

# 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.

**Sample:** 21,806 letters, cards, and e-mails received from survivors of ovarian cancer from 1994–2000.

**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.

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

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

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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-Bervers 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](http://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**

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

N = 3,492

### Religious Practices and Experiences

AAA could not be called to route a new course. A repairman could not be sent out to replace a worn-out part. Only God could give me what I needed . . . strength, hope, courage, peace, and joy in the midst of the storm.

I believe there are no coincidences, only God-incidences. My blessings are too many to count. I have so much love in my heart, my cup runneth over. I have enough love for many who are newly diagnosed or just plain afraid no matter how long they have been fighting this war, for I have walked in their shoes. I just keep putting one foot in front of the other. I am never alone, for as so many of us have found, “We can’t give it away, for we receive so much more than we give.”

I keep repeating to myself “God is in control.” It’s been the only thing I do know for sure in the midst of the chaos in my life!

My doctors are amazed I’m holding on. One asked me what church I go to. He said he would love to join. They scratch their heads and wonder. I do have faith, and God is my physician.

I look at my cancer as a test from God. That’s okay. I just would like to know what the question was!

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 hubby 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.

**Figure 1. Religious and Spiritual Practices and Experiences**

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 popu-

lation as well as the scarcity of long-term survivors resulting from the commonly poor prognosis. Women expressed their desire to connect with other women sharing their diagnosis while also expressing their frustrations at the difficulty of finding support resources specific to ovarian cancer. Women described survivors of ovarian cancer as an “endangered species.” Discovery of the *Conversations!* newsletter and support network was the first realization for many women that they were not alone. This connection endowed them with new optimism and encouragement, thus emphasizing the need for the women to have support from others facing ovarian cancer.

**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.

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### Negative

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.

### Positive

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 lining. 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.

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Figure 2. Changes in Religion and Spirituality

### Purpose in Survivorship

I just returned home from taking my youngest child to college. It was a day of excitement, fears, newness everywhere, tears, and, most of all, joy! I was filled with exhilaration that I could be there, be a part of the sorrow and the hope of seeing her grown, off on this new adventure. When I was diagnosed five years ago, I was unsure for many months if I would be alive to see her eighth-grade graduation. My tip for happiness: Never stop giving thanks for being a part of the lives of those you love. Whether the day brings a birthday party or a car accident, I imagine how my family would feel coping with this without me—and I am always glad to be alive.

My new life really began when I recovered from the fourth surgery. I vowed to help other women in any way I could to fight this horrible disease and make it disappear from all our lives. I have two daughters, and I don't want them to have to go through this. I talk to women whenever I can who are currently in treatment. I am constantly amazed and humbled by their courage and fighting spirit. They are all miracles in my mind!

There is nothing like a purpose, a calling, a mission, a goal, a cause, or a self-chosen desire to help others to give us survival power.

### Hopefulness

My oncologist says that as long as you are breathing, there is always hope, and if you are ever told there is nothing you can do by a doctor, *go somewhere else!*

I live now with the hope that better ways of detecting and treating this insidious disease will soon come about, ensuring me and other ovarian cancer survivors far better options for long-term survival and the chance to lead normal lives.

I have learned to live with cancer and have never given up hope. It is a lot easier to die than fight cancer!

Never give up hope. Keep your eyes, prayers, and thoughts ever onward and upward. God is good.

Cancer is like a traffic jam on a hot August day. You want to get on with your life, but you creep inch by inch, feeling trapped and all alone. Waiting for whatever it is that is blocking you from the rest of your life to disappear. Yelling and screaming does not make the traffic go away. You become discouraged, anxious, and tired. Then, just when you think you will be in that jam forever, the roadblock clears, the traffic begins to move a little faster, and you start to feel a sense of hope. You realize that you will eventually get

to where you are going, a little slower than you had anticipated and maybe on a different road, but you will get there. It's a long and lonely trip to make by yourself.

I was ready to sleep when the night nurse walked into my room. I had been in the hospital about 10 days, and the room was filled with hundreds of flowers and smelled like springtime. The nurse took a whiff and said, "Humph, smells like a funeral in here." I remember thinking, "That's it. You can look at life—and your cancer experience—as a funeral parlor or a garden shop." At that moment, I vowed to do my part so that no woman would have to deal with ovarian cancer alone or without hope.

Hope is the heart of each moment. It's the very breath of each waking day. Hope is like warm arms wrapped around us. That special feeling we get when we laugh and we play. Hope is the place we go when we need comfort. It's the whisper that says we're okay. Hope is all of our tomorrows. It's the smile of each special friend along our way.

### Awareness of Mortality

My time is limited, and they are keeping me as comfortable as possible. My attitude is still positive, but I have also accepted my fate and I am at peace with our decision.

I am so afraid. I don't want to die yet and leave my wonderful family.

Yes, it scares me and saddens me to read the names of women who have left this world, but in a way it's joyful to know that we will not be forgotten and that our spirit will be honored as well as the courage of the friends and family we leave behind.

I just dread the hurting a cancer patient does before the final crossing over. I want to die young as late in life as possible.

I have had the time to completely prepare for my death. I have written instructions for my husband at the time of death, planned my entire funeral service, and have written something to be read to the congregation in place of a eulogy. I am an organ donor, but all they will be able to use are my eyes. I only hope that the recipient of them can look at the beauty of life as I see it.

I, and perhaps others, too, have used the word "poofing" to mean dying suddenly without much prelude. I always think of it as "going out like a light." It wasn't used to avoid the word "dying." I believe many of us used it as a way to capture the suddenness that we hope our deaths might be graced with. I don't want to linger. I prefer to slip away suddenly rather than slowly.

## Figure 3. Other Spiritual Themes

**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.** 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 there 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 2. Survivorship Themes With Illustrative Quotations

Cancer Survivorship Theme <sup>a</sup>	Quotation From Ovarian Cancer Survivors
Quality of life (QOL) in cancer survivorship means having a balance between the experience of increased dependence while seeking both independence and interdependence.	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.
QOL in survivorship means seeking a sense of wholeness after a life-changing experience. Achieving wholeness in QOL restores a sense of life purpose.	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.
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.	"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.
QOL in cancer survivorship means struggling between the element of basic survival, counterbalanced by the profound search for meaning and reclaiming one's life.	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.
QOL in cancer survivorship means managing the physical symptoms associated with disease or treatment that lingered and persisted long-term.	I began to experience cancer treatment-related fatigue, an overwhelming sense of exhaustion that assaults 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.
QOL in cancer survivorship means facing multiple losses (e.g., financial, physical, relationships, function, sexuality, fertility).	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.  Perhaps by coincidence, most of us were young and the loss of fertility many experienced was derailling 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.
QOL in cancer survivorship means gaining a sense of control in life, rather than being controlled by cancer.	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.
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.	If someone had told me on the day of my diagnosis that I would be battling this disease five years later, my inclination would have been to find the nearest cliff, close my eyes, and jump for the heavenly realms. As it has turned out, my journey to heaven has been much slower (and harder) but with abundance of blessings along the way. I have learned three major lessons: to live each moment with much joy, that fostering important relationships is more important than housework, and that God will give me daily grace to handle each challenge as it comes.

(Continued on next page)

<sup>a</sup> Themes from Dow et al., 1999

**Table 2. Survivorship Themes With Illustrative Quotations (Continued)**

Cancer Survivorship Theme <sup>a</sup>	Quotation From Ovarian Cancer Survivors
QOL is a dynamic concept changing over the trajectory of survivorship.	I was diagnosed with advanced ovarian cancer minutes after my daughter's birth. Although her infancy was clouded by the shroud of chemo, her growth and development have become a clear marker by which I judge my remission and the quality of everyday life. Suddenly a year is a long time when seen through the eyes of a child's development rather than as a statistic for survival. There are walks to be taken, parties to celebrate, siblings to interact with, and new things to manipulate. There is sleeping, lying, sitting, crawling, and walking to be accomplished. A month becomes a time of transforming sounds into sentences rather than a wait for another marker test. A week becomes a time for a first haircut, first steps, and first swim rather than a dreaded chemo treatment. A day becomes a time of hearing "mommy" for the first time and moving up to toddler-size clothing rather than another struggle with fatigue. In many ways, my journey with ovarian cancer has been made easier by having her to love. My fears of time, limitations, and the future are replaced by the impact I have had on transforming her from fetus to infant to interactive, loving toddler. Her growth and steadier stature help me to visualize the many other aspects of my life not as readily measurable. I have learned that time is relative and truly a matter of perspective and perhaps not nearly as important as the events that fill it.
The meaning of health is altered for survivors of cancer.	Being healthy is like living on a continent. You get cancer, and they put you on a ship. On this ship, you are watched over and cared for; it's scary but somewhat safe. When your chemo is over, you are put on a raft and told to learn to live normal again. There is a small rope still connecting you to the ship. It's scary out in the dark waves. I call the water death. There are lots of sharks in the water. These are the people that keep saying, "You should be doing this, you should be doing that." Time passes; you start calming down. You look around your raft and go, "I can use this for a fishing pole or I can make shelter with someone else." You start to enjoy your life again. You start to enjoy each day and each sunset. Then a recurrence, and the big ship starts towing you again.
QOL in cancer survivorship means that survivorship is a family experience. Cancer does not occur as an individual, isolated experience, but, rather, cancer is an illness having an impact on the entire family.	My husband of 15 years is naturally stunned, shocked, and reeling, but we are coping day by day. My children are afraid, but we are very open with what is going on, and when things look bleak they give reason to go on. We were just all swimming, and they greeted me with a chorus of "we love to go swimmin' with bald-headed women." My oldest boy wants me to look like and act like all the other moms and was horrified when I wanted to paint my head red, white, and blue for the Fourth of July town parade. My four-year-old daughter had me take off my wig at preschool, and when all the other four-year-olds screamed, she loved it.

<sup>a</sup> 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 hesitance 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.

**Table 3. Survivorship Themes Specific to Ovarian Cancer**

Ovarian Cancer Survivorship Theme	Quotation From Ovarian Cancer Survivor
<b>Theme 1:</b> On diagnosis of ovarian cancer, women experience a sense of isolation and struggle to find other women living with the disease.	Through the surgery, beginnings of chemotherapy, even with the wonderful support of family and friends, the general sense has been one of being alone.
<b>Theme 2:</b> 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.	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.
<b>Theme 3:</b> 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.	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."
<b>Theme 4:</b> Women with ovarian cancer guide their own treatment, 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.	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.
<b>Theme 5:</b> Ovarian cancer often is an insult to femininity, evoking loss of fertility and sexuality.	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?
<b>Theme 6:</b> 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.	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.
<b>Theme 7:</b> 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.	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.
<b>Theme 8:</b> For many women, the unique experience of ovarian cancer results in a profound appreciation of life and deep meaning.	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 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 did in previous studies, 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. Until reliable screening methods exist, delayed diagnosis will pervade the meaning of ovarian cancer. An early-stage diagnosis is paramount in improving long-term survival statistics.



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 experi-

ence 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 "stepsister 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 endow 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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