Meaning of Illness and Spirituality in Ovarian Cancer Survivors

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Purpose/Objectives: To describe spirituality and meaning of illness in survivors of ovarian cancer.

Design: Ethnographic study based on seven years of natural correspondence among survivors of ovarian cancer and a support newsletter.


Methods: Analysis was based on the Quality of Life (QOL) Ovarian Cancer Instrument: Data were bracketed and assigned within a table according to QOL themes.

Main Research Variables: Spirituality, meaning, QOL, and cancer survivorship.

Findings: Spirituality was relied on heavily as a coping mechanism, as well as a method of deriving meaning from the cancer experience. Data from survivors of ovarian cancer validated previously established meaning in cancer themes and identified eight new themes specific to meaning in ovarian cancer survivorship.

Conclusions: The nature of ovarian cancer implicates specific characteristics that alter the meaning of QOL and survivorship. Spirituality is an important component of QOL and contributes to the process of deriving meaning from the ovarian cancer experience.

Implications for Nursing: Knowledge of the unique survivorship issues of patients with ovarian cancer can enable nurses to improve their care for these women.

Key Points . . .

➤ Spirituality is relied on heavily as a coping mechanism, as well as a method of deriving meaning from the ovarian cancer experience.

➤ A diagnosis of ovarian cancer is characterized by specific factors that alter the meaning of quality of life and cancer survivorship.

➤ Nurses must be aware of the unique survivorship issues that women with ovarian cancer face, in addition to general survivorship concerns.

An ovarian cancer diagnosis will bring distinct fears, changes, and uncertainties for the 23,400 women predicted to be diagnosed in annually. As the deadliest of the gynecologic cancers, ovarian cancer claims the lives of almost 14,000 women each year (Jemal, Thomas, Murray, & Thun, 2002). Characterized by subtle symptoms, ovarian cancer commonly is diagnosed in the late stages of disease, when the five-year survival rate is only 35%. Although early-stage diagnosis has a five-year survival rate of more than 90%, no reliable screening methods are available to promote early detection (Trimble, 1994). As the number of more effective treatments has increased, so has the number of women who survive the disease without recurrence for two years or longer. Survivors who recover from the onslaught of this aggressive disease can begin to decipher meaning from their experience with cancer.

The concept of meaning has been a focus in oncology literature for the past decade, as nurses have come to understand the life-altering experience of cancer (Brown-Saltzman, 1994; Coward, 1990). The process of deriving meaning from the cancer journey includes elements of evaluating relationships, beliefs about life and death, spirituality, and exploring the significance of life events (Ferrell & Dean, 1995). The search for meaning has been described as an effort to understand events, why they have happened, and their impact on an individual’s life. Patients with cancer struggle with questions of “Why me?” including perspectives on what caused cancer to occur and what the purpose for the experience could be (Coward, 1997).

Spirituality has been described as an aspect of quality of life (QOL) for patients with cancer that encompasses not only religiosity but other dimensions such as hopefulness, transcendence, and purpose (Burton, 1998; Ferrell, 1996). Spirituality is linked to life meaning, and previous literature has described the importance of spirituality as a component of deriving meaning from cancer. Finding meaning in cancer through spirituality and other aspects of life helps patients and their families to cope and maintain a sense of hopefulness (Taylor, 1998).

The process of deriving meaning in illness also has been described as assisting individuals with recognizing positive outcomes from negative experiences, such as seeing the positive changes in life that may result from a cancer diagnosis (Ferrans, 1994; Ferrell, Taylor, Sattler, Fowler, & Cheyney, 1993). A goal of oncology nursing is to promote patients’ search for meaning as a means of restoring integrity to lives and a sense of equilibrium despite the disruption of life-threatening illness (O’Connor, 1998). This article reports on research...
related to spirituality and the search for meaning in the experience of ovarian cancer. This work analyzes more than 21,000 pieces of correspondence from survivors of ovarian cancer who wrote to Conversations!: The international newsletter for those fighting ovarian cancer.

Literature Review

Borneman and Brown-Saltzman (2001) reviewed meaning in illness and described important processes of finding meaning in terminal illness. They identified themes common in clinical practice and research, including “an imposed transition,” which is described as having prison doors slammed shut when hearing the diagnosis of terminal illness. Other dimensions described by these authors include loss and confusion, “the dark night of the soul,” and randomness in the absence of God and life. These authors also described the meaning of cancer as including a sense of brokenness and life reappraisal, among many other themes.

The nursing literature contains descriptions of the meaning of QOL in cancer survivorship, which often has included the dimension of spirituality (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997; Kemp, 2001). Although recent studies have focused on meaning in cancer or spiritual well-being as an aspect of QOL, no previous studies specific to ovarian cancer could be identified. In fact, ovarian cancer often is underaddressed, likely because of its lower incidence as a cancer diagnosis and because greater attention has been given in recent years to other primary cancers. For example, in one of the larger recent studies of QOL in survivors of cancer conducted by the National Coalition of Cancer Survivors, only 8% of the 687 survivors responding had ovarian cancer (Dow, Ferrell, Haberman, & Eaton, 1999).

Ovarian cancer has many unique characteristics that likely affect the meaning derived from this type of cancer diagnosis (Houck, Avis, Gallant, Fuller, & Goodman, 1999). Women describe ovarian cancer as a “minority” cancer because it frequently is overshadowed by the focus on breast cancer. The ovarian cancer experience also is one with tremendous uncertainty, stemming from a typically poor prognosis (Basen-Engquist, 1997; Bodurka-Bevers et al., 2000; Ersek, Ferrell, Dow, & Melancon, 1997). As the genetic association of ovarian cancer increases, so do women’s concerns about passing this genetic predisposition to daughters. This clearly affects the meaning of the illness for survivors (Franco et al., 2000; Fry, Busby-Earle, Rush, & Cull, 2001; Hughes et al., 2002).

Nurse researchers have contributed significantly to the understanding of spirituality and meaning in cancer. Nurses have explored aspects of meaning such as self-transcendence, cultural influences, and suffering (Coward, 1997; Ferrans, 1994; O’Connor, 1998; Taylor, 1998). This study contributes to existing knowledge of meaning in cancer by exploring spirituality and meaning in ovarian cancer. The voices of thousands of women living with this disease inform nurses of the care required to support patients and families through ovarian cancer.

Background

The data reported within this paper are derived from correspondence sent to Conversations!. The editor, Cindy Melancon, began the newsletter in 1993 shortly after her own diagnosis of ovarian cancer. While searching for information and support, she was unable to find anyone or anything specific to ovarian cancer survival. Feeling a strong need to connect with other women sharing her diagnosis, she initiated the newsletter as a means of providing information, support, and camaraderie for women and families fighting ovarian cancer.

The first issue of Conversations! was mailed in October 1993. Nine years and 114 issues later, the newsletter is distributed to 3,600 people in all 50 of the United States and 30 other countries. The actual outreach of the newsletter likely is larger in scope because individuals are encouraged to duplicate the newsletter and distribute it to all who would find it helpful. The newsletter project now has become a 501(c)(3) not-for-profit corporation that is eligible for donations and has a Web site (www.ovarian-news.org).

As the editor, Melancon encourages communication from readers about topics for upcoming issues and, thus, received a significant volume of correspondence from 1994–2000. Her connections with the investigators of City of Hope National Medical Center in Duarte, CA, began in 1994, when, after reading their research related to QOL issues in breast cancer, she contacted Betty Ferrell, PhD, a nurse researcher, and suggested that similar research be done with survivors of ovarian cancer. The readers of Conversations! completed a survey, and the results subsequently were published in the Western Journal of Nursing Research (Ersek et al., 1997). The study revealed priority QOL concerns unique to survivors of ovarian cancer.

In 2001, Melancon again contacted Ferrell to suggest that the correspondence from the newsletter perhaps be analyzed to more broadly share the experiences of Conversations! readers with others. The archived correspondence was sent to the City of Hope investigators. A total of 21,806 letters, cards, and e-mails were received, reflecting seven years of “conversations” between Melancon and her readers.

Methods

The data consisted of all correspondence from survivors of ovarian cancer from 1994–2000. The letters were sent in a variety of formats, primarily personal stationery, greeting cards, and, particularly in recent years, e-mail. The correspondence between members of a newsletter mailing list functions to a degree as a support group and was a unique source of data. Methods of content analysis were used to derive themes from this data (Krippendorff, 1980; Leininger, 1985).

This study was approved by the City of Hope National Medical Center Institutional Review Board. The steps of the content analysis were as follows.

1. All of the original data were numbered to provide identification; data then were duplicated and the copies organized in numerical order for further analysis and to protect the integrity of the original documents.

2. The data were read by one of two research assistants to bracket significant responses that could be useful for written analysis. All identifying factors, including patients’ and family members’ names, physicians’ names, and treatment centers, were changed to preserve confidentiality.

3. The data were analyzed using content analysis techniques in which themes from the data were identified in margins (Krippendorff, 1980).

4. After all of the data were bracketed and initial content codes were assigned, the investigators used a “cut and...
paste” approach to place the comments into tables organized according to the individual items within the four QOL domains of the QOL Ovarian Cancer Instrument (Ersek et al., 1997). Use of the QOL model for this qualitative analysis was considered appropriate given the extensive use of the model in cancer survivorship studies. The investigators avoided forcing data into categories and discussed any discrepancies to decide how best to code.

5. The research team met on a weekly basis for a year to review the process and analysis. All aspects of the bracketing, coding, and cutting and pasting were validated by the principal investigator and a master’s-prepared research specialist with extensive experience in qualitative data.

6. Several revisions of the final analysis tables were prepared and reviewed by the research team. Seven external nursing consultants with extensive backgrounds in ovarian cancer and a surgical oncologist also reviewed the final tables.

Results

This article is limited to the results of the data analysis related to spiritual well-being and meaning in illness. Results related to the QOL dimensions of physical, psychological, and social well-being are reported separately. Although analysis was primarily qualitative, Table 1 illustrates a quantitative breakdown of the comments to demonstrate the frequency with which they occurred.

Spirituality

Major findings within the spiritual well-being domain of QOL validated previous studies. Participation in religious activities through churches and prayer groups was a primary source of support for women (see Figure 1). Many women expressed their belief that God was in control of their disease and that only God could control their fate. Many expressed spiritual changes resulting from their experiences with ovarian cancer (see Figure 2). Although many of these changes were described as positive, a number of women communicated negative spiritual experiences evoked by ovarian cancer. These negative experiences included loss of faith, uncertainty, and hopelessness. Other spiritual themes (see Figure 3) expressed included a newfound purpose in survivorship, enduring hopefulness, and awareness of mortality. The spiritual growth that occurred in

Table 1. Comments Related to Quality-of-Life Domains and Themes Specific to Spiritual Well-Being

<table>
<thead>
<tr>
<th>Quality-of-Life Domain</th>
<th>n</th>
<th>%</th>
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<tbody>
<tr>
<td>Physical well-being</td>
<td>677</td>
<td>19</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>1,352</td>
<td>39</td>
</tr>
<tr>
<td>Social well-being</td>
<td>776</td>
<td>22</td>
</tr>
<tr>
<td>Spiritual well-being</td>
<td>687</td>
<td>20</td>
</tr>
<tr>
<td>Religious practices and experiences</td>
<td>316</td>
<td>–</td>
</tr>
<tr>
<td>Spiritual activities and experiences</td>
<td>26</td>
<td>–</td>
</tr>
<tr>
<td>Changes in religion and spirituality: positive</td>
<td>64</td>
<td>–</td>
</tr>
<tr>
<td>Changes in religion and spirituality: negative</td>
<td>124</td>
<td>–</td>
</tr>
<tr>
<td>Other spiritual themes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose in survivorship</td>
<td>76</td>
<td>–</td>
</tr>
<tr>
<td>Hopefulness</td>
<td>40</td>
<td>–</td>
</tr>
<tr>
<td>Awareness of mortality</td>
<td>41</td>
<td>–</td>
</tr>
</tbody>
</table>

N = 3,492

Religious Practices and Experiences

As Christmas approached, my husband and I talked about what I wanted for Christmas. I felt I wanted something that would remind me each day of all my blessings and give me strength to make it through the next six months. We came up with the idea of a blessing bracelet with four charms: a cross to remind me of my faith and that God was walking with me, a heart to remind me of my love for God and my family and friends and their love for me, an angel to remind me that I had a guardian angel and that I was never alone, and a dove to remind me that peace would be mine if I would remember what the other symbols meant.

Spiritual Activities and Experiences

I was in emergency surgery for my colon that had exploded and was poisoning my entire body. As I lay near death on the table in surgery, I saw an angel standing in the corner of the surgical suite but thought at first it was myself. I felt a rising up from the table but never saw myself being worked on, just heard people talk and say we are losing her, work harder. The fluttering of the being in the corner just barely hovering above the floor in the corner seemed to convey to me it would be okay, and I had to remain here for longer. I did not see light or family but sensed it was someone I loved. My grandmother and mother and others. I woke up 14 days later and in a couple more weeks came home, and nothing was said nor did I remember until my husband told the visiting nurse that I had actually died on the table and they brought me back. Then the picture came to mind. Such peacefulness.

I should perhaps tell you that I do not have any religious belief myself but have the greatest respect for those who do. I do believe in good and evil and that you only get things given in your life that somewhere inside you can find courage and determination to deal with. People tell me I’m brave. I’m not at all, just determined.

Follow inner guidance. The western medical folks are good at surgery. But other treatments are harsh and based on statistics. No one is a statistic. Everybody and every life is individual. It is the inner guidance that is essential for tailoring actions to what each person needs and what the soul desires.

I meditated; joined a cancer group; talked to other women battling cancer all over the country and globe; prayed; forgave and asked forgiveness from all those I’d wronged either real or imagined; stayed pretty connected to my family and close and good friends; avoided or limited contact with negative souls and thoughts; visualized a healing taking place; listened to inspirational tapes, emotionally satisfying music; sought out beauty everywhere; gave thanks for all my blessings; and acknowledged knowing that I was healed through faith even before it was medically confirmed when my gynecologic oncologist/surgeon could not find any cancer during my “second look” surgery. Today, I still give thanks daily for my healing both spiritually and physically. I stay in contact with those near and dear to me. I work out of my home with its soothing, healing, breathtaking view of the Pacific Ocean to remind me that we all are spiritual beings who have chosen a physical experience here and now, and “in this moment” I am well and I am happy.
these survivors was reported as the foundation for optimism, improved relationships, and personal strength.

**Meaning in Cancer Survivorship**

**General cancer survivorship themes:** A study of a large sample of survivors of cancer identified 11 themes specific to the meaning of QOL in cancer survivorship (Dow et al., 1999). The data from this study were compared to these themes to investigate whether the themes were valid for survivors of ovarian cancer. The investigators found that the previous themes of survivorship had application to ovarian cancer, yet significant and unique themes also emerged. Table 2 illustrates each of the original survivor themes from the previous study and a representative comment from the ovarian cancer survivor data illustrating that theme. This was done as an attempt to apply the general survivorship model to the population of ovarian cancer survivors.

**Survivorship themes specific to ovarian cancer:** In addition to the previously established overarching themes of meaning in cancer survivorship, the investigators identified an additional eight themes specific to ovarian cancer. Table 3 presents a summary of the themes specific to ovarian cancer accompanied by an illustrative quotation from the data. The themes follow.

**Theme 1:** On diagnosis of ovarian cancer, women experience a sense of isolation and struggle to find other women living with the disease. Survivors described ovarian cancer as an isolated cancer, because of its lower prevalence in the population of ovarian cancer survivors.

**Theme 2:** Prediagnosis symptoms often are ignored, delaying diagnosis of ovarian cancer to its late stages. Women struggle with the question of what if they were diagnosed sooner. Most women were insistent that they had experienced some degree of symptoms prior to diagnosis. They contested ovarian cancer’s classification as “silent” and preferred to describe it as “subtle.” Delayed diagnoses were common among women whose symptoms were ignored or misdiagnosed as benign syndromes. Many women reported vague symptoms to their physicians for several months before ovarian cancer was diagnosed. Understanding that advanced disease portends a much poorer prognosis, most of the women were haunted by the question of what if they had been diagnosed sooner. Women scoured their medical histories looking for symptoms that could or should have indicated early-stage disease to them or their physicians.

<table>
<thead>
<tr>
<th>Negative</th>
<th>Positive</th>
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<td>For my life now, I am definitely a happier person than I was prediagnosis. I have a greater appreciation for all of the pleasures, big and small, that living has to offer. For about the past 15 years, I had stopped celebrating my birthday. I hated growing older, felt that the best years were behind me, and was not particularly looking forward to 50 and beyond. As I mentioned, I celebrated my 48th birthday in the hospital. All of a sudden I confronted the alternative to not celebrating another year of life—and believe me, I know which is a better choice! Last year’s birthday celebration began at midnight and lasted for days. This year I intend to give great thanks for having the opportunity to celebrate turning 50! However, I am determined not to sit down or lie down and let this thing get me. I am going to live until I die—however long that is. God has been so good to me. I’ve said many times I wouldn’t take a million dollars for the experiences I have had. Only those who have had cancer understand that. Many times I have wondered if I could go back and had the opportunity to choose a different path, would I? Without question, I would not. Because I would not be the same person without the experience. I located the enclosed article, “Follow This Advice to Make Life Easier.” The first point of advice: Ignore the silver living. Use the cloud. Caught my attention. While cancer is definitely a black cloud, it has enabled me to become less “type A.” To relax, take time to appreciate small things, beautiful things (like rain drops clinging to branches, a squirrel’s nest high up in the elm tree, sunrises, sunsets, the clouds). All in all, it has enabled me to regroup and to realize that it is critical that I maintain a better balance in my life. Emotionally, I am also much better. I now take joy in such small things—a beautiful snowfall, cottony clouds in the sky, the ability to walk quickly up a flight of stairs without becoming completely exhausted when I reach the top.</td>
<td></td>
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<tr>
<td>I think you are farther along than me in the religious aspect, because I haven’t come to terms with all that and am not sure I’m ready to even try. I had dreams of being tortured. I felt abandoned by the Lord. I was mad at God! I said this is not fair. Why am I going through this? I hadn’t even had a good life—no grandchildren—why! why! I am going to be very mad when I get to heaven. I am feeling so discouraged. People tell me to have faith, but right now I’m questioning that, too. I am and have been experiencing some fears and uncertainties as my doctor struggles with where to go next. Why not? Why are we battling to stay alive if we’re going to reach a point where no one knows whether to go on or not? I know I am not curable, but what is the future here for us? But where do we go from here? Do we just sit by and let that insidious ovarian cancer creep through our abdomens in thin sheets, covering all our organs and choking out our lives? Now that the crisis has passed, I find myself feeling restless, emotional, and a little fearful. I’m not the same person as before my illness, and I can’t simply back up and pick up where I left off. Someone said that now I could get on with my life, but they don’t understand that this experience is not simply an interruption but an important part of my life. I never stopped getting on with life. This damn cancer never gives up. This is the lowest I have been mentally, knowing with two recurrences my chances dwindle. I’m having a hard time accepting this and at times do pray to die. I guess I find that it is so hard for me to have “a positive attitude” when it really didn’t seem to help any of my loved ones. Sometimes feels like there is no hope at all. It has been hard for me to come to grips with this more or less hopeless situation, and, needless to say, my acceptance has not been the best. When you are given a limited time to live, each day is precious, and I am trying to live each of them to the fullest. I have some good days, and some are not very good.</td>
<td>I am feeling so discouraged. People tell me to have faith, but right now I’m questioning that, too. I am and have been experiencing some fears and uncertainties as my doctor struggles with where to go next. Why not? Why are we battling to stay alive if we’re going to reach a point where no one knows whether to go on or not? I know I am not curable, but what is the future here for us? But where do we go from here? Do we just sit by and let that insidious ovarian cancer creep through our abdomens in thin sheets, covering all our organs and choking out our lives? Now that the crisis has passed, I find myself feeling restless, emotional, and a little fearful. I’m not the same person as before my illness, and I can’t simply back up and pick up where I left off. Someone said that now I could get on with my life, but they don’t understand that this experience is not simply an interruption but an important part of my life. I never stopped getting on with life. This damn cancer never gives up. This is the lowest I have been mentally, knowing with two recurrences my chances dwindle. I’m having a hard time accepting this and at times do pray to die. I guess I find that it is so hard for me to have “a positive attitude” when it really didn’t seem to help any of my loved ones. Sometimes feels like there is no hope at all. It has been hard for me to come to grips with this more or less hopeless situation, and, needless to say, my acceptance has not been the best. When you are given a limited time to live, each day is precious, and I am trying to live each of them to the fullest. I have some good days, and some are not very good.</td>
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**Figure 2:** Changes in Religion and Spirituality
Theme 3: Initially, women may avoid others with ovarian cancer to avoid confronting their disease. Ultimately, these women find significant support through the sisterhood of ovarian cancer. These bonds provide a mixed blessing of opportunity to help others more recently diagnosed while creating anguish in confronting whose disease is more advanced. Although some survivors admitted initial hesitance to contact others for fear of confronting advanced disease, ultimately women in this group embraced the support of others with ovarian cancer. As a self-proclaimed sisterhood, they cherished the support offered by others who had “walked in their shoes.” Some even proclaimed that they were glad to have had ovarian cancer because it introduced them to the support network of ovarian cancer “sisters.” Throughout the later years of correspondence, many women participated in weekend ovarian cancer survivor camps and cited the physical and mental encouragement they received as fuel for their fight for life.

Many women became proactive in ovarian cancer advocacy groups, fulfilling their need to help others facing the disease. The letters included countless lists of resourceful therapies, creative complementary and alternative treatments, and suggestions about medication doses with hopes that others would benefit from their experiences.

Theme 4: Women with ovarian cancer guide their own treatments, combining conventional and complementary therapies. Alternative therapies often are viewed as less toxic than conventional treatments for symptoms and are seen as offering hope for a cure. Active involvement is a means of exerting control over an uncontrollable disease. Women anxiously await new options. Throughout the correspondence, women with ovarian cancer described their poor statistical prognoses as a signal to take their treatments into their own hands. Large numbers of the women were diagnosed with advanced disease and revealed fears that their conventional treatment options were limited. Extensive listings of complementary and alternative therapies throughout the correspondence illustrated the resolve and resourcefulness of survivors to seek out all treatment options for symptom management, minimal toxicity, and possible cures. They scoured the Internet for new information regarding clinical trials and complementary and alternative treatments.

Theme 5: Ovarian cancer often is an insult to femininity, evoking loss of fertility and sexuality. Major abdominal surgery, including total hysterectomy and bilateral oophorectomy after cancer diagnosis, left women with a sense of injured femininity. Women described the distress of coping with this permanent physical transformation, citing long abdominal scars and...
<table>
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<tr>
<th>Cancer Survivorship Theme</th>
<th>Quotation From Ovarian Cancer Survivors</th>
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<tr>
<td>Quality of life (QOL) in cancer survivorship means having a balance between the experience of increased dependence while seeking both independence and interdependence.</td>
<td>I finally decided that the cancer, this evil, had happened to me, and whether I cried or laughed, the facts remained the same, but I always felt better when I laughed, and so did my family. This doesn’t mean that I didn’t cry buckets—we could have filled a swimming pool cheap! I try to find ways to turn evil to good and in the process turn the focus from myself to someone else. So many people are in need emotionally and physically. I’m no saint by any means. I’m just sharing some of my survival tricks. I still have some bad moments, but I just try to work through them by changing the focus from myself and staying busy.</td>
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<td>QOL in survivorship means seeking a sense of wholeness after a life-changing experience. Achieving wholeness in QOL restores a sense of life purpose.</td>
<td>Through these five years, I’ve met such remarkable people. I volunteer for hospice at our local hospital when I’m feeling well. The experiences I’ve had through hospice work were spiritual and enriched my life.</td>
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<tr>
<td>QOL in cancer survivorship means facing the challenge of putting their cancer experience within the context of life. The meaning of QOL is having life that is unique to the individual experience.</td>
<td>“Survivor”—what a privilege to have that title. To have defied the odds of a life-threatening disease and be given second chances. Second chances to see a sunrise, hear a new melody, touch a rose petal, smell the first raindrops, taste a snowflake, and say I love you. Second chances to buy a season ticket, attend my child’s wedding, and hold my new grandchild. Maybe second chances are for helping others through support, love, and understanding. We listen; we know we’ve been there.</td>
</tr>
<tr>
<td>QOL in cancer survivorship means struggling between the element of basic survival, counterbalanced by the profound search for meaning and reclaiming one’s life.</td>
<td>Today I awoke to celebrate that magical fifth year of survivorship. I remember thinking about it so much when I was first diagnosed—would I make it, what would life be like, how would I feel, etc. Over the five years, the meaning of time and how I view it has significantly changed. The quality has become the focus, not the quantity. My thoughts have been realigned to think not “Will I make it?” but “I am making it each day and every day.” Survivorship is not a period of time that one can label. It is every day when you awake to see, feel, and touch and be part of all the things that you come in contact with. You are surviving with each new breath and each new look at the world. I will hold you all in my heart as I close my eyes and make a wish for health, inner peace, and an ability to keep on keeping on.</td>
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<tr>
<td>QOL in cancer survivorship means managing the physical symptoms associated with disease or treatment that lingered and persisted long-term.</td>
<td>I began to experience cancer treatment-related fatigue, an overwhelming sense of exhaustion that assaul ts you and robs you of your every attempt to maintain some semblance of QOL. For me, the experience of fatigue was a one-way ticket on an emotional roller coaster. Each time this happened, I felt like I was losing the battle. I could barely get out of bed. When I did, I’d have to crawl to the bathroom, resting at designated points along the way. I couldn’t watch TV because I could not focus. I couldn’t read. I couldn’t even carry on a coherent conversation with my friends or family for any length of time.</td>
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<tr>
<td>QOL in cancer survivorship means facing multiple losses (e.g., financial, physical, relationships, function, sexuality, fertility).</td>
<td>This disease really had an adverse affect on my life. I suffered mental and physical stress. I went through early menopause, which destroyed my ability to bear children. It was hard for me to function as a normal adolescent, and during the dating process it was difficult to express and explain what I went through.</td>
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<tr>
<td>QOL in cancer survivorship means gaining a sense of control in life, rather than being controlled by cancer.</td>
<td>Perhaps by coincidence, most of us were young and the loss of fertility many experienced was derailing to deal with in addition to the cancer. Some were newlyweds, some engaged, others single. The social worker who runs the group calls it the “double existential whammy” of ovarian cancer because you don’t know if you will live and you know you will not be able to have children to have a trace of yourself.</td>
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<tr>
<td>QOL in cancer survivorship means there is a contrast between a focus on the moment (now; seizing every day) and a focus on the future.</td>
<td>The most exciting thing I have done is taken up my old hobby/passion of riding motorcycles! No, it’s not a sublimated wish. To me, it is the exhilaration of being alive in the world; a mixture of skill, vigilance, and courage; starting something that evokes fear in many people and not letting it stop me, learning to ride adeptly along on something powerful and dangerous. Sort of like having cancer, only lots more fun. So each time I ride, I think of this metaphor of me being masterful and agile in my relationship to the motorcycle and to the cancer. Now I know this is pretty strange to most people, but it works for me. And I probably would have never given myself permission to resume motorcycling if I hadn’t had cancer.</td>
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*Themes from Dow et al., 1999*
early menopausal symptoms such as hot flashes and vaginal dryness as areas of concern. In addition to physical concerns, the psychological effects of the procedures were devastating. Women expressed that the “core of their womanhood” was destroyed. Changes in physical appearance and sexuality added to the burden that ovarian cancer had placed on personal relationships. Women who still were of childbearing age were devastated by the loss of fertility.

Theme 6: Great anguish exists in the genetic legacy of ovarian cancer when women recall the disease of their mothers and grandmothers and fear the future for their daughters. The women voiced a profound fear of the genetic implications of ovarian cancer. Women confided the anguish of losing a mother, grandmother, or sister to ovarian cancer and the uncertainty and grief rekindled by their own diagnoses. They watched their daughters with empathetic terror, understanding firsthand the distress of watching a loved one battle ovarian cancer. They communicated a resolute determination to have the women in their families screened routinely, but this was coupled with feelings of futility because of the unreliability of available tests.

Theme 7: The trajectory of ovarian cancer includes aggressive, often toxic treatment. Periods of remission and recurrence create the stress and uncertainty of living with this chronic, life-threatening illness. Letters described ovarian cancer as a cycle of treatment, remission, recurrence, and treatment. Awareness that disease recurrence was common often clouded disease-free periods with anxiety and fears. Letters from women in remission more frequently described the distress of uncertainty and the fear of “not if, but when” the cancer would return. Because of the increased risk of recurrence, survivors expressed hesitation to classify themselves as survivors. Many coped by treating ovarian cancer as a chronic illness and resigned themselves to frequent treatments to keep their advancing disease at bay.

Theme 8: For many women, the unique experience of ovarian cancer results in a profound appreciation of life and deep meaning. Survivors of ovarian cancer demonstrated a profound appreciation for life. The ability to appreciate life’s simple pleasures and live “one day at a time” was of utmost importance to them. Many women dealt with the chronic uncertainty of ovarian cancer with the philosophy to live life to the fullest and appreciate family and friends without dwelling on the cancer that threatened their lives.

Discussion

The prevalence of comments within the spiritual QOL domain emphasizes the importance of meaning and spirituality to the survivors. Conversations! was a comfortable forum to share and discuss spiritual and religious issues. Women in this study relied on their spirituality to discern meaning from their cancer and to maintain hope throughout a life-threatening illness.
The quest to find meaning in a diagnosis of ovarian cancer presents a formidable challenge to women. Although ovarian cancer exhibits the same dimensions of meaning as general cancer survivorship, it also carries unique implications specific to women with this disease. Profound isolation often accompanies the disease because of its lower prevalence and poor prognosis. The discovery of a support network through Conversations! enabled women to discover meaning by sharing their experiences with others who had “walked in their shoes.” Sharing treatment options and complementary and alternative therapies was a way to exert new control over their disease and assign meaning.

Growing knowledge of the genetic legacy of ovarian cancer will continue to define the meaning of the disease. The inability to effectively screen for ovarian cancer exacerbates fear and uncertainty in families with disease history. Ovarian cancer survivorship means a continued fear for female relatives. Uncertainty in families with disease history. Ovarian cancer survivorship means a continued fear for female relatives. Uncertainty in families with disease history.

Table 3. Survivorship Themes Specific to Ovarian Cancer

| Theme 1: | On diagnosis of ovarian cancer, women experience a sense of isolation and struggle to find other women living with the disease. |
| Theme 2: | Prediagnosis symptoms often are ignored, delaying diagnosis of ovarian cancer to its late stages. Women struggle with the question of what if they were diagnosed sooner. |
| Theme 3: | Initially, women may avoid others with ovarian cancer to avoid confronting more advanced disease. Ultimately, these women find significant support through the sisterhood of ovarian cancer. These bonds provide a mixed blessing of opportunity to help others more recently diagnosed while creating anguish in confronting those whose disease is more advanced. |
| Theme 4: | Women with ovarian cancer guide their own treatment, combining conventional and complementary therapies. Alternative therapies are often viewed as less toxic than conventional treatments for symptoms and are seen as offering hope for a cure. Active involvement is a means of exerting control over an uncontrolled disease. Women anxiously await new options. |
| Theme 5: | Ovarian cancer often is an insult to femininity, evoking loss of fertility and sexuality. |
| Theme 6: | Great anguish exists in the genetic legacy of ovarian cancer when women recall the disease of their mothers and grandmothers and fear the future for their daughters. |
| Theme 7: | The trajectory of ovarian cancer includes aggressive, often toxic treatment. Periods of remission and recurrence create the stress and uncertainty of living with this chronic, life-threatening illness. |
| Theme 8: | For many women, the unique experience of ovarian cancer results in a profound appreciation of life and deep meaning. |

Through the surgery, beginnings of chemotherapy, even with the wonderful support of family and friends, the general sense has been one of being alone.

I am one of those people who feel that the diagnosis of ovarian cancer was delayed. I had regular Pap smears and pelvic exams and had inquired at least three times about a CA 125, as my mother died of ovarian cancer in 1991. I believed then, as I do now, that someone with a family history should be tested.

It’s Sunday, D-Day. I looked at the clock at 9:30 and remembered that’s when I reached my internist’s office and pleaded with them to see me. I can’t believe it’s been five years. The first three years were really difficult. No list, no support group, feeling very alone and scared. Every time I go through a rough period now, I take a great deal of comfort in knowing how many people there are out there, if I should ever need them. I know many women leave the list, because it is difficult to hear about the losses and the treatments, but I for one will hang on until there are no more people needing support. No more women facing months of chemo and frustration because the doctors didn’t listen. No more family members scared because ovarian and cancer are two of the scariest words in the English language. No more husbands needing to tell us of how they lost the most precious person in their lives. No more daughters who can’t share their most precious moments with their moms. And certainly no more mothers who have to bury their daughters. I will stay until the cover story on MAMM isn’t “Silent No More,” but “Ovarian Cancer the Most Curable Cancer.” Alternative complementary therapies like these are “unproven” to the traditional medical community, but to a person who has cancer, we are dealing with life or death and we want to do everything we can. We don’t just want to kill off the cancer symptoms, we want to get rid of the cause. And when we compare with success rates of chemotherapy (20%–25% for topotecan, which is good, my oncologist says), it’s easy to see why cancer patients would want to maximize their chances of overcoming this disease.

While in the recovery room, the surgeon told me it was cancer and that he had to do a total hysterectomy. I was devastated, I think, more about the hysterectomy at first. I was 30 years old and have always wanted many children. Now I would never realize that dream. I am single and feel that I have almost no chance of finding love and happiness. I’ve almost thought at times that, if I can’t have kids, is life worth living?

My mother died at the age of 53 from ovarian cancer. I was 13 years old at the time, and I watched my mother die a horrifying death. Her death left an unforgettable impact on my family. My sister and I lived with the knowledge that ovarian cancer could strike us. My sister had a hysterectomy at the age of 46. She was experiencing some minor problems but opted for surgery to eliminate any possibility of cancer. So, that leaves me.

I was informed in his office that my worst nightmare had indeed occurred. The cancer was back. All I remember at that moment was the incredible anger that welled up inside of me. Anger at the cancer for daring to come back and show its ugly face again. Anger at the oncologist for being “the messenger” after he told me four and a half years previously that this would almost certainly not happen again. Anger at the idiot internist who couldn’t see it coming even after I practically handed him the diagnosis on a silver platter. But most of all, anger at the world for going on while my life, as I knew it, had just stopped.

It is amazing to me how much better life is after this past year. I appreciate everything. The little things that used to bother me like a dirty house, bad weather, cranky people, not knowing what to fix for dinner, busy numbers, long lines, bad hair days, all the little irritations of life don’t phase me in the least! I am so grateful for this contentment. So I have decided that my cancer has some perks to it. I’m back as CEO of our family, back to work, planning a vegetable garden with my four-year-old grandson and husband, planning a vacation, and generally getting our lives back on track.
The appreciation of life demonstrated by these women was remarkable. By illustrating their incredible ability to find blessings amid adversity, the women exemplified the extraordinary nature of survivors of ovarian cancer. The ability to discern meaning from the diagnosis highlights the courage and resolve of the women to cope with the disease’s aftermath. The unique themes identified as affecting the meaning of QOL in ovarian cancer define the experience of this disease.

The rare, candid source of data reported in this article provided a poignant investigation of the meaning of ovarian cancer. A diagnosis of ovarian cancer carries unique implications that alter the meaning of the cancer experience. This study was limited to narrative data of a socially proactive group of survivors. Further research is needed to assess QOL and survivorship needs in this population using quantitative and qualitative methods in conjunction with access to demographic and treatment data. The 21,806 Conversations! contributions provided a unique and poignant insight into the need for future research and quality care.

**Implications**

In the process of caring for women with ovarian cancer, nurses must be aware of the unique survivorship issues they face, in addition to general survivorship concerns. Many women will be diagnosed with advanced disease; therefore, attention to spirituality and meaning will be of particular importance. Nurses should recognize that many women may experience distress related to delayed diagnosis and may need psychosocial intervention to cope. Many women will experience feelings of isolation and distress because of their statistical prognosis, which can be lessened by access to support networks specific to ovarian cancer such as Conversations!

**Conclusions**

Women with ovarian cancer have demonstrated exceptional resolve, courage, and an undaunting spirit in the face of a threatening enemy. The women faced the test of a cancer with a poor prognosis and applied meaning to their experience by supporting others, seeking further knowledge, and determining to persevere. Frustrated with feeling as if they have a “step sister cancer” to other women’s cancers, survivors of ovarian cancer responded by reaching out to others to increase awareness and QOL. The women relied on their spirituality for consolation throughout numerous challenges and to dow them with hope during a difficult time. These “conversations” with 21,806 women painted an intensely candid and often heartbreakingly honest portrait of a survivor of ovarian cancer. The voices of these women have enlightened the authors’ understanding of the meaning of ovarian cancer and provided a glimpse of their unending power to endure.

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**References**


Spirituality like religion, derives from mysticism. It carries with it a conviction that the transcendent is real and it requires some sort of spiritual practice that acts as catalyst to inner change and growth. It is primarily personal, but it also has a social dimension. Although spiritual growth is a type of healing from which most of us could benefit, a trauma survivor’s sense of spirit is acutely dimmed due to systemic victimization. Over time, however, as the survivor heals in all areas, the potential for spiritual growth may become greater than ever before and greater than for many people. A cancer survivor is a person with cancer of any type who is still living. Whether a person becomes a survivor at the time of diagnosis or after completing treatment, whether people who are actively dying are considered survivors, and whether healthy friends and family members of the cancer patient are also considered survivors, varies from group to group. Some people who have been diagnosed with cancer reject the term survivor or disagree with some definitions of it. An ovarian cancer diagnosis may bring to mind grim statistics instead of optimistic ovarian cancer survivor stories. Why? The numbers can be discouraging. Each year, approximately 22,000 women are newly diagnosed with the disease. An estimated 14,000 die from ovarian cancer (OC) yearly. Every woman diagnosed with breast cancer (BC) knows at least one BC survivor she can look to with hope and questions. But ovarian cancer is diagnosed more infrequently and often at a later stage. OC patients are typically older, and the symptoms of ovarian cancer can be confused with any of a number of illnesses... But the meaning of the teal-colored OC ribbon is still largely unknown. Ignoring Your Health. Women know what to do when they feel a breast lump.