One Step at a Time: Self-Management and Transitions Among Women With Ovarian Cancer

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Women with ovarian cancer often experience late-stage diagnosis, immediate major surgery, and an arduous chemotherapy regimen (Jemal, Siegel, Xu, & Ward, 2010). Effective self-management of the cancer and its psychosocial ramifications is critical to women's quality of life (Lowe, Ferrell, & Leong, 2007). Self-management includes the tasks that individuals undertake to deal with the medical, role, and emotional management of their health condition (McCorkle et al., 2011). Self-management is a daily, interactive, and dynamic process requiring skills such as problem solving, goal setting, decision making, resource use, forming patient-provider partnerships, action planning, and self-tailoring (Grey, Knafl, & McCorkle, 2006; Lorig & Holman, 2003).

Development of self-management skills is particularly urgent for women with ovarian cancer as frequent recurrence, limited treatment options, and an often short prognosis abruptly propel these women into a period of intense transitions (Power, Brown, & Ritvo, 2008). Transitions, or passages between two relatively stable periods of time during which an individual moves from one life phase, situation, or status to another (Schumacher, Jones, & Meleis, 1999), are times of vulnerability to risks that may influence health and well-being (Davies, 2005). Experiences of self-management and transitioning may be more intensive in ovarian cancer than in some other cancers because of its shorter prognosis that condenses the duration of self-management. The purpose of this exploratory study was to describe self-management experiences among women with ovarian cancer, particularly during transitions between health and illness. Having a clearer picture of how women with ovarian cancer handle their health and well-being during such transitions will assist in the development of interventions that teach self-management skills for women with advanced cancer.

Purpose/Objectives: To describe experiences of self-management and transitioning among women with ovarian cancer.

Research Approach: Interpretive description.

Setting: Participants' homes.

Participants: Purposive sample of 10 women with ovarian cancer.

Methodologic Approach: Individual interviews about women's self-management and transition experiences.

Main Research Variables: Self-management, transitions, and ovarian cancer.

Findings: Participants self-managed to increase their sense of control and to self-advocate. They managed their care one step at a time to prevent becoming overwhelmed. Common transitions were diagnosis, surgery and recovery, starting chemotherapy, managing symptoms, and recurrence. Transitions were challenging, even if previously experienced, and influenced the ability and willingness of women to self-manage. Barriers and facilitators to self-management were identified.

Conclusions: The approach to self-management of one step at a time is somewhat illusory, as women face multiple transitions simultaneously. The short trajectory of ovarian cancer leaves little time between transitions and an awareness of mortality. Women are forced to confront goals of care quickly, which may affect their ability to self-manage.

Interpretation: Women with ovarian cancer need clinical and social support to prioritize and manage transitions. Introducing palliative care shortly after diagnosis could facilitate women's anticipation of and adjustment to transitions.

Ovarian Cancer

In 2012, about 22,280 women will be diagnosed with ovarian cancer (American Cancer Society, 2012). Detected at its earliest stage, ovarian cancer has a five-year survival rate of 89%; however, diagnosis often occurs at advanced stages as a result of subtle physical symptoms and lack of effective screening techniques (Buys et al., 2011; Clarke-Pearson, 2009; Dutta, Wang,

Phalen, & Fishman, 2010). Five-year survival rates for ovarian cancer decrease significantly through later stages, dropping to 18% at stage IV (American Cancer Society, 2012). Although standard treatment achieves a complete clinical response in about 80% of women with advanced disease, 70%–90% of these women will experience recurrence (Gardner & Jewell, 2011). Women with ovarian cancer are treated with a range of second-, third-, and fourth-line protocols and, because of this aggressive approach, women are living longer (Lowe et al., 2007), making self-management strategies important for managing transitions and for improving quality of life (Gardner & Jewell, 2011; Grzankowski & Carney, 2011).

Transitions Theory

This study was guided by the nursing theory of transitions. Transitions are a nursing concern when they pertain to health or illness or when responses to transitions include health-related behaviors (Chick & Meleis, 1986). Schumacher and Meleis (1994) identified four types of transitions: developmental, situational, organizational, and health-illness. The current study focuses on health-illness transitions, which are changes that occur following the onset of illness. In a previous study (Schulman-Green et al., 2011), the authors proposed two types of health-illness transitions: personal and care. Personal transitions include physical (changes in symptom distress and functioning), emotional (times of psychological and emotional upheaval and adjustment), and social transitions (shifts in family functioning and routines or roles played). Care transitions include shifts in cancer status, treatment, or approach to care (curative, palliative, or hospice care). In the current study, the authors' goal is to elucidate how women with ovarian cancer self-manage during such health-illness transitions.

Self-Management and Transitions in Ovarian Cancer

Little is known about how women with ovarian cancer self-manage, and the authors could not identify any previous literature documenting how women with ovarian cancer transition. This unique population must manage side effects of the cancer and its treatment, psychological and emotional problems, social and financial difficulties, and sexual issues (Grzankowski & Carney, 2011). Common challenges include uncertainty, existential fears, and lack of control, which affect women's daily lives, relationships, and families (Howell, Fitch, & Deane, 2003). Clinicians may not provide adequate support because of time constraints and an underestimation of women's needs (Fitch & Steele, 2010; Power et al., 2008; Schulman-Green, Ercolano, Dowd, Schwartz, & McCorkle, 2008) and have advocated self-management for women with ovarian cancer (Lydon, Beaver, Newbery, & Wray, 2009).

Women with ovarian cancer vary in their preference to self-manage (Elit et al., 2010; Jolicoeur, O'Connor, Hopkins, & Graham, 2009; Ziebland, Evans, & McPherson, 2006); some prefer that clinicians manage their care while others prefer shared decision-making. Involvement of family and friends in self-management has been described (Klitzman & Chung, 2010). Prior studies have outlined the *what* and *who* of self-management, but exactly *how* women with ovarian cancer self-manage requires clarification, particularly during health-illness transitions.

Methods

Participants and Procedures

The authors recruited a purposive sample of 10 women diagnosed with ovarian cancer who were aged 18 years or older, English-speaking, and receiving any type of treatment. The women ranged in age from 35–72 years, with a mean age of 57.1. All were Caucasian, non-Hispanic. Six of the women had stage IV ovarian cancer, and the median length of time since diagnosis was 16 months (range = 4–65 months) (see Table 1).

Potential participants were referred by a nurse at the participating cancer center. Following consent, each woman was individually interviewed in her home, as requested. On average, interviews lasted 60 minutes, with a range of 30–105 minutes. Interviews began with the question, "How do you generally manage your

Table 1. Participant Characteristics

Characteristic	n
Ovarian cancer stage	
I	2
II	–
III	2
IV	6
Time since diagnosis (years)	
Less than 1	2
1–2	6
More than 2	2
Education	
Trade or technical school	1
Some college	4
College graduate	3
Graduate school	2
Marital status	
Married	4
Divorced	3
Widowed	2
Single	1
Religion	
Catholic	5
Protestant	2
Jewish	1
None	1
Other (unspecified)	1

N = 10

cancer care?" followed by questions on how transitions were experienced and managed. Interviews were digitally recorded and professionally transcribed. Because this population may potentially experience high distress (Grzankowski & Carney, 2011; Schulman-Green et al., 2008), the authors used specialized interview techniques (Schulman-Green, McCorkle, & Bradley, 2009–2010), such as frequent assessment of the women's physical and emotional comfort, to be sensitive to participants and obtain high-quality data. After each interview, the transcript was compared to every transcript that preceded it. Although small, the sample size was adequate to get a meaningful description of participants' experience in the context of an exploratory study. This study was approved by the human subjects research review committee at the School of Nursing at Yale University.

Data Analysis

The authors used interpretive description to generate themes describing how women with ovarian cancer self-manage their cancer care and related health-illness transitions. As a qualitative method, interpretive description employs principles for analytic frameworks, sample selection, data analysis, and rigor to conduct inquiries into human health and illness experiences (Thorne, 2008). The authors began by listening to each recorded interview while reading the accompanying transcript to get a general sense of the interview. During a second review of the transcript, data were openly coded with descriptive phrases to capture key concepts. Once this process had been completed by two members of the research team for the first three transcripts, the coders met to compare and discuss until agreement on codes and their meanings was achieved (Bradley, Curry, & Devers, 2007; Miles & Huberman, 1994) and a coding scheme was produced. The authors documented their ideas and questions about the data and, as new concepts were identified in subsequently reviewed transcripts, an iterative process was used to consolidate codes into conceptual categories. The final code key was applied to all transcripts and Atlas.ti® qualitative software was used to facilitate data organization. The authors then analyzed and integrated codes to discover themes that described women's self-management and health-illness transitions. Data were triangulated by discussing results of the analysis with two of the study participants as well as with experts in ovarian cancer and self-management.

Findings

Participation in Self-Management

To varying degrees, all of the participants were interested in self-management. Two main reasons participants wanted to self-manage were to have a sense of control over what was happening to them and to be their own advocate. Understanding their cancer treatment, prognosis, and what to expect over time helped participants to maintain a sense of control over what was happening to them. A participant explained how self-managing reduced her uncertainty.

> Nobody wants to be faced with their own mortality, but, when you're diagnosed with cancer, that's the first thing you think about, "Oh, my lord, am I going to die? And if I'm going to die, what's going to happen to me? What can I do to help myself?" I want to be in control of my own destiny.

Another participant described how self-managing helped her to feel calm.

> That's calming when you feel you have some control over what seems like an out of control situation, when you know what you can do.

Some participants felt compelled to self-manage because they felt if they did not take ownership of their health care, no one would manage it for them.

> I think people are beginning to realize that the healthcare system . . . the doctors are so focused on their one area and have so many patients that if you don't advocate for yourself, nobody else is going to do it for you.

Another participant described her self-advocacy.

> I don't know what people do if they're not proactive. I mean, I'm on top of everything, "Did you do this? What about this?"

Self-Managing One Step at a Time

A main theme in the data was that of managing care one step at a time. In other words, women took a short-term approach to managing their care, dealing only with the immediate situation or need with which they were confronted instead of taking a long-term or broader approach. Self-managing one step at a time helped to prevent becoming overwhelmed with fear, uncertainty, anxiety, or too much information. A participant explained how the short-term approach mitigated her fear of the future.

> I'm scared actually to look at the future. I try to think of it one step at a time. . . . Some of what I've learned, having gone through this, is just try to look at today. Don't look too far ahead. I try to take it one day at a time.

Another participant shared how she did not want to know her prognosis; she preferred to deal with her situation on a day-to-day basis.

> When I first came down with the cancer, I didn't really specifically ask for a prognosis because I didn't

want to hear them say, "You're going to die in two years." We just didn't go there, and in a way that was better for me because I could deal with it on a day-to-day basis and not look at that kind of issue.

Still another participant took the approach of one step at a time because she realized that aspects of her care or of her life would change unpredictably.

I deal with what comes along next, probably because I know it will change. Why do I have to deal with next week or the week after that? Like trying to . . . give them an estimate of when I'll return to work. It's like, "I don't know," 'cause I don't know what's really coming. It's not like with surgery where, in about six weeks, physically, you should be able to go back. It's not quite like that. I try to, I guess, plan for as short a term as I can.

The same woman described prioritizing what she would manage.

I always go by priority. I need to know about this critical symptom. I need to know what to do about this. This is what's on my mind, and other things are just pushed on the back burner because they're not as important.

Transitions as Challenging Steps

Commonly reported transitions included specific events, including initial diagnosis, surgery and recovery, starting chemotherapy, managing symptoms, and recurrence. These and other transitions were perceived as the process the women encountered in their experience with ovarian cancer. The women described self-managing from one step to the next because these transitions came one after the other, often overlapping and with short intervals in between. In the self-management process of one step at a time, goal-setting often meant getting to the next anticipated step (i.e., making it to the next event or activity with which participants had to cope). In that respect, transitions were described as challenging, even if the same or a similar transition had been experienced before, such as starting a new chemotherapy cycle.

Influence of Transitions on Self-Management

Participants' experiences illustrated how transitions influenced their ability and willingness to self-manage. For example, the physical transition of mental confusion as a side effect of taking pain medication prevented full, active participation in self-management. One participant said, "There was a time period where I was really foggy. There's no way I could have taken a leading role. . . . I was like just kind of out of it for several months, pain killers and you know."

Emotional transitions, including increased anxiety, sadness and, most prominently, uncertainty, hindered self-management. Being distressed and not knowing what to expect made it difficult to engage in decision-making. Emotional transitions were usually precipitated by other transitions, which affected self-management. For example, a participant who had a response to treatment described her increased uncertainty about her self-management plan.

Well, now I've had to transition, I think, even again, from "I'm going to die" to "not right now." I would say there's no way to know how long, but, at least for the foreseeable future. It's been difficult. It's hard to plan what I'm going to do, not knowing whether I'm going to be in treatment or not. So, I'm kind of in limbo.

Ongoing uncertainty made it difficult to keep up the ability and willingness to self-manage.

It's like stamina for getting through it all—keep it positive and look for what you need for all these months. You can do it if you know it's like a month, but I have to keep going, and that's hard to do sometimes. To feel like you can keep that upbeat. "Can't this be over with tomorrow? Do I have to keep going for that long?"

Another way transitions affected self-management was that participants delegated self-management to others when they struggled with transitions, particularly physical and emotional transitions.

When I was recuperating from the surgery, I was so out of it that it was hard to even ask any questions or take in the information. . . . I had to rely on other people because I'd get home and I'd say, "What did [the doctor] say?"

Barriers and Facilitators to Self-Management

Although participants described having very trusting relationships with their physicians, time constraints, getting differing opinions on treatment options, and problems navigating the healthcare system inhibited self-management. A participant who wanted information to self-manage described how, because of time constraints, she had to be proactive about getting answers to her questions. "I think if [my doctor] could spend a little more time with people, that would be better . . . without me having to put my foot down. Literally, I was like, 'Stop, I need to ask you a question.'" This participant described not knowing which clinician to go to for answers.

I was conversing with the nurses and my doctor at the same time. I couldn't make any decisions at that point and they couldn't help me . . . they just said, "We're only dealing with the surgery part of it. You need to get in touch with. . . ." Did they

say the neurologist? So [because I was confused] I called my gynecologist. In fact, he was upset. He said, "Why didn't you tell me?" I said, "I didn't think you were the doctor to call."

Several facilitators of self-management also were identified. Having partners in self-management was extremely important. Both family members and clinicians were welcomed as partners. A participant related how family members helped her to get information and make decisions, but that she was the ultimate decision-maker.

> My family would call me and I talked to my cousin about it. He wouldn't tell me what to do. He'd say, "Who did they refer you to? Would you like me to look up [someone] . . . I know some people." "Okay, fine, go ahead and do that. That's fine." . . . And so I sought family out as a sounding board. They didn't make the decisions for me, though. I made the decisions.

Participants placed great trust in their physicians and generally followed their physicians' advice after discussion. Such partnership and communication with their physicians were seen as very important to obtain information, to weigh decisions, and to get reassurance. One participant described her partnership with her clinicians. "I like to hear the facts—what would happen if you did it and what would happen if you didn't, and, for the most part, I trust the doctors that I've had."

A facilitator of particular importance was having some sense of what to expect, which reduced uncertainty and imparted a sense of control. A participant explained,

> I got more information . . . you know, what was actually going on. . . . I had more of a handle on things, and my family had time to get used to things a little bit, how different it was going to be and what the time frame was. By November, I'll probably be starting back to feeling better and recovering and it's temporary. I'm not going to feel this way forever. To be able to say that, kind of see a goal. Whenever you set a goal, or see that you have information—here's what you have to do to get where you want to be—it's a lot better.

Empowerment was also a key facilitator of self-management. Some participants were reticent to self-manage because they hadn't yet found their voice. One participant shared how she hid her desire for support.

> [The nurses] will always ask, "How you doing?" and of course I'm saying, "I'm doing pretty good," so they don't have a clue that I really need to talk to somebody. A lot of it, probably, is my needing to initiate things more, but it's hard to do.

Empowerment came from family members and clinicians. A participant described how her husband encouraged her to speak up.

> [My husband says,] "Don't you go in and say everything is okay when everything is not okay." I said, "Okay, I won't." So the first thing, [the doctor] comes in and goes, "How are you?" and I said, "We were just fighting, but I'm fine. I'm doing much better starting about now," which was true.

Another participant described how she needed encouragement to become a self-manager, but that she was able to do it with just a small prompt.

> I'm the type of person that I don't want to bother anybody, so I was very quiet. . . . You don't know what the routine is, but I was that way for a little while longer because I never wanted to rock the boat. Finally, one of the [nurses] yelled at me in front of everybody one day, and they said, "Look!"—and it was something as simple as I was having a hard time having a bowel movement—and they said, "This is what we're here for. It doesn't matter. We don't get offended. We don't get upset. We're here for you." So, from that day on, I told them everything, and to this day I still call them.

Discussion

The study offers preliminary data on how women self-manage when confronted by a life-threatening cancer accompanied by a shorter trajectory. Using personal accounts, the authors described the interplay between self-management and transitioning and identified specific challenges and supports.

A key finding was that participants managed their care one step at a time. The data indicate that, although self-management seemed to proceed one transition at a time, in actuality, with each step, multiple transitions arose. For example, starting second-line chemotherapy triggered new symptoms and anxiety. Because patients focused on the transition they perceived to be the most important, this may have given the illusion of self-management proceeding one step at a time. In addition, a conscious or unconscious shift of particular transitions from the foreground to the background may take place over time, as has been described with individuals' shifting perspectives on illness and wellness (Paterson, 2001). For example, the physical transition of recovering from surgery may ebb as the emotional transition of coping with the diagnosis emerges. The approach of one step at a time may prevent becoming overwhelmed. However, the findings suggest that therapeutic intervention must address the trigger transition as well as all of the subsequent transitions it

engenders, particularly because concurrent transitions intensify each other (Chick & Meleis, 1986). Patients may require assistance to prioritize which transition to deal with first.

The participants also reported that a repeat transition was as challenging as an initial transition; this contrasts with findings from the authors' previous study of women with breast cancer (Schulman-Green et al., 2011) in which participants reported that experience with a transition made subsequent similar transitions easier. That difference may be explained by the role of time in the management of transitions. Women with ovarian cancer may experience transitions in more rapid succession than do women with breast cancer, leaving less time to rally between transitions. The struggle with transitions may be compounded by the women's awareness that ovarian cancer is more life threatening and has a shorter prognosis than some other cancers (Ferrell, Smith, Cullinane, & Melancon, 2003; Howell et al., 2003). That awareness forces women to confront goals of care sooner after initial diagnosis than might be the case with other cancers, which may affect women's ability and willingness to manage transitions. That thought is supported by transition theory, which postulates that differences in perception of a transition can affect reactions and responses to the transition (Chick & Meleis, 1986). Early introduction to palliative care can provide ongoing support to women with ovarian cancer as they contemplate their goals for living.

Limitations

A few limitations to this study should be noted. One is that the sample is fairly homogenous. Although Caucasian women have the highest incidence rate of ovarian cancer (Centers for Disease Control and Prevention, 2010), future work should explore how non-Caucasian women with ovarian cancer self-manage and negotiate transitions. Additional research also is needed to determine how this phenomenon is experienced in populations with other types of cancer or with other serious illnesses, including those that affect men. In addition, although a small sample size is appropriate in qualitative research, the current small sample size inhibited the authors' ability to examine differences in the sample by stage of ovarian cancer.

Conclusion

To the authors' knowledge, this study is the first to examine self-management and transitions among women with ovarian cancer. An understanding of their experiences will inform future work aimed at assisting these women to effectively self-manage during an extremely challenging time. Nurses caring for women with ovarian cancer should be alert to common transitions these patients experience to ensure adequate support. Future research should examine this phenomenon in individuals with other cancers that manifest with sudden, advanced diagnoses, such as pancreatic and some forms of lung cancer. Such work would help to clarify the role of time in management of transitions.

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