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Transforming the Death Sentence: Elements of Hope in Women With Advanced Ovarian Cancer

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Purpose/Objectives: To describe the experience of hope in women with advanced ovarian cancer.

Research Approach: Grounded theory methodology with interviews.

Setting: Oncology clinics in the northeastern United States.

Participants: 20 women aged 42–73 who had completed initial chemotherapy and had no evidence of recurrence.

Methodologic Approach: A personal data form and focused interview guide supported data collection. The core variable and related themes were identified using the constant comparative process. Demographic and treatment information was analyzed using descriptive statistics.

Main Research Variables: The process of hope in women with advanced ovarian cancer.

Findings: Facing the death sentence emerged as the main concern. The core variable in dealing with the concern was transforming the death threat. The three phases of the trajectory were shock (reverberating from the impact), aftershock (grasping reality), and rebuilding (living the new paradigm). Healthcare provider communication and spirituality influenced women's abilities to transform the death sentence. Support and perceived control emerged as key dimensions of the core variable.

Conclusions: Women experience significant distress and trauma symptoms associated with a diagnosis of ovarian cancer. Hope was linked closely to the core variable and was necessary for finding meaning in the experience. Women with high support and perceived control seemed most hopeful and able to transform the death sentence.

Interpretations: Evidence-based interventions and strategies are needed to foster improved provider communication, symptom management, and peer support for women facing ovarian cancer. Future nursing research should focus on strategies that enhance support, perceived control, hope, and spirituality.

Key Points . . .

- Life-threatening illnesses such as ovarian cancer are associated with loss of control.
- Shifting expectations, focusing on realistic goals, and finding meaning in the cancer experience enhanced women's sense of control.
- Provider communication and spirituality provided a context that influenced women's abilities to transform the death sentence.
- Perceived support and control emerged as key dimensions of the core variable that influenced women's hopes.

1997; Ferrell et al., 2005). Newly diagnosed women also experience significant levels of trauma symptoms, such as intrusive thoughts and avoidance behaviors (Posluszny, 2001), including a sustained trauma characterized by "living in the face of death" (Thompson, 2005, p. 72). Some prominent themes in recent studies include hope and finding meaning (Bowes, Tamlyn, & Butler, 2002; Sivesind & Baile, 1997). Hope is a dynamic process believed to change over time (Cutcliffe, 1996; Farran, Herth, & Popovich, 1995; Herth, 1990; Nowotny, 1989) and is "characterized by a confident yet uncertain expectation of achieving a future good, which to the hoping person is realistically possible and personally significant" (Dufault & Martocchio, 1985, p. 380). Although a cancer diagnosis may threaten one's hope (Rustoen &

Approximately two-thirds of women diagnosed with ovarian cancer have advanced disease because the disease is difficult to diagnose in its early stages. Survivorship issues are becoming increasingly important as women live longer and treatment and supportive care for ovarian cancer improve (Christopher, 2006; Ferrell, Virani, Smith, & Juarez, 2003; Payne, 2006). Women with ovarian cancer have identified significant quality-of-life (QOL) concerns, including threats to physical, social, spiritual, and functional well-being (Cella, 1994; Ersek, Ferrell, Dow, & Melancon,

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Digital Object Identifier: 10.1188/07.ONF.E70-E81

Hanestad, 1998), maintaining hope can provide meaning and direction (Bowes et al.; Post-White et al., 1996) and is associated with improved coping and QOL (Ballard, Green, McCaa, & Logsdon, 1997; Chi, 2007; Herth & Cutcliffe, 2002a; Post-White et al.; Rustoen, 1995). Hope has been explored in diverse contexts, including patients with advanced cancer or HIV, palliative care, and terminal illness (Buckley & Herth, 2004; Herth & Cutcliffe, 2002a). Limited research has addressed hope in women with ovarian cancer, and further research is needed to address hope and QOL concerns associated with long-term treatment (Ferrell et al., 2005; McCorkle, Pasacreta, & Tang, 2003). The purpose of this study was to describe the experience of hope in women with advanced ovarian cancer. The study used grounded theory methodology with an interview approach.

Conceptual Orientation

With the grounded theory method, a comprehensive literature review is not done initially so that the substantive theory emerges from the participant data. When the theory is sufficiently developed, relevant literature is integrated as it relates to the emerging theory (Glaser, 1978; Stern, 1980; Wolcott, 2002). The conceptual orientation underlying this research was based on symbolic interactionism and constructivist paradigms. Symbolic interactionism focuses on meaning that arises through social interaction and is modified through interpretations that influence actions (Anells, 1996; Blumer, 1969). A constructivist approach recognizes the interactive nature of data collection and analysis (Guba & Lincoln, 1989; Lincoln & Guba, 2000) and emphasizes mutually created constructions that allow the data to guide the investigator (Glaser, 1978; Glaser & Strauss, 1967).

Methods

Design

The present study used a modified version of grounded theory based on Glaser and Strauss's (1967) classic work and Glaser's (1978, 1992) updates. The method is appropriate for the topic because grounded theory is process oriented and seeks to discover theoretical explanations when little information is available on a topic.

Participants and Setting

Purposive sampling was used to identify women with a diagnosis of stage III or IV ovarian cancer who had completed an initial course of chemotherapy and had no evidence of recurrence at the time of interview. Women within five years of diagnosis and with no other life-threatening comorbidities were eligible. Participants were recruited from oncology clinics at two community-based hospitals, two large teaching hospitals, and a private group hematology and oncology practice in the northeastern United States. Permission was obtained from the respective institutional review boards and a university's committee on protection of human subjects. Interviews were conducted at participants' or close family members' homes, workplaces, treatment facilities, and a local restaurant.

Instruments

Two instruments were used to support data collection: a **personal data form** and a **focused interview guide**. The

personal data form included demographic, illness, and treatment-related questions. The interview guide (see Figure 1) was developed by the investigator and included open-ended questions about women's experiences of hope. Questions were based on a preliminary literature review of the concept of hope with input from clinical nurse experts and doctorally prepared nurses with expertise in grounded theory method. New interview questions were added to address emerging themes as guided by the ongoing analysis (Hutchinson & Wilson, 2001). Participants were asked to tell about their experiences of diagnosis and treatment at the start of the interviews.

Procedures

Most referrals came from clinic nurses and a few from the medical or surgical oncologists. Those providers performed initial screening and obtained permission to relay contact information. Informed consent was obtained, and participants were given a copy of the personal data form to complete prior to the interview meeting. Each participant identified a pseudonym used to label tapes and transcriptions. Interviews lasted one and a half to two hours and were taped and transcribed verbatim by experienced transcriptionists. Data were collected until saturation or when no new themes emerged related to the categories (Hutchinson & Wilson, 2001). Saturation of the categories occurred after completion of about 17 interviews; however, three additional interviews were analyzed to ensure saturation and include all enrolled participants.

Data Analysis

Data were analyzed concurrently using the constant comparative process to guide subsequent data collection (Glaser, 1978; Glaser & Strauss, 1967). Initial analysis consisted of reading the entire transcript followed by line-by-line coding to identify all key concepts. Ethnograph 5.08 (Qualis Research Associates) software was used to record memos and label key text segments with succinct codes. Similar incidents were combined into categories with the goal of accounting for the core variable that helped participants deal with their main concerns. The core variable is the central theme that relates to the many categories and accounts for most of the variation in the data. The variable was classified as a basic social process because it represented a trajectory of stages occurring over time. Theoretical coding was employed to conceptualize how the substantive codes relate to each other. In addition, methodologic and theoretical memos were written to focus the categories and increase

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1. What does the word "hope" mean to you personally?
 2. Tell me about your experience of hope before being diagnosed with cancer.
 3. Can you identify any experiences, people, or situations that have influenced your hope since your diagnosis with cancer?
 4. Tell me about your experience of hope since being diagnosed with ovarian cancer.
 5. Describe any changes in your hope since your diagnosis.
 6. What gives you the most hope at the present time?
 7. Some women have identified concerns related to their diagnosis or situations that threaten their hope. Can you describe any experiences that have made you feel less hopeful?
 8. Is there anything else you would like to add about your experience of hope?
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Figure 1. Initial Interview Guide

the conceptual level of the data. Trustworthiness of the data was addressed through close adherence to the method and included classic techniques such as credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985, 2000). Credibility was addressed, in part, through analysis of negative cases to ensure fit of the data with the emerging theory (Lincoln & Guba, 1985; Patton, 1990; Sandelowski, 1986). Nurses with expertise in grounded theory method audited several transcripts and examined process issues and data interpretations. In addition, one participant commented on the findings during the final stages of analysis.

Results

Participant Characteristics

Twenty women met the eligibility criteria and agreed to participate (see Table 1). Most women were diagnosed with stage III epithelial ovarian cancer; most were Caucasian, postmenopausal, and married with children. The mean age was 58 years (range = 42–73 years). Four women had children age 12 or younger. Fifty percent held a college degree or higher.

Overview: Facing the Death Threat

Most women had been healthy prior to diagnosis and their lives were greatly changed on receiving the news. Women experienced significant losses and changes as they dealt with the physical and psychological impact and reported challenges such as living with ongoing uncertainty and fears of recurrence and death. One participant described the experience as “rebuilding from ground zero.” Acknowledging the reality of a poor prognosis occurred over time as women dealt with their main concern, facing the death threat. The basic social process, or core variable, that helped women deal with the concern was transforming the death sentence. Although individual responses varied, the process involved three major phases: shock (reverberating from the impact), aftershock (grasping reality), and rebuilding (living the new paradigm) (see Figure 2). Women’s abilities to move through the phases were influenced by perceived levels of support and control, which emerged as key dimensions of the core variable.

Hope and the core variable: Although hope did not emerge as the participants’ main concern, it was closely linked to the core variable. Women described hope as a feeling that changed over time and associated it with the ability to return to normal, participate in meaningful activities, and survive the disease. Most women expressed that hope needed reinforcement (Penrod & Morse, 1997) and described strategies and situations that supported and threatened their hope. Hope played a key role as a condition and a consequence of transforming the death sentence and was necessary for finding meaning (Bowes et al., 2002). Hope as a condition was dynamic and associated with certain recurring contextual themes related to the core variable.

Healthcare provider communication and spirituality: Contextual themes, including healthcare provider communication and spirituality, recurred throughout the phases and influenced women’s abilities to transform the death sentence. Because ovarian cancer is less common than other cancers, many women did not immediately understand the implications and relied on their providers for cues for interpreting the illness. Communication was perceived as a process over time as women tried to understand the meaning of the illness. Women were sensitive to providers’ communications and almost hypervigilant

in monitoring their responses. Several women relied on their providers’ assessment, and most felt more hopeful as a result. Women valued communications that were honest yet optimistic and were encouraged on hearing positive information.

I think when I met Dr. M, to me that was probably when my hope changed when he said, “No, this doesn’t have to be a death sentence. We treat this as more like a chronic illness and we follow it that way.” That gave me a lot of hope when he just said that to me.

Alternatively, women who experienced negative communications felt more anxious and less hopeful.

I guess at one point towards the end, it was made to sound like I could just expect a recurrence and I was very surprised at that. . . . So, I think that was probably

Table 1. Participant Characteristics

Characteristic	\bar{X}	Range
Age (years)	58	42–73
Months since initial diagnosis	15	7–49
Characteristic	n	%
Diagnosis		
Epithelial ovarian cancer	18	90
Primary peritoneal cancer	2	10
Stage		
III	15	75
IV	5	25
Race		
African American	3	15
Caucasian	17	85
Income (\$) (N = 14)		
< 20,000	2	14
20,000–40,000	2	14
41,000–60,000	5	36
61,000–80,000	3	21
> 81,000	2	14
Education		
High school graduate	4	20
Some college	6	30
College degree	5	25
Some postgraduate	1	5
Master’s degree	4	20
Employment status		
Employed	7	35
Unemployed	1	5
Retired	10	50
Medical leave	2	10
Religious preference^a		
Christian	3	15
Catholic	7	35
Protestant	9	45
Jewish	1	5
Marital status		
Single	1	5
Married	13	65
Divorced	2	10
Widowed	4	20

N = 20

^a Religious preference was self-reported by participants.

Note. Because of rounding, not all percentages total 100.

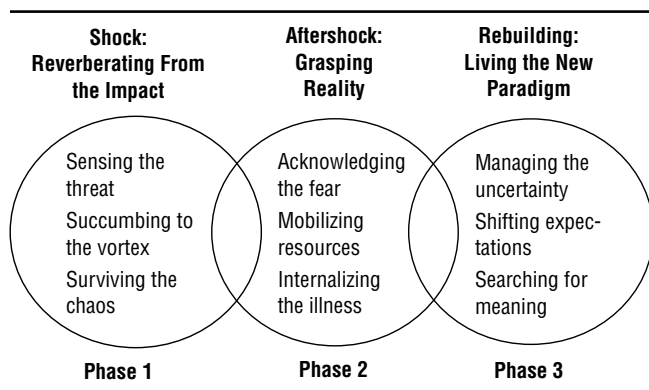


Figure 2. Phases: Transforming the Death Sentence

the most disconcerting thing I could have heard. . . . I said, “Well I’m just gonna set that aside. . . . Try to keep that out of your mind too much, because you don’t want to . . . deal with it.”

Several women relied on spirituality and their relationship with God or a higher power as a source of hope and comfort. Although women were frightened by negative statistics, they relied on prayer for strength and to help keep their fears under control.

The first thing I did is to ask God to give me the strength so I could help my family when I tell them, and it wasn’t as hard telling my husband, but it was very hard telling my daughters. And I couldn’t tell my sons at all.

Alternatively, some participants experienced spiritual struggles in dealing with the physical and emotional challenges imposed by the illness. Overall, spirituality and healthcare provider communication provided a context that influenced women’s abilities to transform the death sentence.

Shock: Reverberating From the Impact

Sensing the threat: The shock phase consisted of three stages: sensing the threat, succumbing to the vortex, and surviving the chaos. During the initial stage leading up to the diagnosis, many women experienced vague symptoms and sensed that something was wrong but did not suspect cancer. Most women sought care from their primary providers, and a few sought specialist care. Although some women were satisfied with those interactions, many felt distressed because of misdiagnoses or delayed diagnoses that they believed contributed to being diagnosed at a more advanced stage. Unless significant physical findings existed, the diagnosis usually was missed initially either by the primary provider or the specialist. Although some were referred to a specialist immediately, several were treated symptomatically until symptoms worsened or they insisted on further workup.

So all this pussyfooting around went on. I went back and forth with the doctor. Yes, I am in pain and no, I am not seeing anything or feeling anything or protecting anything. . . . Finally, by the time I got to the scheduled day of surgery of the gallbladder, I could hardly walk.

Women experienced other delays related to lack of coordination of follow-up appointments or when providers did not call to expedite referrals to specialists.

I went for my annual Pap [examination] . . . and it came back abnormal. I ended up having to go several times because [of] scheduling problems with the office. . . . The doctor, again, wasn’t there, and I finally said, “I’ve had it. I’ll see anybody—whoever’s there.”

These concerns contributed to the distress experienced when the diagnosis was confirmed.

Succumbing to the vortex: Many women felt overwhelmed, scared, and traumatized on hearing the diagnosis.

I thought I was going to die. I thought I was going to pass out. I was upset. I called my roommate and I was hysterical. I didn’t know what to do. . . . I was like blown away. . . . It was a complete shock. . . . To me, ovarian cancer is a death sentence.

One woman was so upset that she was oblivious to the fact that she damaged her car in the parking lot.

Well, I was so upset that morning, when I pulled up, I tore the whole right side off my car, because I was going to the doctor and I was just very upset. . . . I didn’t realize what I had done till after I had done it.

Women experienced a whirlwind of activity as they prepared for upcoming surgery, and some women did not realize the impact until they had more time to process the news.

And I honestly think that, at the time, it actually hit my husband a lot harder than it hit me. I think that was because I was just so sick that I really just didn’t think of it too much. . . . I was just feeling terrible and in so much pain that I didn’t think too far in the future and I just wanted to feel better.

Surviving the chaos: Women managed the chaos by adopting various coping styles and control measures such as preparing for treatment and controlling the information about the disease. They controlled the information using somewhat contradictory strategies, including seeking and avoiding information. Women initially sought out information from various sources, including the Internet and their healthcare providers, but frequently felt threatened and reported mixed feelings related to the negative statistics.

I had sorta mixed emotions about that. If I came upon something that really said something about it, I wanted to read it. But I wasn’t really looking for it. In the beginning, I was looking for information on it and like I said I was afraid if I started reading, after I started reading about different things, it sort of scared me.

Women relied on various coping styles such as fighting spirit, denial, minimization, and avoidance to help them manage the psychological impact. For example, some participants denied or minimized the significance of their illness.

You really don’t [take the time to process that you had cancer]. You kind of deny it. . . . I’m fine, don’t tell me I need to go home. . . . I think that’s one way you can get through it.

Other participants avoided or selectively ignored information they perceived as threatening. The use of various control measures and coping styles helped women achieve a greater sense of control, which facilitated the transition to the next phase.

Aftershock: Grasping Reality

During the aftershock phase, participants were more introspective in recognizing their vulnerability and relied on various coping strategies as they struggled with the realization of a potentially limited future. The phase consisted of three stages: acknowledging the fear, mobilizing resources, and internalizing the illness.

Acknowledging the fear: Several participants expressed that their biggest fear was recurrence and dying, described as “standing on shaky ground.” Women reported feeling more anxious and scared at night, coined by one participant as the “danger zone.”

Probably when I'm alone is the hardest. Alone with my thoughts because it allows me to think more and go to places that I don't really want to go to. . . . At night, when I lie down to go to sleep, it's probably the hardest time. Because my mind wanders; it goes places I don't want to go to.

Many participants expressed mixed feelings or anxiety after completing chemotherapy when no longer under the protection of cancer-fighting drugs.

[I felt] scared and fearful that every time he give me a pelvic or something that he will say, “Oh, something is not normal.” . . . I even told my husband that I am scared. If I die, don't give all of my things away.

I guess the only thing that worries me is having less frequent checkups at the doctor's office, then trying to decide, based on symptoms, do I go in. . . . It is kind of comforting to go in on a predetermined schedule on dates that are not too far apart.

Conditions that influenced or delayed the process included functional limitations and significant life events such as stress related to a family crisis.

Mobilizing resources: Women mobilized resources and familiar coping strategies as they sought to regain control. They relied on inner strength, including prior challenging life events, which helped them to cope with the illness. Women also appraised their support systems in considering who would be most helpful for emotional or practical assistance and reached out to people who were optimistic and encouraging.

Sometimes I could talk very easily and comfortable with someone and share my innermost feelings. But I didn't want anyone weeping, upchucking, and really upset with what happened. . . . I wanted someone to say, “We will work at this together.”

Many women were concerned about the impact of the illness on their families and considered their needs as they dealt with the illness. Some women tried to protect their families by minimizing their own fears or confiding in a close friend rather than a family member.

Although support was critical, it could be overwhelming at times, and women took steps to manage it. Women frequently relied on their husbands or a trusted friend to relay information or coordinate offers of help. Some participants actively avoided certain people who were negative or unsupportive in their communications.

There was a couple of people who called me and told me some negative things that made me sorta not feel so good. . . . I know I won't be talking to them for a while.

Many women received a significant source of support from other survivors. Although some actively sought out survivors, others feared that attending support groups or encountering others who were doing poorly would be a negative experience. However, those women were grateful for unexpected sources of support.

It was like having these people in your life, coming to me and talking to me about it. It really helped, and I was really confident. It helped me realize that you can do it. Not just talking to somebody on the phone.

Internalizing the illness: Women looked back at the experience as being somewhat surreal and realized that their lives had changed completely. A few women referred to it as “stepping through the looking glass,” an analogy from *Alice in Wonderland*, and described a feeling of being on the outside looking in, as if this were happening to someone else.

You have to deal even [though] you know on some level, it's sort of like there's two people operating. You have to deal with it, but then sometimes it feels like somebody else is actually going through it. Yeah. I don't know whether that's just to escape it.

Women recognized the many losses and changes in their roles and relationships, including grief related to the realization of a potentially limited future.

I think I have always looked to my kids that I was the rock. That I could do anything. . . . All of a sudden, it was like, it is not going to be always that way. . . . When I came home after seeing Dr. B that day, I pulled in my driveway . . . and cried uncontrollably. Because I said I finally found my house . . . and now I'm going to lose it.

The process of facing the poor prognosis occurred over time and involved struggling with uncertainty, fears, and loss of control. Women struggled to hold onto the belief that they would be okay while not being certain.

I wanted to know right now if I was going to be okay. . . . The patience is hard. That made me shaky. You get through that. It was out of my control. It was difficult; I wanted it to be in my control.

Other participants described a turning point or pivotal event that helped them to face the poor prognosis, such as having a sudden realization upon encountering another young woman dying of cancer. Women's abilities to internalize the illness helped them to better manage the uncertainty and begin to rebuild their lives.

Rebuilding: Living the New Paradigm

Women continued to experience fears during the rebuilding phase but were coming to terms with the losses and learning to live with the uncertainty. The phase consisted of three stages: managing the uncertainty, shifting expectations, and searching for meaning. The transition generally occurred sometime after completing therapy, as participants had more time to reflect on their experiences.

Managing the uncertainty: Women relied on various coping styles to help them manage the underlying sense of uncertainty. They struggled with the reality that cancer may recur while trying to figure out how to go on with their lives, adopting an attitude of living one day at a time.

You know 'cause you always want to be proactive and now you're in the wait-and-see mode. . . . But there's nothing you can do. . . . It's mostly trying to figure out how you go on with your life without dwelling on the fact that three months from now you are going to have an exam or . . . the blood work. . . . You can't—you just can't think that far in advance.

Women continued to rely on coping styles, including rationalization, minimization, humor, and social comparisons. Participants compared themselves to others in similar circumstances and engaged in downward and upward comparisons. For example, several participants compared themselves with long-term survivors, which provided inspiration and hope that they too could survive.

So we were talking and she [a neighbor with ovarian cancer] just got her five-year mark. You talk about happy now, I was happy then I was really, really happy. . . . My feet weren't on the ground.

Maintaining positive alliances with survivors provided reassurance and great meaning to participants.

Shifting expectations: Several women revised their expectations and goals as they focused on meaningful priorities in their lives. The process occurred over time and involved accepting losses such as changing jobs or career goals or adjusting expectations related to the disease. Women focused on meaningful goals, such as returning to work and usual activities, because they wanted their lives to be normal again. However, the inability to return to one's normal activities was associated with decreased hope.

Hope is just a realistic expectation of things getting better. That's what I gotta have. Not just a pie in the sky. . . . I want to get up and get around. . . . I want to resume a reasonably normal life. . . . I want to be able to control living and not just vegetate.

Searching for meaning: Women tried to move beyond their present circumstances to find meaning and a new perspective on life. Many focused on living day to day, expressed a renewed appreciation for life and close relationships, and were realistic yet optimistic about the future.

I don't take anything for granted. I try to stop and enjoy, take things at a slower pace, and really enjoy and not just rush through everything. Enjoy watching the girls grow up, not just going through the motions every day but actually being there.

The process of searching for meaning occurred over time and involved reflection and examination of values and priorities. Some women found meaning through participation in clinical trials and several expressed a desire to help other survivors. Closer to treatment, many women sought to help others in some way but were uncertain how to fulfill that goal. However, women further out from treatment had more time to decipher how they could contribute. Developmental tasks and functional limitations affected the process, including constraints imposed by family and work obligations.

Dimensions and Associated Categories

In examining the phases of transforming the death sentence, perceived support and control emerged as dimensions of the core variable. Life-threatening illnesses are associated with

loss of control, and efforts to regain control were evident during the phases (see Table 2). Support assisted women in focusing on positive aspects and seemed to positively influence perceived control. However, unsupportive interactions with family or friends contributed to distress. For this group of women, perceived control seemed to play a greater role in the process of transforming the death sentence. Women who felt in control of their environments and confident in their ability to manage symptoms and other areas of their lives were more hopeful.

Four categories of the core variable were identified based on levels of support and perceived control (see Table 3). Women with greater levels of support and control were more hopeful and able to face the death threat, whereas those with lower levels were least hopeful (see Table 4). Although the categories were somewhat fluid, most women aligned with the "going it alone" and "waiting for the other shoe to drop" categories. Women who aligned with "trapped in the illness" generally perceived the least support and control related to the disease or their environments. Women aligned with "waiting for the other shoe to drop" had difficulty coping with the losses and changes, but some were able to regain control with the encouragement of close others. Women aligned with "going it alone" were somewhat stoic and frequently reached out for support through ovarian cancer list serves or other venues. Women aligned with "facing the death threat" focused on tasks such as positive reappraisal and finding meaning.

Discussion

The study supports findings from other studies of women with ovarian cancer and reveals new insights regarding women's experiences in dealing with the disease. Women with ovarian cancer have reported fears related to uncertainty and the possibility of early death (Bowes et al., 2002; Ferrell et al., 2005; Howell, Fitch, & Deane, 2003; Thompson, 2005). Facing the death threat emerged as women's main concern, and the basic social process, or core variable, in dealing with the concern was transforming the death sentence. Progression through the phases was influenced by overarching contextual themes, including healthcare provider communication and spirituality. Support and control emerged as key dimensions of the core variable that influenced women's hope. Based on those dimensions, four categories were identified that characterized women's abilities to transform the death sentence.

Table 2. Strategies That Enhanced Control in Each Phase

Phase	Strategies
I	Seeking and controlling the information Preparing for treatment Coping styles such as fighting spirit, denial, and avoidance
II	Mobilizing resources and support Managing the support Relying on faith Preparing for the future
III	Rationalization; upward and downward comparisons Shifting expectations or goals Finding meaning through altruistic activities

Table 3. Categories of Transforming the Death Sentence

Category	Characteristics	Support	Perceived Control	Example Quotations
Facing the death threat	Focusing on meaningful goals Living day to day Finding meaning in the experience	High	High	<p>You're at least able to groan about getting up and going to a job that you love, so being able to live my daily life everyday consistently is incredibly hopeful for me. That fills up the jar as well. When I'm in touch with my new friends who are such an inspiration to me. Other survivors ahead of me. The fact that people look to me as their inspiration to survive, whether they've had the cancer or not.</p> <p>I don't believe that God's done with my life at this point. He has given me people to talk with. At the National Institutes of Health, this woman, she just let me go on about God and my life and she just kept asking me more questions. . . . I think that's what life is about is knowing God and his love for us—letting others know it.</p>
Waiting for the other shoe to drop	Struggling with fears, uncertainty Relying on support to help re-appraise the situation Control enhanced by supportive others	High	Low	<p>For a couple of weeks there, I didn't do anything. I wasn't on the thing with the diet, the exercise, or anything. Nothing . . . I guess it is like when you have chemo, you're fighting to survive and then you have made it. Well, I was talking with my aunt last night and . . . it will be five years for her. She said, "I understand because it is like you wait for the other shoe to fall." It is interesting when you can meet somebody that understands what you are saying.</p> <p>I feel a bit like a failure even though a lot of people say you're a survivor. . . . Inside, I feel kind of different, and it's hard to share that. I just told my mom that the other night. She got really upset and told a friend of mine. She said, "I look at her as . . . being so strong, and I really can't get that she feels like a failure." It's taken a lot from me.</p>
Going it alone	Relying on inner strength, determination Reaching out for support	Low	High	<p>I was born at the height of the Depression. . . . You grew up quick. . . . You have to learn to go get what you want. And not to expect it. It builds character. I think it molds you one way or the other. I think it helped me through this [experience].</p> <p>So that being the case, I didn't see the need, um, I probably had enough of the resources within me that I didn't have that need to have that talk with God yet. And could be that it wasn't my time to have it but the inner resources are just, I think that they just come from an unexplained place.</p>
Trapped in the illness	Overwhelmed, uncertain about the future Significant symptoms, functional limitations Preoccupied with intrusive thoughts Difficulty seeing beyond present circumstances	Low	Low	<p>The pain started to overwhelm me and control me. I couldn't ignore it, I couldn't function with it, and I couldn't move. It just wouldn't go away. . . . My feet kept me awake at night. If I kept my feet out from under [the blanket], it was not too good either. I am preoccupied with it.</p> <p>Well, I feel like this, being human, I mean, I know I pray, I pray daily, and then the next thing I know I'm thinking about the same. I said, Lord, just take this out of my thoughts, out of my mind, just make me be free from thinking. And I'll be fine for a while, and the next thing I know, it's back up in my head again. I say, "Lord I'm not going to deal with that."</p>

Although not the main concern, hope was a strong underlying theme that influenced the ability to transform the death sentence. The relationship of hope to the substantive theory in the study is supported by other models in the literature such as the Hope Process Framework (Farran et al., 1995; Farran, Wilken, & Popovich, 1992), which addresses four key processes of hope (see Table 5). Although some overlap exists, the Hope Process Framework provides a general framework to compare the theory emerging from the study with existing research findings.

Experiential Process of Hope

Women experienced tremendous loss and devastation associated with ovarian cancer, and their hope fluctuated during the course of the illness (Farran et al., 1995; McGee, 1984). Women reported uncertainty, loss of control, and losses related to a limited future (Howell et al., 2003; Thompson, 2005) and

social and work roles (Ferrell, Smith, Ervin, Itano, & Melancon, 2003; Howell et al.; Little, Jordens, Paul, Montgomery, & Philipson, 1998; Navarre, 2004). Women relied on various coping styles and strategies to enhance control and manage the uncertainty, including reaching out for support.

Relational Process of Hope

Support from family, friends, and other cancer survivors was a major theme in women's descriptions of hope. Women managed the support so that it did not become overwhelming and avoided negative people or situations that threatened their hope (see also Crooks, 2001). Other research supported that stress related to unsupportive interactions with family or friends contributes to psychological distress among patients with cancer (Ekman, Bergbom, Ekman, Berthold, & Mahsneh, 2004; Marlow, Cartmill, Cieplucha, & Lowrie, 2003;

Table 4. Relationship of Hope to the Dimensions and Categories of the Core Variable

Category	Level of Perceived Control	Level of Support	Level of Hope
Trapped in the illness	Low	Low	Low
Waiting for the other shoe to drop	Low	High	Wavering
Going it alone	High	Low	Moderate
Facing the death threat	High	High	High

Norton et al., 2005). Social support plays an important role in reducing illness uncertainty and improving QOL (Sammarco, 2003). Women used coping styles such as social comparisons as one way to reduce their fears and uncertainty (see Breetvelt and Van Dam [1991] for discussion of Festinger's social comparison theory). Although studies suggest that downward comparison is most prevalent among those with chronic illness (Bogart & Helgeson, 2000; Bowes et al., 2002), many women in the study were inspired when comparing themselves to other survivors who were living their lives. Other studies support that upward social comparisons inspire hope and motivation in patients with cancer (Salander, Bergenheim, & Henriksson, 1996; Thompson, 2005). Although some women avoided support groups, most were inspired by communicating with other ovarian cancer survivors. Other studies support that connecting with similar others (Navarre, 2004) and support group participation provide hope and optimism about the future (Ahlberg & Nordner, 2006; Sivesind & Baile, 1997). Furthermore, sharing feelings and fears with others who had "walked in their shoes" validates women's experiences and helps them to realize that they are not alone (Ferrell, Smith, Juarez, & Melancon, 2003).

Spiritual and Transcendent Process of Hope

Women reported that spiritual beliefs and affirming relationships were important to their sense of hope. Many women found meaning through spirituality and spiritual practices, which facilitate positive reappraisal during stressful situations (Folkman, 1997; Lin & Bauer-Wu, 2003). Other research supports that spirituality is a source of hope (Ferrell, Smith, Juarez, et al., 2003; Kennelly, 2001) and that hope is linked to purpose or meaning in life (Ballard et al., 1997; Bowes et al., 2002; Farran et al., 1992; Herth, 1991; Post-White et al., 1996). Searching for meaning is a common existential theme (Bowes et al.; Ferrell, Smith, Juarez, et al.; Sivesind & Baile, 1997) and involves reflection, reevaluation (Halstead & Hull, 2001; Skaggs & Barron, 2006), and development of new short-term goals (Bowes et al.). In the present study, the process occurred over time and involved assessment of personal resources and preferences within the context of women's social environments.

Rational Thought Process of Hope

Assessment of goals: Hope involves revising goals so they are flexible and realistic because people are more motivated to achieve attainable goals (Farran et al., 1992; Felder, 2004; Herth, 1990). Shifting expectations and setting realistic goals

promote a sense of meaning and personal control (Folkman, 1997; Folkman & Greer, 2000; Folkman & Moskowitz, 2000; Rothbaum, Weisz, & Snyder, 1982; Thompson & Collins, 1995; Thompson & Kyle, 2000). Participants reflected on their priorities and focused on getting back to normal. However, most were uncomfortable planning long term, perhaps because of the uncertainty associated with a life-threatening illness. Other studies support that hope is associated with short-term goal-setting and living as normally as possible (Ahlberg & Nordner, 2006; Benzein, Norberg, & Saveman, 2001; Pilkington & Mitchell, 2004). For example, Ferrell, Smith, Ervin, et al. (2003) found that returning to work and normal roles provided a sense of achievement in overcoming cancer and regaining normalcy.

Assessment of control: Sense of control is important in maintaining hope (Bunston, Mings, Mackie, & Jones, 1995; Ersek, 1992; Farran et al., 1995; Flemming, 1997). Women described experiences that supported and threatened their sense of control. Controlling the information about ovarian cancer was a major strategy that helped women to manage their fears. Rees and Bath (2001) also reported that women sought information to facilitate decision making and regain control over an uncontrollable situation. Women in the current study also avoided certain threatening information. Brashers (2001) noted that avoiding information about long-term prognosis may be positive because it supports optimism. Furthermore, patients may be ambivalent about the amount of information they desire (Bowes et al., 2002; Hack, Degner, & Parker, 2005; Pilkington & Mitchell, 2004) and may prefer hearing information about diagnosis in stages (Bowes et al.; Fitch, Deane, Howell, & Gray, 2002) to cope with it in "manageable bytes" (Dickerson, Boehmke, Ogle, & Brown, 2006). Threats to control included negative communications and financial and social pressures such as job discrimination. Unanticipated symptoms and physical impairments also threatened sense of control (Lockwood-Rayermann, 2006; Norton et al., 2005). Other studies support that symptom distress interferes with the ability to attain meaningful goals (Lee, Cohen, Edgar,

Table 5. Processes of Hope

Process	Focus
Experiential (Health)	Relationship of hope to suffering and loss; determining the relationship between patients' health status and hope
Relational (Others)	Importance of relationships in promoting hope during difficult experiences; assessment of patients' support system and available resources
Spiritual and transcendent (Purpose)	Purpose in life or religious and spiritual orientation; assessment of patients' source of hope, which may involve spiritual assessment and the meaning of spiritual or religious practices
Rational thought (Engaging)	Assessment of goals; internal and external resources that support hope and actions to attain goals. Assessment of sense of control and ways to increase control to foster hope. Assessment of perception of time in relationship to hope

Note. Based on information from Farran et al., 1992, 1995.

Laizner, & Gagnon, 2006) and is associated with decreased hope (Benzein et al., 2001; Bowes et al.; Bunston et al.; Chang & Li, 2002; Felder, 2004; Herth, 1990, 1992; Kennelly, 2001).

Study Limitations

In patients with chronic illness, more than one interview may be needed to cover the topic area (Charmaz, 1990, 2000). The constructivist approach emphasizes developing a relationship through sustained involvement with participants, consistent with the symbolic interactionist's emphasis on meaning that emerges through social interaction. Although only one interview was conducted, the investigator spent additional time establishing rapport during consent meetings. Prospectively addressing women's experiences and hope over time in relationship to different phases of the illness trajectory would be helpful for future studies (Herth & Cutcliffe, 2002b).

Nursing Implications

Healthcare Provider Communication

Communication style and relationship with healthcare providers were significant recurring themes that influenced hope. Research supports the importance of patients' relationships with providers in influencing QOL (Lockwood-Rayermann, 2006; Pilkington & Mitchell, 2004) and meeting communication and psychosocial needs (Hack et al., 2005; Henman, Butow, Brown, Boyle, & Tattersall, 2002; Kornblith et al., 1995; Salander, 2002). Although many women experienced supportive interactions, some reported significant distress related to isolated negative communications. Information delivery can be challenging because information-seeking behaviors are highly individualistic (Hack et al.; Rees & Bath, 2001), and these behaviors may be indirect, potentially causing confusion and communication of information that patients perceive as intrusive (Brashers, Goldsmith, & Hsieh, 2002). Healthcare providers can support women by being sensitive to their information goals (Brashers et al.; Hack et al.; Rees & Bath) within the context of an ongoing supportive relationship (Salander).

Several women reported distress related to diagnostic delays, especially during the diagnostic period. Other studies of ovarian cancer survivors reported similar concerns related to delayed diagnosis (Bowes et al., 2002; Ferrell, Smith, Cullinane, & Melancon, 2003; Ferrell, Smith, Juarez, et al., 2003; Fitch et al., 2002; Koldjeski, Kirkpatrick, Swanson, Everett, & Brown, 2005). Other newly diagnosed patients with cancer emphasized the importance of individualized communication within the context of a crisis process and being given timely follow-up appointments (Salander, 2002).

Education

Women reported limited knowledge regarding support services and most healthcare professionals did not offer information about community resources. Other studies have reported dissatisfaction with information regarding psychosocial and practical issues (Ferrell, Smith, Ervin, et al., 2003; Fitch, Gray, & Franssen, 2001). Because various studies have emphasized the need for peer support with women facing the same illness (Ahlberg & Nordner, 2006; Bowes et al., 2002; Ferrell, Smith, Ervin, et al.; Fitch et al., 2000; Thompson, 2005), development of an Internet-based tool kit would assist providers and women with locating support resources (see Figure 3 for additional strategies).

Symptom Management

Women experienced significant distress and fears of recurrence at various time points. For example, women reported intermittent anxiety prior to periodic checkups and increased vulnerability during milestones such as completion of therapy (Hoskins & Haber, 2000; Lee et al., 2006; Schaefer, Ladd, Lammers, & Echenberg, 1999). Other studies support that women experience fears of recurrence after completing therapy (Ekman et al., 2004), which leads to physical hypervigilance, including anxiety associated with experiencing vague symptoms (Thompson, 2005; Schaefer et al.). Brief screening measures completed in the clinic may help to identify women at increased risk for distress (Fitch, 2003; Kornblith et al., 1995; McCorkle et al., 2003). Research supports the benefits of intervention by advanced practice nurses in reducing distress in newly diagnosed women (McCorkle et al.).

Future Research

Further research is needed regarding ovarian cancer-specific interventions (Thompson, 2005) that include a group support component (Ahlberg & Nordner, 2006). Conceptual models, such as the Theoretical Model of Appraisal and Coping (Folkman & Greer, 2000), the Medical Crisis Counseling Model (Koocher & Pollin, 2001; Shapiro & Koocher, 1996), the Social Cognitive Transition Model (Brennan, 2001), and the Hope Process Framework (Farran et al., 1992, 1995), may provide a framework for nursing interventions because they focus on enhancing well-being, perceived support, and control. Furthermore, interventions that enhance sense of control may facilitate coping and hopefulness (Buckley & Herth, 2004; Bunston et al., 1995).

Because women experience considerable distress at various transition points, such as the time of diagnosis and recurrence (Ferrell et al., 2005; Fitch, Deane, & Howell, 2003; McCorkle et al., 2003), targeted interventions are needed to support women at critical points during the illness (Ferrell et al., 2005; Thompson, 2005). Research supports the benefits of a phased approach in delivering interventions that account for concerns over time (Hoskins, 2001; Hoskins

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- Expedite timely follow-up appointments and referrals, especially during the diagnostic period.
 - Provide options and encourage active involvement in decision making.
 - Assess education needs and clarify information presented on Web sites or from other sources.
 - Listen to concerns and balance the communication of information with the need to maintain hope.
 - Provide information about community resources, support groups, ovarian cancer list serves and advocacy groups (e.g., Association of Cancer Online Resources; *Conversations*; Ovarian Cancer National Alliance, the National Ovarian Cancer Coalition).
 - Refer women to and lead or colead support groups.
 - Screen for psychosocial distress using brief screening measures and refer to appropriate services.
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Figure 3. Strategies to Facilitate Communication and Sense of Control

Note. Based on information from the Association of Cancer Online Resources, 2007; *Conversations*, 2006; Dickerson et al., 2006; Felder, 2004; Fitch, 2003; Henman et al., 2002; Lammers et al., 2000; National Comprehensive Cancer Network, 2007; Ovarian Cancer National Alliance, 2007; Pilkington & Mitchell, 2004; Salander, 2002; Wright et al., 2004.

& Haber, 2000; Krupnick, Rowland, Goldberg, & Daniel, 1993). Because women do not always perceive that they receive adequate support from family and friends (Ekman et al., 2004; Ferrell, Smith, Ervin, et al., 2003; Schaefer et al., 1999), including significant others in interventions may facilitate adjustment.

Successful interventions require flexibility (Targ & Levine, 2002) and consideration of patient preferences (Carlsson & Strang, 1996; Lee et al., 2006; Palmer, Kagee, Coyne, & DeMichele, 2004). Group support approaches include traditional in-person groups, complementary therapy groups, various Internet-based forums, and telephone and community-based interventions (Davis, Cohen, & Apolinsky, 2005). As a result of geographic, illness, and cost limitations, interest in alternative modalities for delivering support and education has increased (Wilmoth, Tulman, Coleman, Stewart, & Samarel, 2006). Creative interventions, such as Internet- and telephone-based groups, may be more effective in reaching greater numbers of women because ovarian cancer is less common than breast and other cancers. The flexibility, convenience, and cost-effectiveness of the Internet, including Web-based support groups and nursing interventions, merit further research to assess the benefits (Dickerson et al., 2006; Winzelberg et al., 2003) and limitations of these forums (Im, Chee, Tsai, Lin, & Cheng, 2005; Winzelberg et al.). Searching for meaning and spirituality are common themes in the ovarian cancer population; therefore, including complementary therapies in intervention research may be desirable because they focus on well-being (Lengacher et al.,

2006), spirituality, and finding innate meaning in situations (Targ & Levine; Taylor, 2005).

Conclusion

Women with ovarian cancer are vulnerable because of the unique challenges they face in the context of living with a life-threatening illness. Women with high levels of support and perceived control were best able to transform the death sentence and find meaning in the experience. Evidence-based interventions and strategies are needed to foster communication, symptom management, peer support, and spirituality. Holistic interventions that focus on enhancing support, perceived control, and hope should be a priority for future nursing research.

The author gratefully acknowledges the special women who generously shared their time and experiences and are applauded for being a source of hope, courage, and inspiration in helping other women facing ovarian cancer and advancing research in this area; her dissertation chair, Mary Elizabeth O'Brien, PhD, RN, FAAN; committee members, Janice Agazio, PhD, CRNP, RN, Marilyn Tuls Halstead, PhD, RN, AOCN®, and Elizabeth A. McFarlane, PhD, RN, FAAN; James F. Barter, MD, FACOG, and Jonathan A. Cosin, MD, FACOG, FACS, for their review and contribution to the study design; Patricia Goldman, president emeritus of the Ovarian Cancer National Alliance; and the nurses, doctors, and community leaders who helped facilitate this research. Special thanks are extended to Diane G. Cope, PhD, ARNP, BC, AOCNP®, for her thoughtful review and comments on this article.

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