

Sword of Damocles Cutting Through the Life Stages of Women With Ovarian Cancer

Sandra K. Cesario, PhD, RNC, FAAN, Leslie S. Nelson, PhD, MN, Anita Broxson, PhD, RN, OCN®, and Anastasia L. Cesario, BA, JD

According to Greek legend, Damocles was a courtier to Dionysius II. When Damocles remarked to Dionysius that his power and authority made him a fortunate man, Dionysius offered to trade places with Damocles for a day. As Damocles was enjoying the evening banquet after a day of kingly treatment, he noticed hanging above his head a sharp sword attached by only a single horsehair. Dionysius had ordered it to be placed there to show Damocles that he lives in constant fear. Damocles quickly realized that fortune and happiness cannot be totally achieved when one lives in constant fear. Waiting for the sword to fall overshadows all other aspects of life and well-being.

Ovarian cancer is the fifth-leading cause of cancer death in women and the most deadly of the gynecologic cancers. Because of inadequate screening procedures and diagnostic tools, the disease may not be identified until it is in an advanced stage. In the United States, 21,880 women are diagnosed annually and about 14,000 women will die within five years of diagnosis (American Cancer Society [ACS], 2010). Even with the advances in cancer diagnosis and therapy, the incidence and death rate in the Western world continues to rise (Parkin, Bray, Ferlay, & Pisani, 2005).

Three types of ovarian cancer are distinguished by cell type and ovary location. Each variety has different characteristics and prognoses. Epithelial ovarian cancer is the most common and is diagnosed most frequently in women of middle or older age. Oftentimes diagnosed at a late stage, epithelial ovarian cancer is associated with a poor prognosis. Germ cell tumors account for more than 30% of tumors found on the ovary, but only 5% are diagnosed as a malignancy. The vast majority of germ cell tumors are benign teratomas. Tumors arising from the germ cell layer are seen most often in girls and adolescents with a generally good prognosis for recovery. Stromal (or sex cord) tumors account for about 8% of ovarian tumors and are found in younger women. As with the other forms of ovarian cancer, the earlier the diagnosis, the more favorable the prognosis.

Purpose/Objectives: To identify the most prevalent worries and fears of women diagnosed with ovarian cancer.

Research Approach: Online survey design was used to elicit qualitative data. Examination of worry was a single question extracted from a broader investigation.

Setting: A “virtual interview” enabled women from 12 countries and 44 states to participate in this study.

Participants: 360 English-speaking women aged 19–82 years with a diagnosis of ovarian cancer. Ninety-one percent of the women were partnered, were Caucasian, and had received at least some college education. The sample was equally stratified on income, geographic location (rural versus urban), and distance to healthcare services.

Methodologic Approach: A descriptive survey was used to investigate “worry” among women with ovarian cancer. Colaizzi’s qualitative method was used to analyze the narrative responses.

Main Research Variables: Worries and fears of women with ovarian cancer stratified by age and development stage.

Findings: Consistent with previously published studies, worry about recurrence and fear of death were expressed by most women, regardless of age, ethnicity, or stage of life. Other worries expressed by study participants varied by age and development and were found to correlate with the last three stages of life as described in Erikson’s Theory of Psychosocial Development.

Conclusions: Age and development stage are key determinants of the needs and concerns of women with ovarian cancer.

Interpretation: Age and development stage should be considered when developing an individualized plan of care. Because recurrence is common among this population, the fear of death exists regardless of age and should be explored by nurses, particularly during periods of remission.

Ovarian cancer commonly appears in postmenopausal women; only an estimated 20% of women with ovarian cancer are of reproductive age. Chan et al. (2006) suggested that younger age is an independent prognostic factor for survival because this age group tends to be diagnosed at an earlier stage, have lower grade cancers, and contract tumors with a lower malignancy potential.

In addition, younger women are able to tolerate more aggressive chemotherapy regimens because of a generally better overall health.

The majority of women diagnosed with ovarian cancer in the United States are Caucasian. However, trends seems to suggest increasing incidence of ovarian cancer in non-Caucasian populations and a slight decrease in the average age at the time of diagnosis (National Cancer Institute, 2010).

Methods

Research and Methodologic Approach

A descriptive survey was used to explore “worries” described by women with ovarian cancer. The virtual online interview was designed to elicit narrative data from study participants suitable for qualitative analysis. The study questions were developed by the authors, including one who was an ovarian cancer survivor, and were pilot-tested with an ovarian cancer support group in Oklahoma City. The appropriateness of the questions were further validated and revised by an eight-member focus group. Examination of worry was a single question extracted from a broader investigation that explored the feelings and understanding of ovarian cancer survivors regarding their inclusion in or exclusion from clinical trials. One of the questions posed to the women in the parent study was, “When you lay in bed at night and cannot sleep, what worries you most?” The responses to this single question were analyzed and the findings are presented here.

An invitation to participate in the study was sent via e-mail to online ovarian cancer support group leaders, ovarian cancer organization newsletters, and ovarian cancer healthcare providers around the world. Initially the invitation was e-mailed to State Ovarian Cancer Alliance chapters, the International Ovarian Cancer Connection, National Ovarian Cancer Coalition, Ovacome (UK), the Sisters Network®, Ovarian Cancer Canada, OvCa.net (Australia), FORCE: Facing Our Risk of Cancer Empowered, Gynecologic Cancer Foundation, Gilda’s Club chapters, and the Inspire Online Community. The call for participants also was published in *Conversations: The International Newsletter for Those Fighting Ovarian Cancer and Nursing for Women’s Health*.

Snowball sampling resulted in an overwhelming response from women around the globe. Approval was obtained from the institutional review board of Texas Woman’s University in Houston prior to beginning the study.

Participants and Setting

During the seven-month period of time in 2008 that the online survey was available on PsychData™, 360 English-speaking women ranging in age from 19–82

years ($\bar{X} = 53$) who had received a diagnosis of ovarian cancer at some time in their lives completed the survey. The majority of the women (91%) were partnered, Caucasian, and had received at least some college education. The sample was equally stratified on income, geographic location (rural versus urban), and distance traveled to access healthcare services. Enrollment of study participants continued until common themes and patterns emerged. Participants were informed that completion of the online survey implied consent.

Data Analysis

Using Colaizzi’s method of analyzing qualitative data, the narratives were read and reread by a team of four researchers. Specific phrases and sentences that directly pertained to the investigated phenomenon were extracted by team members individually and discussed as a group. The responses were organized into categories or clusters by manual indexing and coding in an attempt to formulate meanings. Recategorizing of data continued until consensus was reached and an exhaustive description of the investigated phenomenon had been determined. Validation of study findings with ovarian cancer survivors verified the accuracy of interpretation (Colaizzi, 1978).

During this process, age and development stage emerged as distinct predictors of the type of worry or concern expressed most frequently by women with ovarian cancer. The findings of the current study parallel the well-known Theory of Psychosocial Development described by Erikson (1963) in which each of eight life stages is characterized by crisis of identity that an individual must overcome. Successful resolution of the crisis strengthens identity, whereas failure to resolve causes the conflict to be carried forward into later life. The last three life stages described by Erikson (1963) were consistent with the age groups, development tasks, and, therefore, the worries of the women in the current study. These three stages are summarized in Table 1.

Findings

Young Adulthood

The typical picture of a young adult is that of a healthy and strong individual actively engaged in building a life independent from parents and forming a new family unit. Consistent with Erikson’s (1963) sixth psychosocial stage, intimacy versus isolation, this stage encompasses the time of life when an individual explores personal interaction in an attempt to develop close and committed relationships with other people. This development task was at the forefront of the young adult study participants. In the current study, 43 women self-identified as being between the ages of 19–39 years. Three themes emerged in young adult participants that reflected the development conflict of

Table 1. Stages of Psychosocial Development

Stage	Age (Years)	N	Basic Conflict	Life Task	Development Outcome
Stage 6: Young adulthood	19–39	43	Intimacy versus isolation	Relationships	Develops and commits to warm and meaningful relationships; success equals strong relationships and failure leads to loneliness and isolation.
Stage 7: Middle adulthood	40–59	217	Generativity versus stagnation	Work and parenthood	Maintains the continuity of work and life; seeks fulfilling experiences based on personal or intellectual, rather than financial, goals; and guides the development of the next generation. Success leads to feelings of usefulness and accomplishment and failure equals shallow involvement in the world and disconnectedness.
Stage 8: Older adulthood (maturity)	60–82	99	Ego integrity versus despair	Reflection on life	Ability to look back over the years and feel satisfied and fulfilled aids in the adjustment to aging and, inevitably, death. Success is feelings of wisdom and failure is regret, bitterness, and despair.

Note. Based on information from Erickson, 1963.

young adulthood: the inability to have children, the effect of the cancer on relationships, and the desire to “get back to normal.”

Although the youngest women diagnosed with ovarian cancer are more likely to have fertility sparing debulking surgeries in which the uterus is left intact (Chan et al., 2006), reproductive issues are of the greatest concern to this age group. Statements addressing the inability to have children were short and to the point. A 27-year-old said, “[What bothers me most is] not being able to have children.” A 34-year-old said, “My chemotherapy has made me sterile and I cannot have children.”

In regard to the effect of the cancer on intimate relationships, both successes and failures were described by the participants. The majority of women in the sample relayed supportive and well-established relationships with partners. A variety of partner relationships were described and included married heterosexual partners, fiancés, and same-sex partners. Consistent with the work of Mitchell (2007), partners often served as gatekeepers and protectors.

My husband saw me through to the end. He went to my appointments, helped me make decisions, and took care of me when I couldn’t take care of myself. Besides my parents, he was my whole support group. I think not having someone there for you during this time would be extremely difficult to handle! (26 years old)

He does everything for me. It feels almost like it happened to him too. He also lost his chances for a family. He never thought of leaving me. I had a huge hole in my stomach for eight months; he came home to pack it twice a day. (33 years old)

However, some of the responses revealed the stress that the cancer placed on the relationship, resulting in isolation and despair.

At the time, my diagnosis had a direct impact in the dissolution of my relationship. My fiancé decided that my illness was too much for him. The hospital trips, my mood swings resulting from the medications, always being sick or in pain or drugged . . . it was a major factor in us ending the engagement. He could not handle my illness, and I needed a partner who could support me. We broke up two weeks before my second surgery. (33 years old)

The majority of women diagnosed with ovarian cancer are older than 50, have epithelial cancer, and the cancer is found at a late stage. When younger women are diagnosed with this disease, they express a desire to “get back to normal.” This may be in part because the more common forms of ovarian cancers found in younger women carry with them a better prognosis and younger women are in better general health, making them more resilient. In addition, the age-specific roles and responsibilities associated with being in college, beginning a career, and life planning necessitate resuming a daily routine to achieve these goals (Baker, Denniston, Smith, & West, 2005). Women expressed this theme in the following ways.

In general, my long to-do list of things that need to get done. During treatment, I think I worried about the outcome, dealing with unpleasant side effects, etc. (28 years old)

Everything. . . . If the cancer will come back. How do I live without thinking about my cancer? Why hasn’t my hair grown back? How do I resume normal life or feel normal again? What happens financially to me if the cancer comes back again? How do people view me now? How do I regain confidence? (37 years old)

It was a 37-year-old who summed up the young adulthood stage most comprehensively. She addressed each

of the themes the authors identified independently, including the ever-present threat of recurrence.

That the cancer will come back. That I cannot have children now, and I know this disappoints my husband, even if he won't admit it. That even though I'm cancer-free and, according to my gynecologic oncologist, "as close to cured as I'm going to get," I still have complications to deal with, even over a year out from my debulking surgery and almost a year since the end of my treatment. When is it ever going to end and when is life going to get back to normal—if it ever gets back to normal? It's a combination of all these things . . . and menopause.

Middle Adulthood

A person in middle adulthood is in the midst of career achievement, raising children, and looking forward to having grandchildren. Erikson (1963) described the seventh psychological stage of development as generativity versus stagnation, in which the individual focuses on the tasks that create and nurture things that will carry on a legacy when they are gone. Raising children or creating memorable changes in their professions or society that benefit others aids in achieving success in this stage of life. Ovarian cancer, because of its poor prognosis, frequent recurrence, and debilitating therapies, often interrupts a woman's ability to care for children or remain employed. The reality that her life may be cut short by this disease leads to frustration in knowing that she may not complete this stage of her development. Worries of women in this age group focused on three distinct areas: not being able to complete childrearing, work-related issues, and finances.

Almost all of the women in the study made some reference to their children. This suggests that the roles of mother and caregiver are of utmost importance and gives a sense of purpose to their lives. The statements about children in this age group also were succinct. A 54-year-old said, "And I worry about leaving my children who are young adults." A 43-year-old said, "Not seeing my children get married and have their own families." A 48-year-old said, "Just my kids." And a 53-year-old said, "The well-being of my young adult children."

The worries were more intense when the children were not capable of independent living, exacerbating the fear of dying and leaving these dependent children alone.

What would happen to my son who has significant disabilities due to eight major strokes in 10 years if I do not win the war on ovarian cancer? I am his primary caregiver. (57 years old)

My boy is in jail and, if I die, who will be there for him? (47 years old)

The realization that recurrence often occurs also affected this group.

Dying before I've been able to help my daughters (who have many medical issues) be independent. Dying before my husband and I can have some free time together. I've been in remission for three years and feel great but am not so naive as to think it couldn't reoccur. (47 years old)

Work-related issues and financial concerns appear to go hand in hand; however, they are two different types of worry. The generativity described by Erikson (1963) addresses one's need to be productive and contribute positively to society. The inability to work leads to financial instability, loss of insurance, and a strain on resources. Sherwood, Donovan, Rosenzweig, Hamilton, and Bender (2008) identified that financial expenses and the frustrations of dealing with insurance companies were major sources of worry for many patients undergoing chemotherapy. Most participants considered themselves "lucky" or "thankful" when most of the treatment costs were being covered by insurance or personal income. Financial assistance provided by friends, family, personal savings accounts, and support organizations are additional sources of worry when the woman feels others are required to sacrifice financial security to meet her needs. As with other categories, thoughts of recurrence are interwoven throughout.

. . . keeping my job while taking time off for treatment. (42 years old)

Will the next test bring me to more treatment? The length of time I have left to live, will treatment keep me from working? How will I have health insurance if I don't work? Will my illness leave my husband in debt? What will dying be like? Will we have to move from our remote mountain town home? Will I be able to leave my husband with enough money to survive? (50 years old)

Being around in 20 to 30 years to enjoy retirement; having enough money for retirement. (49 years old)

The cancer returning and I will no longer be able to support the people who depend on me financially. (46 years old)

Erikson (1963) noted that the stages of life are sequential. When one is not successful at a previous stage, moving through subsequent stages is difficult. A 53-year-old woman seemed to be struggling with relationship issues that were not solidified during her younger years.

My husband has not played a major role in my health care. . . . My husband is an alcoholic and, after my treatment was completed, he was injured in an industrial accident with a brain injury. This injury has only increased the progression of his disease. Sometimes I feel cheated when I think back as to how I feel he could have helped me. Sure he was there some times, but having to put up with

an intoxicated partner was tough. I also was dealing with an alcoholic son, too. At times you would lose yourself in the battle, because you had other ones to take on. At my support group, I hear about other spouses, and I know that it could have been different.

Older Adulthood (Maturity)

During older adulthood, the individual battles integrity versus despair—the eighth and final stage of development described by Erikson (1963). This stage occurs with the normal course of aging and is focused on reflection of the personal life journey (Huitt, 2008). When battling an illness that could be viewed as fatal, this stage may be accelerated or have an increased sense of urgency. Women in this age group reflect on the past and worry about what is yet to come and what they may not be able to enjoy. During this stage, the focus shifts from the woman's own children to a focus on their grandchildren and the role of grandparent.

Other caregiving roles were described by the study participants, primarily concern for an aging spouse or other elderly relatives. The most unique theme expressed by this group, however, was that they had no worries. They described being at peace, indicative of conquering despair and exhibiting integrity. Therefore, the three themes apparent during older adulthood were not being able to watch grandchildren grow, leaving a spouse or partner or another dependent relative, and no worries or being at peace.

If my life is shortened by this disease, I will leave behind my adult son, his wife, and their baby. This breaks my heart as I know my son will be devastated and my granddaughter will miss out on knowing me and having me in her life. I have the same worry about my sister who has been my rock since my diagnosis. I can't imagine losing my sister, and I'm sure she feels the same way about the possibility of losing me. I also worry about the quality of my future life. I want it to be normal and yet I know I will always battle this disease and I don't know how that will impact my life. (60 years old)

I have found that I am actually at peace with my situation. If I lie awake at night and if I could classify my thoughts as "worried," it would be that I might not live to see my grandsons participate in their sporting activities at high school, see them through college, or make me a great-grandmother. (64 years old)

Several women expressed concern about leaving their husbands alone. A few others mentioned elderly relatives.

I have some personal family issues with an elderly aunt and cousin. (66 years old)

Since I have had so many types of chemo[therapy] and since there is no cure for my type of cancer, I worry about getting everything in order and would hope to outlive my spouse because he is so helpless. (65 years old)

The successful completion of Erikson's eighth stage was apparent in several of the study participants. As the women got older, they described their adjustment to aging and preparation for death. There was less worry about the cancer itself and they expressed their worldly wisdom. None of the women in the sample older than age 60 expressed regret, bitterness, or despair.

I worry about which fabric I need to finish a quilt or what I am going to fix for dinner the next night. I worry about getting everything done that needs to be done. I do not worry about my cancer. (73 years old)

I have been well for 23-plus years, but pain and being kept clean are my biggest concerns and these have been stated in my advanced directives and power of attorney. (78 years old)

I don't worry 95% of the time . . . but I hope they find a cure in my lifetime. (61 years old)

Recurrence and Death—Cutting Across All Development Stages of Life

There was nothing more striking, however, than the expressions of fear related to the cancer "coming back." Baker et al. (2005) determined that 68% of cancer survivors, more than one year after treatment was completed, continued to have worries about their cancers returning. The Baker et al. (2005) study involved participants who had been diagnosed with one of the 10 most common cancers other than ovarian cancer. The authors of the current study hypothesized that, because of the poor prognosis of ovarian cancer in many cases, the percentage would likely be even higher in this group. This supposition was supported in this study because approximately 80% of the women expressed worry about recurrence at some point during the "virtual" interview. This number is consistent with the actual disease recurrence rate of 60%–85% (Ferrell et al., 2005), so their fears are not unfounded.

Living with recurrence has been described by Ekwall, Ternstedt, and Sorbe (2007) as "living in limbo" (p. 275). Women in this study described recurrence as being denied a future, yet hoping to delay the progression of the cancer. Even women who have been told that their cancers have been cured expressed feelings that it may someday return (Ferrell, Ervin, Smith, Marek, & Melancon, 2002).

The most common response to the question about worry in all age groups was a single-word response:

recurrence. Oftentimes, this word was written in all capital letters, accented with exclamation points, or augmented with descriptions of death and dying associated with recurrence. The following is a list of quotes representing the age spectrum. Although other concerns may be specific to age and life stage, thoughts of recurrence and death are not.

REOCCURENCE!!!!!!!!! How close I came to dying.
(33 years old)

The uncertainty of the disease—could this twinge, could this ache, could this pain, could this feeling be signs of a recurrence? (44 years old)

I thought I was the only one who had this issue. After all these years, I still lay awake not knowing what the next day will bring. I am thankful that I have a next day, but cancer never leaves my mind.
(51 years old)

That the cancer will, at some point, come back and not be treatable. My oncologist told me that I probably have seven years to live, according to the latest research. I'm trying to remain hopeful that something new will come along before I get to that point, but it's not easy. (52 years old)

Waiting for the other shoe to fall and how it will fall. All of the info on my OvCA sites scares the daylights out of me, but I feel I have to keep reading so that I will know when the shoe does start to fall. (61 years old)

I worry that I won't survive at least five years. I want to live 10 years more for sure. Since I only had a three-month remission after the first line of chemo[therapy], the doctors sounded like that was not a good thing. . . . I try not to think of the poor stats regarding ovarian cancer and know that I can be a survivor of 10 years too. I try to focus on knowing that I may not have a remission but can still maintain a good life with chemo[therapy]. I try to focus on today, and I am doing a lot of fishing.
(67 years old)

Figure 1 summarizes the themes identified in this study categorized by life stage.

Discussion

Ovarian cancer, up until the late 1990s, has been viewed as a death sentence (Reb, 2007). However, with progress being made in increasing public awareness and provider vigilance, coupled with improved chemotherapeutic regimens, the number of ovarian cancer survivors is slowly increasing. Consistent with the findings of the current study, Ferrell et al. (2005) noted that women with ovarian cancer have worries and concerns that are specific to this diagnosis when compared to other cancer diagnoses. In addition,

Young Adulthood

- Not being able to have children
- Impact on relationships
- Getting back to normal
- Recurrence of cancer and death

Middle Adulthood

- Not being able to complete childbearing
- Work-related issues
- Finances
- Recurrence of cancer and death

Older Adulthood

- Not being able to watch grandchildren grow
- Leaving a spouse/partner or another dependent relative
- No worries and at peace
- Recurrence of cancer and death

Figure 1. Summary of Themes by Life Stage

they found that quality of life was significantly different depending on the age of the ovarian cancer survivor.

Ovarian cancer is most often diagnosed in women older than age 50. Unlike cancers that appear more often in younger years, special consideration is needed to address the aging process, existing comorbidities, functional status, and frailty when the woman is diagnosed at a later age (de Gaetano & Lichtman, 2004; White & Cohen, 2008). Breast cancer, probably as a result of higher cure rates, does not appear to elicit the same degree of constant worry about recurrence as does an ovarian cancer diagnosis (Vickberg, 2003). However, after being told of disease recurrence and metastasis, similar feelings of stress, anxiety, disappointment, and worry are described by breast cancer survivors (Svensson, Brandberg, Einbeigi, Hatschek, & Ahlberg, 2009). Women with a family history of breast or ovarian cancer, or those testing positive for the *BRCA1* or *BRCA2* mutation, had higher levels of worry (Andersen et al., 2007; Bennett et al., 2008).

Worrying is characterized by unrelenting thoughts regarding threats to health and well-being when confronted with a diagnosis such as cancer. This constant stressor oftentimes contributes negative cognition resulting in detrimental effects on health behavior and the ability to cope with illness or loss (Lehto & Cimprich, 2009). Lobchuk and Bokhari (2008) concluded that women experienced more anxiety and depression when their informal caregivers lacked support and empathy. The degree of worry and its negative effects are moderated by the woman's available social support, coping style (particularly the use of avoidance), level of the threat to her personal well-being, and neuroticism (Bennett et al., 2008). It was noted by Anderson et al. (2008) that healthcare providers do not always respond empathetically to patient expressions of worry or concern. When women use words such as "scared," "worried," or "nervous," clarification of their specific concerns should be explored and addressed. Healthcare professionals should provide support to both the patient

and the family (together and individually) as each has a different set of issues and concerns associated with the diagnosis and treatment (Mitchell, 2007).

The “Damocles Sword” of ovarian cancer seems to be the constant threat of recurrence and subsequent health deterioration or death. Gynecologic cancers, perhaps more so than other forms of cancer because of the “privateness” of the organs involved and the potential loss of fertility, alter a woman’s roles, relationships, and self-image (Ekwall et al., 2007). Several studies have shown that being diagnosed with a recurrence is more stressful than a primary cancer diagnosis (Burnet & Robinson, 2000; Fitch, 2003; Howell, Fitch, & Deane, 2003; Mahon & Casperson, 1997). The poor survival rate in ovarian cancer exacerbates this phenomenon. Reb (2007) found that women receiving high levels of support from family, friends, and healthcare providers, coupled with perceived control over the situation, were most successful in transforming their “death sentences” to find meaning or purpose in the ovarian cancer experience.

Because cancer is the second-leading cause of death among Americans older than age 65, much of the research and resulting intervention is targeted to meet the needs of older adults (ACS, 2010). In older women, comorbidities, geriatric function scores, and degree of dependency are more predictive of prognosis and the ability to tolerate standard therapies than traditional oncology prognostic measures (de Gaetano & Lichtman, 2004). As a person ages, difficulty in processing and retaining information increases, resulting in needed alternations in the manner in which health information is disseminated (Posma, van Weert, Jansen, & Bensing, 2009).

Other studies have indicated that women in stratified age groups were affected by cancer diagnoses differently. Consistent with the findings of the current study, Stewart, Wong, Duff, Melancon, and Cheung (2001) described that younger, premenopausal women reported a greater sense of loss related to reproductive function and sexuality. Young women also reported greater worry and less confidence about future health. Older women, on the other hand, were more able to be accepting of the cancer diagnosis, were able to use humor more effectively, and reported less worry about the future. Baker et al. (2005) also indicated that younger patients were likely to have, on the average, three more problems than patients older than age 55. Older adult cancer survivors tend to have fewer expectations for full recovery and less worry related to the disease. This may be, in part, the result of the different roles assumed by persons at different stages of their lives.

Tian and Robinson (2008) reported that patients with cancer varied by age in their abilities to use the Internet as a health resource. The findings of this current study suggest that this gap may be narrowing as evidenced by the large number of online responses from older women. The majority of participants in the current study were aged

50 or older (\bar{X} , median, and mode = 53). These women appeared to be quite facile in navigating the Internet to access information, drug trials, and support groups.

As the concept of worry becomes more intrinsically entwined in quality of life and length of survival issues, an increasing number of research tools are being developed to address this concept. The Assessment of Survivor Concerns is a five-item questionnaire designed to measure fears related to recurrence and perceptions of health among cancer survivors. Research involving fear of recurrence has been increasing, indicating that it is an important concern among cancer survivors (Gotay & Pagano, 2007). Similarly, the Brief Cancer-Related Worry Inventory was developed by Hirai et al. (2008) to measure cancer-related worry. This scale has three subscales: (a) future prospects, (b) physical and symptomatic problems, and (c) social and interpersonal problems.

The Concerns About Recurrence Scale (CARS) specifically addresses the degree and nature of fear associated with breast cancer recurrence (Vickberg, 2003). The same researcher also has found that younger breast cancer survivors and those who have undergone some form of chemotherapeutic regimen had the greatest amount of worry about death, future treatment, and general health. The CARS subscales are based on the categories of worries described by the women in the Vickberg (2003) study, and include death, health, role, and womanhood. In general, these categories are very similar to the concerns identified in this current study.

The Impact of Cancer [v.2] also was designed and validated in a large sample of long-term breast cancer survivors with the express purpose to measure quality-of-life outcomes (Crespi, Ganz, Petersen, Castillo, & Caan, 2008). This psychometric tool is comprised of a positive impact summary scale consisting of four subscales (altruism and empathy, health awareness, meaning of cancer, and positive self-evaluation), a negative impact summary scale also consisting of four subscales (appearance concerns, body change concerns, life interferences, and worry), and two additional scales for employment and relationship concerns. All of these tools are useful in identifying women with high levels of worry and anxiety as well as aiding in determining the most pressing concerns for a particular patient. Employing these instruments for assessment purposes, in addition to their uses in research, can guide the individualized plan of care and maximize outcomes.

Conclusions and Implications for Nursing

Nurses should anticipate the needs, fears, and concerns of women diagnosed with ovarian cancer by considering the age and development stage of each individual. Nurses are key members of the interprofessional teams

that should be incorporated into the care of all women to aid in managing stress along the cancer continuum, particularly during periods of remission. Maintaining closer contact with women during periods of remission to offer support for the life events that may be occurring during their stages of development may alleviate some of the stress and worry that permeate their lives (Steele & Fitch, 2008). Because recurrence is the most commonly reported source of worry for women diagnosed with ovarian cancer, encouraging women to voice their thoughts on this subject is of utmost importance. Open communication with healthcare providers and a patient's spirituality provide hope amidst the uncertainty of an ovarian cancer diagnosis (Reb, 2007).

A common coping strategy used by women newly diagnosed with ovarian cancer is blunting. Often expressed as avoidance, blunting helps women cope with the overload of frightening information and poor statistics made available to them at the time of diagnosis (Power, Brown, & Ritvo, 2008). Nursing support that directs women and their families to small doses of essential information often is the most effective way to begin this education process. The National Ovarian Cancer Coalition (NOCC) has declared its mission to raise awareness and promote ovarian cancer education for providers, patients, and the general public. The coalition is dedicated to improving the quality of life through its many products and services, including specific guidance for women who have experienced a recurrence (NOCC, 2007).

When organizing support groups or planning education activities for ovarian cancer survivors, considering the age and stage of life of each participant is essential. Tailoring the agenda to meet specific needs of group members will improve retention and facilitate achievement of the desired objectives. For example, women who have never had the opportunity to have children may become increasingly distressed if other women in the group are discussing sadness related to not being there to see their children or grandchildren reach certain milestones. The dilemma here, however, is the infrequency with which younger women are diagnosed with ovarian cancer. Offering support groups by both cancer type and age is not always feasible. In this situation, certain topics, such as the inability to have children because of cancer, may be better addressed in groups of mixed cancer types, but include women of similar ages experiencing the same concerns. If a young ovarian cancer survivor cannot attend a group with women her own age and

development stage, then the group leader must be sensitive to the varying needs of members within the group on certain topics.

Until the advent of new chemotherapeutic agents developed in the past decade to treat ovarian cancer, the survival time for women diagnosed with ovarian cancer had been quite short when compared with other cancer diagnoses; therefore, less research has been done to determine the most effective interventions for improving the quality of life for these women. Now that treatment options for ovarian cancer have increased in number and effectiveness, women are living longer and more fulfilling lives. Today is the ideal time to initiate individually-crafted strategies to minimize worry and maximize quality of life (Ferrell et al., 2005). Channeling the energy expended on worry into a positive and constructive age-appropriate focus has the potential to promote adherence to healthy behaviors, build supportive relationships, and comply with medication or other treatment protocols (Mosher et al., 2008).

Ovarian cancer survivors, aware of their disease's deadliness and tendency to recur, have common thoughts and fears related to recurrence, the process of dying, death and the afterlife, pain, finances, and the inability to work or care for their families. In addition, these thoughts are mediated by age and stage of life. Like Damocles fixating on the sword looming above his head, women with ovarian cancer are hypervigilant, fearful that any new sign or symptom might indicate disease progression or metastasis. As progress is made in the treatment of ovarian cancer, Damocles' sword will become less of a threat.

Anastasia L. Cesario, BA, JD, passed away on July 12, 2009, following a more than five-year battle with stage IV epithelial ovarian cancer. Her passion for serving as an advocate for women with cancer was the impetus for this study.

Sandra K. Cesario, PhD, RNC, FAAN, is the doctorate program coordinator and a professor in the College of Nursing at Texas Woman's University in Houston; Leslie S. Nelson, PhD, MN, is a regional educator in the inpatient division of Select Medical Corporation in Mechanicsburg, PA; Anita Broxson, PhD, RN, OCN®, is the former program director of the Young Breast Cancer Survivors' Program at the University of Texas M.D. Anderson Cancer Center in Houston; and Anastasia L. Cesario, BA, JD, was an attorney in the Indigent Defense System in Norman, OK. No financial relationships to disclose. Sandra K. Cesario can be reached at scenarios@twu.edu, with copy to editor at ONFEditor@ons.org. (Submitted March 2009. Accepted for publication September 28, 2009.)

Digital Object Identifier: 10.1188/10.ONF.609-617

References

- American Cancer Society. (2010). *Cancer facts and figures, 2010*. Atlanta, GA: Author.
- Andersen, M., Drescher, C., Zheng, Y., Bowen, D., Wilson, S., Young, A., . . . Urban, N. (2007). Changes in cancer worry associated with ovarian cancer screening. *Psycho-Oncology, 16*, 814-820.
- Anderson, W., Alexander, S., Rodriguez, K., Jeffreys, A., Olsen, M., Pollak, K., . . . Arnold, R.M. (2008). "What concerns me is . . ." Expression of emotion by advanced cancer patients during outpatient visits. *Supportive Care in Cancer, 16*, 803-811. doi: 10.1007/s00520-007-0350-8

- Baker, F., Denniston, M., Smith, T., & West, M. (2005). Adult cancer survivors: How are they faring? *Cancer*, 104(11, Suppl.), 2565–2576. doi: 10.1002/cnrc.21488
- Bennett, P., Wilkinson, C., Turner, J., Edwards, R., France, B., Griffin, G., & Gray, J. (2008). Factors associated with intrusive cancer-related worries in women undergoing cancer genetic risk assessment. *Familial Cancer*, 8, 159–165. doi: 10.1007/s10689-008-9221-9
- Burnet, K., & Robinson, L. (2000). Psychological impact of recurrent cancer. *European Journal of Oncology Nursing*, 4, 29–38. doi: 10.1054/ejon.1999.0033
- Chan, J., Urban, R., Cheung, M., Osann, K., Husain, A., Teng, N., . . . Leiserowitz, G.S. (2006). Ovarian cancer in younger versus older women: A population-based analysis. *British Journal of Cancer*, 95, 1314–1320. doi: 10.1038/sj.bjc.6603457
- Colaizzi, P.F. (1978). Psychological research as the phenomenologist views it. In R. Valle and M. King (Eds.), *Existential phenomenological alternatives for psychology* (pp. 48–71). New York, NY: Oxford University Press.
- Crespi, C., Ganz, P., Petersen, L., Castillo, A., & Caan, B. (2008). Refinement and psychometric evaluation of the Impact of Cancer scale. *Journal of the National Cancer Institute*, 100, 1530–1541. doi: 10.1093/jnci/djn340
- de Gaetano, C., & Lichtman, S. (2004). Care of elderly women with ovarian cancer. *Geriatric Nursing*, 25, 329–335. doi: 10.1016/j.gerinurse.2004.09.015
- Ekwall, E., Ternstedt, B., & Sorbe, B. (2007). Recurrence of ovarian cancer—Living in limbo. *Cancer Nursing*, 30, 270–277. doi: 10.1097/01.NCC.0000281729.10362.3a
- Erikson, E. (1963). Chapter 7: Eight ages of man. In *Childhood and society* (pp. 247–274). New York, NY: W.W. Norton & Company, Inc.
- Ferrell, B., Cullinane, C., Ervin, K., Melancon, C., Uman, G., & Juarez, G. (2005). Perspectives on the impact of ovarian cancer: Women's views of quality of life. *Oncology Nursing Forum*, 32, 1143–1149. doi: 10.1188/05.ONF.1143-1149
- Ferrell, B., Ervin, K., Smith, S., Marek, T., & Melancon, C. (2002). Family perspectives of ovarian cancer. *Cancer Practice*, 10, 269–276. doi: 10.1046/j.1523-5394.2002.106001.x
- Fitch, M. (2003). Psychosocial management of patients with recurrent ovarian cancer: Treating the whole patient to improve quality of life. *Seminars in Oncology Nursing*, 19(1, Suppl.), 40–53.
- Gotay, C., & Pagano, I. (2007). Assessment of Survivor Concerns (ASC): A newly proposed brief questionnaire. *Health and Quality of Life Outcomes*, 13(5), 15–25. doi: 10.1186/1477-7525-5-15
- Hirai, K., Shiozaki, M., Motooka, H., Arai, H., Koyama, A., Inui, H., & Uchitomi, Y. (2008). Discrimination between worry and anxiety among cancer patients: Development of a Brief Cancer-Related Worry Inventory. *Psycho-Oncology*, 17, 1172–1179. doi: 10.1002/pon.1348
- Howell, D., Fitch, M., & Deane, K. (2003). Women's experiences with recurrent ovarian cancer. *Cancer Nursing*, 26, 1–9. doi: 10.1097/00002820-200302000-00001
- Huitt, W. (2008). Socioemotional development. In *Educational psychology interactive*. Valdosta, GA: Valdosta State University. Retrieved from <http://chiron.valdosta.edu/whuitt/col/affsys/erikson.html>
- Lehto, R., & Cimprich, B. (2009). Worry and the formation of cognitive representations of illness in individuals undergoing surgery for suspected lung cancer. *Cancer Nursing*, 32, 2–10. doi: 10.1097/01.NCC.0000343363.75752.f1
- Lobchuck, M., & Bokhari, S. (2008). Linkages among empathic behaviors, physical symptoms, and psychological distress in patients with ovarian cancer: A pilot study. *Oncology Nursing Forum*, 35, 808–814. doi: 10.1188/08.ONF.808-814
- Mahon, S., & Casperson, D. (1997). Exploring the psychosocial meaning of recurrent cancer: A descriptive study. *Cancer Nursing*, 20, 178–186. doi: 10.1097/00002820-199706000-00003
- Mitchell, T. (2007). The social and emotional toll of chemotherapy—Patients' perspectives. *European Journal of Cancer Care*, 16, 39–47. doi: 10.1111/j.1365-2354.2006.00701.x
- Mosher, C., Lipkus, I., Sloane, R., Kraus, W., Snyder, D., Peterson, B., . . . Demark-Wahnefried, W. (2008). Cancer survivors' health worries and associations with lifestyle practices. *Journal of Health Psychology*, 13, 1105–1112. doi: 10.1177/1359105308095964
- National Cancer Institute. (2010). Surveillance Epidemiology and End Results (SEER). Fast stats: Ovarian cancer. Retrieved from <http://seer.cancer.gov/faststats/index.php>
- National Ovarian Cancer Coalition. (2007). *Ovarian cancer resource guide for women with recurrent disease*. Retrieved from <http://www.ovarian.org/Images/ResourceGuideRecurrentOvarianCancer.pdf>
- Parkin, D., Bray, F., Ferlay, J., & Pisani, P. (2005). Global cancer statistics, 2002. *CA: A Cancer Journal for Clinicians*, 55, 74–108. doi: 10.3322/canjclin.55.2.74
- Posma, E., van Weert, J., Jansen, J., & Bensing, J. (2009). Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives, and professionals. Retrieved from <http://www.biomedcentral.com/1472-6955/8/1>
- Power, J., Brown, L., & Ritvo, P. (2008). A qualitative study examining psychosocial distress, coping, and social support across the stages and phases of epithelial ovarian cancer. *Health Care for Women International*, 29, 366–383. doi: 10.1080/07399330701876521
- Reb, A. (2007). Transforming the death sentence: Elements of hope in women with advanced ovarian cancer [Online exclusive]. *Oncology Nursing Forum*, 34, E70–E81. doi: 10.1188/07.ONF.E70-E81
- Sherwood, P., Donovan, H., Rosenzweig, M., Hamilton, R., & Bender, C. (2008). A house of cards: The impact of treatment costs on women with breast and ovarian cancer. *Cancer Nursing*, 31, 470–477. doi: 10.1097/01.NCC.0000339255.75947.a8
- Steele, R., & Fitch, M. (2008). Supportive care needs of women with gynecologic cancer. *Cancer Nursing*, 31, 284–291. doi: 10.1097/01.NCC.0000305743.64452.30
- Stewart, D., Wong, F., Duff, S., Melancon, C., & Cheung, A. (2001). "What doesn't kill you makes you stronger:" An ovarian cancer survivor survey. *Gynecologic Oncology*, 83, 537–542. doi: 10.1006/gyno.2001.6437
- Svensson, H., Brandberg, Y., Einbeigi, Z., Hatschek, T., & Ahlberg, K. (2009). Psychological reactions to progression of metastatic breast cancer—An interview study. *Cancer Nursing*, 32, 55–63.
- Tian, Y., & Robinson, J. (2008). Incidental health information use and media complementarity: A comparison of senior and nonsenior cancer patients. *Patient Education and Counseling*, 71, 340–344. doi: 10.1016/j.pec.2008.02.006
- Vickberg, S. (2003). The Concerns About Recurrence Scale (CARS): A systematic measure of women's fears about the possibility of breast cancer recurrence. *Annals of Behavioral Medicine*, 25, 16–24. doi: 10.1207/S15324796ABM2501_03
- White, H., & Cohen, H. (2008). The older cancer patient. *Nursing Clinics of North America*, 43, 307–322. doi: 10.1016/j.cnur.2008.03.003