Cella (1987) included somatic distress as an example of how a cancer survivor may experience intrapersonal distress. Somatic distress includes physical concerns such as fatigue and lethargy, as well as anxiety about recurrences of cancer. Aging issues in cancer survivorship were explored by Auchincloss (1995), when she wrote of cancer survivors feeling old after cancer treatment, especially gynecologic cancer survivors who experienced treatment-related (and distressing) menopause symptoms during what normally would have been their childbearing years.

Psychological functioning as a QOL category in cancer survivors also is supported by the preliminary literature review. Some psychological indicators of intrapersonal distress in cancer survivors have been proposed, including mood, self-esteem, and cognitive dysfunction (Cella, 1987). Social support also has been cited as an important determinant of mental health (Lackner et al., 1994).

These articles provide support for quantitative measures used to gather information about QOL in ovarian germ cell cancer survivors. These readings, however, may provide a theory-limited and clinician-centered viewpoint of specific issues important in the QOL of cancer survivors. Qualitative research articles and other readings might provide broad, experiential descriptions of what is important in the quality of living as a cancer survivor and, specifically, as a woman surviving ovarian cancer. Some ideas from this literature echoed those found in more traditional research and clinical articles, whereas other experiences were more anecdotal about patients experiencing a chronic illness. These writings served to open the minds of the researchers to themes that may be constructed from narrative data but in no way limit the themes to those already found in existing literature.

Qualitative literature included Breaden’s (1997) hermeneutic phenomenology inquiry to interpret narrative data from six women surviving cancer. Breaden developed two main themes from the interview data: living in a body and living in time. Living in a body included the more specific themes of feeling whole from an experience of disembodiment to embodiment and the body as a house of suspicion. Feeling whole represented the idea that the women in this study spoke of feeling a separation of mind and body and that their bodies and selves sometimes were not united. The body as the house of suspicion mirrored Cella’s (1987) psychosocial issue of somatic distress wherein the women voiced continuing anxiety

^a The authors use the term “quality of living” to differentiate this qualitative, subjective view from the more standard quantitative concept of “quality of life.”

regarding the recurrence of cancer and a hypervigilance of somatic complaints.

Breaden's (1997) larger theme of living in time had four specific subthemes: (a) the future in question, (b) changes in time, (c) a feeling of being lucky to be alive, and (d) sharing the journey. "The future in question" represents a feeling that cancer somehow had disrupted ordinary, continuous time as people usually live in it and mark its passage. Auchincloss (1995) echoed this sentiment in the psychosocial category of aging issues in gynecologic cancer survivors. Auchincloss described women feeling "dislodged in time" because they were denied culturally important milestones, such as menstruation, pregnancy, and childbirth, as a result of cancer treatment and subsequent infertility or hysterectomy. The second subtheme included in living in time was "changes in time." This theme came from the women speaking of how cancer forced them to make changes in their lives, including positive changes that helped them to live better. A feeling of being "lucky to be alive" expresses the idea that some women felt well and lucky to survive after their cancer experience. These two preceding sentiments seem echoed in other cancer survivorship literature, where 95% of cancer survivors responded affirmatively when asked if anything positive came from their cancer experience (Wasserman, Thompson, Wilimas, & Fairclough, 1987). "Sharing the journey" is the last subtheme of living in time, and it represents the idea that the women often wanted to share their experiences of living with and surviving cancer with others, including family, friends, their god, and those in support groups.

A second phenomenologic study uncovered 12 fascinating themes from the narrative data of five women living with ovarian cancer during their childbearing years (Schaefer, Ladd, Lammers, & Echenberg, 1999). Important themes included the ideas of serendipitous diagnosis, managing treatment, the horrible hair experience, hysterectomy violating a sense of being, unfairness of menopause, body changes, intimate dreaming, being with others, being normal versus being different, being vigilant (about the body and its somatic sensations), being heard, and comprehending (the meaning of the experience). Schaefer et al. did not create any overarching patterns from the existing 12. Naming overarching patterns that encompass constitutive themes would have helped to create a shared meaning accessible to readers, practitioners, researchers, or others living with ovarian cancer beyond the limitations of the 12 specific categories.

Because of the inductive nature of the present study, the authors searched for references to lend support and credence to the findings as well as studies that might challenge the findings. The authors looked beyond the scientific and professional nursing literature for descriptions of the experience of surviving serious illness. Frank (1991), through his experiences as a medical sociologist and especially as a person living with chronic illness, provided insight and creative inspiration with his eloquent phrasing of such ideas as "illness as a dangerous opportunity," "mourning what is lost," "valuing illness," "listening to the ill," and "ceremonies of recovery." Kleinman (1988) also reminded health-care providers to listen to the stories of those with chronic illness and emphasized the idea of attentive, empathetic witnessing to whatever the person with a chronic illness wants to share.

Participants

An unusually large group of women surviving a rare cancer was available through the Gynecologic Oncology Group (GOG), a National Cancer Institute collaborative group. The 109 survivors included in this study were from 32 different GOG sites and the University of Texas M.D. Anderson Cancer Center and are part of a larger survivorship study of 135 survivors from 42 sites. Ovarian germ cell cancer survivors were eligible for this qualitative analysis if they had completed both the background questionnaire and telephone interview for the larger GOG survivorship study. Women were eligible to participate in the larger survivorship study if they had been enrolled in clinical trials of cisplatin-based chemotherapy after surgery and were disease-free for at least two years.

Data Collection

Respondents in the study were contacted by their treatment sites and returned written informed consents indicating willingness to participate in a telephone interview. Two women interviewers (social work graduate students with survey experience and didactic training) conducted the telephone survey. The interviewers asked questions from a wide variety of measurement instruments (including seven different QOL scales), and each interview lasted nearly an hour.

At the end of this long telephone call, the interviewers asked four semistructured questions: (a) What would have been most helpful for you during the diagnostic and treatment period? (b) What would be helpful for you now as a cancer survivor? (c) What, if anything, is the most significant challenge or problem for you now related to having had cancer? and (d) What else would you like to tell me about your cancer experience? These questions were aimed at capturing a broader view of the experience of surviving. The interviewers recorded the women's responses in writing (transcribed directly on a laptop computer). The interviewers validated those responses verbally with the participants to ensure accuracy. The entire study, including the four questions, was approved by the institutional review boards of all the institutions involved.

Data Analysis

The authors reviewed the methodologic literature to develop ways of study applicable to analyzing these existing end-of-interview data. Because the authors did not design the questions and were not involved in the interviews themselves, their connection with the questions and answers was loose. The authors received the data after it was collected, and their task was analyzing the semistructured interview questions only. The four questions designed by the researchers involved in the larger study were reviewed by one of the authors after the first 25 interviews, and revisions were suggested to make the questions more open-ended. The narratives existed as relatively short responses to the four questions. The format had three limitations: (a) questions were asked at the end of a long and potentially tiring survey, (b) respondents' answers were possibly influenced by the previous questions, and (c) questions were not completely designed by the authors. Given this situation, qualitative description (Sandelowski, 2000) seemed to provide the method most consistent with the nature of the

data. Sandelowski used the phrase qualitative description to characterize designs aimed at obtaining minimally interpreted answers to real-world research questions. Such studies are less theoretic and philosophic and more naturalistic than grounded theory, phenomenology, or hermeneutic designs. The authors were seeking a comprehensive summary of the responses offered by the participants, using their own words, and the summary did not intend to arise from a philosophic substrate. The authors adhered to a constructivist paradigm in which they determined to make sense of the experiences of the participants. Guba and Lincoln (1989) noted that these constructions may be limited by “the range or scope of information available to a constructor” (p. 71). Although shared meanings and themes were developed from the narrative data, the nature of the questions asked may not have evoked the richest data possible.

In addition to Sandelowski’s (2000) method, the current study used modified naturalistic inquiry techniques (Lincoln & Guba, 1985). The specific steps used were as follows.

1. The text of each interview was read carefully and assigned content labels to identify meaning units, sections of text that are aimed at understanding and can be interpreted in the absence of additional information (Lincoln & Guba, 1985). Meaning units were phrases, sentences, and entire narratives. Labels were focused on content at this early level, rather than attempting early interpretation.
2. Both researchers read all transcripts and coded each independently; then, they met to discuss and reach consensus about code labels.
3. Throughout this reiterative process, the labeled groups were collapsed into subthemes. Reading, writing, thinking, dialogue (Ironsides, 1997), and reflection continued during this constant comparison phase of the qualitative analysis.
4. The researchers developed four larger themes representing constructions regarding the shared meanings from the narrative responses. These four themes comprised the findings of this analysis.

Quality Criteria

Descriptive validity was addressed by having the interviewers recheck their transcripts to ensure accuracy. Because the surveys already were completed when the authors received the data, the authors had no personal access to the respondents and could not check for accuracy. Member checking (i.e., taking the analysis back to the original participants for their agreement about accuracy, discussed by Lincoln and Guba [1985]) was not stipulated in the original institutional review board approval, so this strategy could not be used to validate the conclusions. This absence is a limitation of the design of the study.

Findings and Discussion

Table 1 describes the 109 participants. Four major themes emerged from the narrative data built on nine subthemes (see Figure 1). The themes of celebrating illness, mourning losses, and valuing illness were inspired by Frank’s (1991) narrative of personal experience with chronic illness. The idea of empathetic affirmation was influenced by the writings of Kleinman (1988). The writings of Frank and Kleinman seemed to capture the meanings constructed from subjects’ comments.

The four themes do not constitute a linear or organized process. They varied in their occurrence in the women’s lives and

Table 1. Demographic Characteristics

Characteristic	n	%
Age at interview (years)		
\bar{X} = 35.4	–	–
Median = 35.9	–	–
Range = 19.4–63.6	–	–
Age at diagnosis (years)		
\bar{X} = 26.1	–	–
Median = 24.6	–	–
Range = 10.8–47.9	–	–
Years since diagnosis		
\bar{X} = 9.9	–	–
Median = 9.7	–	–
Range = 2.7–18.6	–	–
Race^a		
Caucasian	88	81
African American	11	10
Other	10	9
Education		
≤ High school	27	25
Some college	31	28
College graduate	33	30
> College degree	18	17
Marital status		
Married or in committed relationship	62	57
Not currently married	47	43

N = 109

^a13 survivors (12%) also indicated having a Hispanic or Latino background

followed no set time pattern. In fact, some women seemed to experience all of the described feelings and ideas simultaneously. For example, when asked what would be helpful to them now, some women talked about what they found helpful now and then freely moved into what was helpful in the past, or what was difficult for them now or in the past. The four themes seem to represent free-flowing experiences that occurred as past or present difficulties or triumphs living as an ovarian germ cell cancer survivor.

Celebrating Illness

According to Frank (1991), to celebrate an illness is to mark its significance or importance. The idea of celebration is one of consciously recognizing an event that never should be forgotten. A celebration is a way to take time to evaluate the meaning that the event holds. This choice is not meant to indicate that the women were happy about being diagnosed and

Celebrating illness

Tangible sources of support (family, spouse, children, friends, church)

Receiving empathetic affirmation

- Being with or staying with
- Being isolated and feeling alone
- Needing to talk or understand what is happening
- Needing to be heard and understood

Mourning losses

- Focusing on the physical
- Emotional difficulties, depression, losing memory
- Feeling uncertain and insecure

Valuing illness

- Being positive or feeling good about oneself, finding good in a bad situation

Figure 1. Themes and Subthemes

living with ovarian germ cell cancer. People celebrate in many ways, and often the topic of celebration or commemoration is difficult or filled with grief.

Some women in this study spoke of having—or not having—their experiences as ovarian germ cell cancer survivors celebrated and recognized. One woman said that she would have liked “to have my family acknowledge the ongoing process of dealing with cancer and the ongoing process of healing and to be willing to talk about it more.” Another woman indicated that the most significant challenge of having ovarian germ cell cancer was “carrying the burden of the experience without family support and never having my family celebrate my survival.” These women wanted their experiences with ovarian germ cell cancer acknowledged and marked as significant by their families and friends. In that sense, they wanted important people in their lives to “celebrate” their illness.

Many women in the study told the interviewers that they found that receiving cards from family, friends, and acquaintances was helpful and supportive. One woman said, “I received many cards from people who I thought were just acquaintances.” When asked what was helpful during her treatment, a young adolescent said, “I received a lot of presents!” Many women spoke of the importance of receiving cards, which was intriguing because on the surface this seems like such a small gesture in light of being diagnosed and treated for cancer. The significance of the act of sending a card, however, becomes clear when placed in the larger context of the women wanting others to be aware of and commemorate their illness.

Receiving Empathetic Affirmation

Empathetic affirmation is a focused and attentive way to truly listen to and acknowledge the suffering of the person experiencing illness. Empathetic affirmation is a profound way of being with a person who is ill but does not necessarily require any active or physical assistance. To engage in empathetic affirmation, a person does not have to “do” anything for the sufferer. Rather, this type of affirmation involves simply trying to hear and recognize, to the best of the listener’s ability, the experiences of the person who is ill. Frank (1991) wrote, “The power of recognition to reduce suffering cannot be explained, but it seems fundamental to our humanity” (p. 104).

Frank (1991) noted that the opposite of empathetic affirmation is denial—denial of the experience of having cancer, of the difficulties of treatment, of suffering, and of being special and different from what they used to be can be extremely detrimental to the mental well-being of people who are ill. Denial is a way in which cancer survivors and others with chronic illness are made to feel that their illness experiences are insignificant and unimportant. According to Frank, the ultimate expression of denial is when friends and family avoid the people with cancer, seemingly forgetting their very existence.

Women in this study spoke of family and friends who used empathetic affirmation to recognize their illness experiences. For example, one woman said, “My family and friends were there for me. It’s not so much anything specific they said, just that they were physically and emotionally available to me.” Another woman said, “People didn’t judge me—if I wanted to scream, they let me scream; if I wanted to laugh, they let me laugh.” Yet another woman said, “They let me be free; free to be angry, outspoken, and to throw fits. People listened and were there with me.” These quotes provide testimony to the

idea that empathetic affirmation is crucial to women who are surviving ovarian germ cell cancer.

About half of the women studied spoke of wanting to talk to others with similar experiences with ovarian germ cell cancer. Their need for this type of support did not seem to diminish over time. Some women wanted to talk to other women with ovarian germ cell cancer at the time of diagnosis and treatment, whereas others wished for a support group to talk about present survivorship issues. Women who had survived ovarian germ cell cancer for more than two years even spoke of wanting to start a support group or be a resource for newly diagnosed patients. Narratives about support groups included statements such as, “It would have been helpful to have contact with and support from other cancer survivors to help me see others who had made it through the treatment process.” Another woman said that she wanted “group support specifically for ovarian germ cell cancer.”

About a third of women in the study also noted, with disappointment, that family and friends failed to understand (or failed to want to understand) the importance of surviving cancer. As an example, when asked what would have been helpful to her at the time of diagnosis and treatment, one woman said,

For others to have given me the opportunity to honestly talk about my feelings, instead of letting me keep a strong face for everyone else, and to have others validate my feelings—that it’s okay not to be okay. I felt people were trying to be supportive but didn’t really want to hear my pain and emotions.

Another woman said that she would have liked “to have people listen to what I went through in a serious manner, without joking about it.” These narratives describe how denying the severity of the illness serves to undermine support for the one surviving ovarian germ cell cancer. The latter quotation also illustrates the continuing need for empathetic affirmation of women’s stories well after the diagnosis and successful treatment for ovarian germ cell cancer.

Mourning Losses

Mourning losses represents grieving all of the physical, emotional, and social changes that occurred after being diagnosed, treated, and surviving ovarian germ cell cancer. Mourning meant saying good-bye to the person that these women were before this major life event. Nearly half of the women spoke of disliking physical body changes, such as weight gain or thinner hair, that occurred during and after chemotherapy treatment. “I feel vain for saying this, but losing my hair was probably the hardest thing about the whole experience.” Another woman said, “I don’t like my hair anymore. It grew back differently . . . it was beautiful before I had cancer and I took a lot of pride and care of it.” One woman told the interviewer, “I feel like I don’t look the same physically. I don’t feel pretty anymore. I experienced weight gain after the cancer, and I can’t lose the weight. I’m depressed with my physical appearance.”

More than half of the respondents felt that they experienced changes in their emotional states, feeling more sad and depressed and having problems with memory and concentration. One woman mourned that she had difficulty “dealing with my body feeling in its sixties and my mind in its forties; it makes me feel insane.” Another woman said, “[It was tough] dealing with concentration and memory difficulties and just not feeling as mentally sharp as I did before I was sick.” Frank’s

(1991) illness experiences as a cancer survivor reflect similar emotions: “Surgery and chemotherapy would irrevocably break my body’s continuity with its past. My history had its share of regrets, but I mourned its passing. After surgery and chemotherapy rearranged me, I would live differently” (p. 38).

Some women mourned the social changes that their illness experience brought to their lives. About a quarter of the women spoke of experiencing decreased sexual interest and desire and talked about the impact this change had on their intimate relationships with spouses or partners. One woman said, “I am afraid to tell a man that I had cancer, especially a man that I would want to be intimate with.”

In addition to the physical, emotional, and social changes brought by surviving ovarian germ cell cancer, mourning what is lost also meant letting go of all the things that the women previously had believed, however presumptuously, were certainties in their lives. Shattering the illusion of presumed certainties, such as marriage, children, and good health, was very difficult for most of the respondents. One woman said, “It’s hard to put the experience behind me. It’s always on my mind, and I’m always dealing with fears and issues related to possible recurrence. I think, what would I do if I got sick again?” Another woman mourned, “The only problem is not having a child. Having children is very important. It’s hard to really believe that I can’t have children.”

Valuing Illness

Valuing illness is the ability to make sense of the illness experience and discover what meaning it holds for a person’s life. The idea of valuing illness is tied intimately to the idea of mourning losses. Although most of the women spoke of mourning the loss of things that were important to them, they also added that through their losses, they became open and available to finding other valuable sources of meaning and contentment. Their illness experiences and initial losses enabled them to discover personal beliefs that came to have critical importance in their lives. Valuing illness does not mean that these women were pleased with being diagnosed with ovarian germ cell cancer. Rather, valuing illness means that the women were able to take their illness experiences and fit their unique meaning into a cohesive pattern of being that helped the women know more clearly who they are and what is important to them. A majority of the women provided narratives that represent the idea of valuing illness. One participant revealed,

It was horrible, but I found—and was reminded while doing this survey—that once I healed emotionally and physically, I now look at life differently. I value and enjoy each moment, tell people how I feel more often, feel a heightened sense of beauty in my life, my relationships, and my religion.

Another woman said,

I have gotten good things out of it, including an increased appreciation for life, the importance of family and friends. I have become more forgiving and understanding. Counseling has helped me to see the good side of the experience and focus on my quality of life and to connect with and relate to other survivors in a positive way.

Still another respondent said, “It made me look at life in a different way, to take nothing for granted and to take better care of myself and others around me.” Lastly, a woman (who ex-

pressed an idea common to many) said, “I am a lot smarter now when it comes to how to be with my kids. I give them more attention and don’t take them for granted.” These women valued their illness for helping them gain a new perspective about living and reminding them about what aspects of living provide them with the deepest meaning.

Surprisingly, the data included few statements about the actual logistics of cancer treatment or how the women perceived that their healthcare providers could make this experience better for them. The study found nothing about experiencing acute treatment side effects (e.g., pain, fatigue, nausea) during the diagnosis, treatment, or survival phases of ovarian germ cell cancer as might be expected in women currently undergoing therapy. Also, no statements were given about death or fear of dying. Possibly, the women did not view the cancer treatment itself negatively, but rather accepted it as a necessary step in their probable full recovery. Another explanation is that the questions asked did not address these specific issues.

Implications for Practice

Lived experiences are as unique as the people that live them; consequently, the constructions of shared meanings are in no way meant to be a complete description of what is important to all ovarian germ cell cancer survivors or to other cancer survivors. Researchers and clinicians must be aware of their own expectations and always listen mindfully for unexpected concerns, feelings, and meanings in the lives of their research participants or clients.

Clinicians of all types who encounter women surviving ovarian germ cell cancer may be able to use this inquiry in caring for these patients. Because of the subjective nature of qualitative description, these findings cannot be generalized to other patients and settings. However, the findings still are useful; in qualitative research, usefulness is enabled by a thorough discussion and vivid description of the participants, the setting, and the conditions of the study. Readers then can decide whether the findings are transferable and applicable for other patients in other settings. These themes simply may serve as a call for clinicians to be aware that their presumptions may not coincide with what is significant and meaningful in the lives of patients.

Specifically, practitioners should engage in assessment of the women’s needs for empathetic affirmation with survivors of ovarian germ cell cancer or other forms of cancer. Through focused, unhurried, and attentive listening, practitioners may be able to learn about previously unrecognized needs and fears. Empathetic affirmation does not require high technology nor is it complicated, but it certainly requires mindfulness from practitioners. By actively attending to women and assessing their needs to address losses and value surviving the loss, clinicians may learn that the women wish people would celebrate their illnesses and mark its significance. This assessment may prompt a suggestion to families or the women themselves to set aside a day for family and friends to honor the women’s experiences and survival. An awareness of a need to celebrate the illness may result in something as simple as sending a greeting card from the practitioner and staff. This sincere gesture meant a great deal to many women surviving ovarian germ cell cancer.

Future Research

The limitations of the methodology of the present study indicate directions for further research into the quality of living

as an ovarian germ cell cancer survivor. Asking four semi-structured questions at the end of a lengthy telephone interview may have limited the data collection because of fatigue or pattern influence (response set) on their responses. Future phenomenologic research that separates the qualitative data collection from the rest of the interview and places the unstructured questions before the quantitative measures in the design is planned. Future research questions will be even more open-ended, starting with an invitation to “tell me a story about your life as a woman surviving ovarian germ cell cancer.” This approach to research may help to generate richer narratives that lead to deeper and more meaningful interpretation of the quality of living for women surviving ovarian germ cell cancer.

Future quantitative studies could consider evaluating the effectiveness of the interventions suggested in the themes (e.g., clinicians could explore and evaluate ways to help women and their significant others recognize and celebrate the cancer experience). The idea of empathetic affirmation suggests that ovarian germ cell cancer survivors should have access to support groups made up of other women with this same disease. Because ovarian germ cell cancer is so rare, a woman’s geographic area may not contain any other survivors. The Internet, such as an interactive Web site, could bring women with this cancer together to hear each other’s stories and affirm one another’s experiences. A study of the effect of


an Internet support group could be a model for other virtual support efforts. Research could be designed to explore the social processes used by these women as they seek meaning and value in their cancer experience. Finally, tangible ways of showing that clinicians hear and value the unique experience of each woman surviving cancer could be proposed and assessed in an effort to improve follow-up care.

Conclusions

The shared meanings constructed from the narrative data provide a fuller understanding of what aspects of surviving were critically important in the lives of these 109 women surviving ovarian germ cell cancer. Celebrating illness, empathetic affirmation, mourning losses, and valuing illness are ways in which the women found comfort and meaning in their lives. This analysis may lend experiential support to known difficulties or reveal unexplored issues important to the quality of living of women surviving ovarian germ cell cancer. These understandings can help clinicians, students, and families to better assess and meet the needs of women who survive cancer and thrive.

Author Contact: Melinda M. Swenson, RN, PhD, can be reached at mswenson@iupui.edu, with copy to editor at rose_mary@earthlink.net.

References

- Andersen, B.L. (1993). Predicting sexual and psychologic morbidity and improving the quality of life for women with gynecologic cancer. *Cancer, 71*(Suppl. 4), 1678–1690.
- Andersen, B.L. (1995). Quality of life for women with gynecologic cancer. *Current Opinion in Obstetrics and Gynecology, 7*, 69–76.
- Auchincloss, S.S. (1995). After treatment: Psychosocial issues in gynecologic cancer survivorship. *Cancer, 76*(Suppl. 10), 2117–2124.
- Breaden, K. (1997). Cancer and beyond: The question of survivorship. *Journal of Advanced Nursing, 26*, 978–984.
- Cella, D.F. (1987). Cancer survival: Psychosocial and public issues. *Cancer Investigation, 5*, 59–67.
- Frank, A.W. (1991). *At the will of the body: Reflections on illness*. Boston: Houghton Mifflin.
- Gershenson, D.M. (1993). Update on malignant ovarian germ cell tumors. *Cancer, 71*(Suppl. 4), 1581–1590.
- Gershenson, D.M. (1994). Management of early ovarian cancer: Germ cell and sex-cord-stromal tumors. *Gynecologic Oncology, 55*(3 Pt. 2), S62–S72.
- Gershenson, D.M., Morris, M., Cangir, A., Kavanagh, J.J., Stringer, C.A., Edwards, C.L., et al. (1990). Treatment of malignant germ cell tumors of the ovary with bleomycin, etoposide, and cisplatin. *Journal of Clinical Oncology, 8*, 715–720.
- Gobel, U., Schneider, D.T., Calaminus, G., Haas, R.J., Schmidt, P., & Harms, D. (2000). Germ-cell tumors in childhood and adolescence. GPOH MAKEI and the MAHO study groups. *Annals of Oncology, 11*, 263–271.
- Guba, E.G., & Lincoln, Y.S. (1989). *Fourth generation evaluation*. Newbury Park, CA: Sage.
- Ironside, P.M. (1997). Preserving reading, writing, thinking, and dialogue: Re-thinking doctoral education in nursing. *Academic Medicine, 75*, 245–251.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.
- Lackner, S., Goldenberg, S., Arrizza, G., & Tjosvold, I. (1994). The contingency of social support. *Qualitative Health Research, 4*, 224–243.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Mitchell, P.L., Al-Nasiri, N., A’Hern, R., Fisher, C., Horwich, A., Pinkerton, C.R., et al. (1999). Treatment of nondysgerminomatous ovarian germ cell tumors: An analysis of 69 cases. *Cancer, 85*, 2232–2244.
- Sagae, S., & Kudo, R. (2000). Surgery for germ cell tumors. *Seminars in Surgical Oncology, 19*, 76–81.
- Sandelowski, M. (2000). Focus on research methods. Whatever happened to qualitative description? *Research in Nursing and Health, 23*, 334–340.
- Schaefer, K.M., Ladd, E.C., Lammers, S.E., & Echenberg, R.J. (1999). In your skin, you are different: Women living with ovarian cancer during childbearing years. *Qualitative Health Research, 9*, 227–242.
- Wasserman, A.L., Thompson, E.I., Wilimas, J.A., & Fairclough, D.L. (1987). The psychological status of survivors of childhood/adolescent Hodgkin’s disease. *American Journal of Diseases of Children, 141*, 626–631.
- Williams, S., Blessing, J.A., Liao, S., Ball, H., & Hanjani, P. (1994). Adjuvant therapy of ovarian germ cell tumors with cisplatin, etoposide, and bleomycin: A trial of the Gynecologic Oncology Group. *Journal of Clinical Oncology, 12*, 701–706.
- Williams, S.D., Gershenson, D.M., Champion, V.L., & Cella, D.F. (2001). [Quality of life for ovarian germ cell cancer survivors]. Unpublished raw data.
- Zeltzer, L.K. (1993). Cancer in adolescents and young adults: Psychosocial aspects. Long-term survivors. *Cancer, 71*(Suppl. 10), 3463–3468. 

For more information . . .

- ▶ International Society for Quality of Life Research
www.isoqol.org
- ▶ Association of Cancer Online Resources: Ovarian Germ Cell Tumor
www.acor.org/types/info.html?pnun=03125
- ▶ National Cancer Institute: Ovarian Cancer Home Page
www.cancer.gov/cancerinfo/types/ovarian

Links can be found using ONS Online at www.ons.org.