The Experience of Being Aware of Disease Status in Women with Recurrent Ovarian Cancer: A Phenomenological Study

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Abstract

Background: Awareness of disease status has been identified as a factor in the treatment decision-making process. Women with recurrent ovarian cancer are facing the challenge of making treatment decisions throughout the disease trajectory. It is not understood how women with ovarian cancer perceive their disease and subsequently make treatment decisions.

Purpose: The purpose of this phenomenological study was to understand the lived experience of women with recurrent ovarian cancer, how they understood their disease and made their treatment decisions.

Methods: A qualitative design with a descriptive phenomenological method was used to conduct 2 in-depth interviews with 12 women ($n=24$ interviews). Each interview was ~60 minutes and was digitally recorded and professionally transcribed. Data collection focused on patients' understanding of their disease and how patients participated in treatment decisions. A modified version of Colaizzi's method of phenomenological reduction guided data analysis.

Results: Three themes emerged to describe the phenomenon of being aware of disease status: (1) perceiving recurrent ovarian cancer as a chronic illness, (2) perceived inability to make treatment decisions, and (3) enduring emotional distress.

Conclusions and Implications: This study revealed how 12 women conceptualized recurrent ovarian cancer as a chronic disease and their perceived inability to make treatment decisions because of lack of information and professional qualifications, resulting in enduring emotional distress. Future research should replicate the study to confirm the persistence of the themes for racially, ethnically, and religiously diverse patient samples and to improve understanding of awareness of disease status and decision-making processes of patients.

Keywords: awareness; disease status; ovarian cancer; phenomenology; qualitative

Introduction

OVARIAN CANCER claims the lives of 14,000 women in the United States each year as another 22,000 receive a new diagnosis for the same disease.¹ The majority of women diagnosed with ovarian cancer present with advanced-stage disease because of lack of effective early screening measures.² The first-line treatments for advanced ovarian cancer are surgical cytoreduction and platinum- and taxane-based chemotherapy.² Patients with recurrent ovarian cancer have

more options today because of advances in treatments, specifically, with the advent of immunotherapies.³ After receiving first-line treatment, however, ~75% of advanced-stage ovarian cancer patients will have disease recurrence within five years that will ultimately lead to death.² There continues to be a slight increase in the five-year survival rate, but it has not surpassed 47.4%.^{1,4}

Researchers have noted that awareness of disease status is one of the factors that impact the treatment decision-making process among patients with ovarian cancer.⁵ Two systematic

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reviews have demonstrated there is lack of consistency in conceptualizing and operationalizing the concept of awareness of disease status,^{6,7} resulting in the inability to compare across cases and a limited understanding of awareness of disease status in patients with cancer. Only three articles have used qualitative approaches to explore the concept of awareness of disease status in adult cancer patients.^{8–10} The aims of these studies varied. One was to understand how patients understood and discussed prognoses,⁸ another was to determine the discrepancy between the information patients receive and their awareness,⁹ and the last sought to determine how patients cope in relation to their awareness.¹⁰ Each of the studies had participants with various cancer types and prognoses. Three qualitative studies captured the complexity of cancer experience from the patient's perspective,^{8–10} yet because of the variation in objectives of the studies, methodologies, and patient populations, no conclusion can be made about a patient-centered conceptualization of awareness of disease status from these studies. Thus, it is important to understand how patients with recurrent ovarian cancer describe their own experiences of being aware of their disease status.

Aim

The purpose of this phenomenological study was to understand the lived experience of being aware of disease status among women with recurrent ovarian cancer. This study sought to answer the following questions: (1) What was "disease status" from the perspective of patients with recurrent ovarian cancer? (2) What was "being aware of disease status" from patient's perspective? (3) How did "being aware of disease status" shape patients' lives and treatment decisions?

Design

A qualitative approach with a descriptive phenomenological method was used to gain an in-depth understanding of the phenomenon to capture the lived experience of a phenomenon and to provide an improved definition or conceptualization.^{11–13}

Ethical Consideration

Institutional Review Board approval for this study was obtained from the university and the cancer center.

Recruitment

Women with recurrent ovarian cancer were recruited from the outpatient gynecological medical service of one large metropolitan cancer center. The inclusion criteria were as follows: (1) older than 21 years of age (recommended age by the participating physicians), (2) diagnosed with recurrent ovarian cancer, (3) had received at least two chemotherapy regimens and were currently receiving treatment, (4) their primary oncologist had estimated a prognosis of at least six months to live, and (5) able to speak and understand English. Participants were excluded if they were (1) too sick to participate, (2) no longer receiving treatment, or (3) not emotionally stable.

Participants and Sample Size

Purposive sampling was used to capture the experience of the phenomenon under investigation.^{14,15} Sampling continued until data were saturated, which in phenomenological studies can range from as few as 5 participants to up to 15.^{14,15} Participants were recruited purposively from six different medical oncologists to account for potential variation of experience because of providers' communication and practice styles.

Data Collection

Each of the women in the study was interviewed twice; the second interview occurred two to four weeks after the first interview. Each interview was ~60 minutes and was digitally recorded and professionally transcribed. Data collection for the first interview focused on patients' understanding of their disease, factors that impacted their understanding, how patients participated in treatment decisions, and the impact of being diagnosed with and treated for recurrent ovarian cancer. During the second interview, participants were asked similar questions to clarify certain statements that were not clear or needed more exploration during the first interview. Data were collected from February 2016 to April 2017.

Data Analysis

A modified Colaizzi's seven-step method was used for data analysis. It is an iterative refinement process to ensure no detail of the phenomenon is missed (p. 59) (Fig. 1).¹⁶ Data analysis began after the transcription of the first interview. Findings were discussed with a group of experts to ensure adequate analysis and interpretation of the data.

Rigor and Trustworthiness

Credibility of this study was ensured by adhering to the following procedures. First, the primary researcher (C.S.F.) was trained by a phenomenological expert (M.R.F.) to conduct the study. Second, the accuracy of these transcriptions was confirmed by listening to the recording of each interview while checking against the transcripts. Third, the emergence of similar data from interviews 1 and 2 demonstrated strong evidence for dependability. Fourth, inter-rater reliability was determined by using NVivo software between researchers C.S.F. and A.D. Fifth, a group of experts discussed the analysis and came to a consensus about the results.

Findings

Fifteen women were enrolled in the study, two patients became too sick to participate, and one was excluded because she was no longer receiving treatment. A total of 12 patients completed the study. The sample size of 12 was determined by data saturation, that is, no new information or new themes would emerge from interviewing additional participants.^{17,18} Data were saturated at 10 participants, and an additional 2 participants were recruited to ensure no new information was missed. All had a diagnosis of recurrent ovarian cancer and were currently receiving treatment. The mean age of the participants was 58 years with a range of 44–74 years and 83% self-identified as white and the remaining as African American, thereby matching national statistics of disease incidence. Participants differed in religious affiliations,

FIG. 1. A modified Colaizzi's seven-step method for data analysis.

marital status, education level, and years with ovarian cancer. Tables 1 and 2 provide their demographic information.

Each of these 12 women had different experiences with the diagnosis of recurrent ovarian cancer. Despite the differences, there were shared essential experiences of how they understood their disease status, the process of making treatment decisions, and emotional distress of managing recurrent ovarian cancer.

Three themes emerged that described the phenomenon of being aware of disease status: (1) perceiving recurrent ovarian cancer as a chronic illness, (2) perceived inability to make treatment decisions, and (3) enduring emotional distress. These three themes comprise the phenomenon of "Being Aware of Disease Status."

Perceiving recurrent ovarian cancer as chronic illness

None of the women felt death was imminent, regardless of a diagnosis of recurrent ovarian cancer despite its incurability. The participants believed that there were more treatment options available for recurrent ovarian cancer and that there was the possibility to keep the disease "stable." All 12 women recognized that they would "have cancer forever" or "be

on chemo" for the rest of their lives. As Emily stated: "That is just like you have something to help you maintain the disease that you have" or as Melissa remarked: "Something that you're diagnosed with that there's no cure for it. But it could be managed clinically."

Many of these women acknowledged the precarious nature of their disease but expressed that there would always be more treatment for managing the disease. Jessica, who died shortly after her two interviews, stated: "I'll assume that I have treatment options that lead somewhere other than death." Lindley understood that it was a chronic illness but did not necessarily think it was going to kill her: "I mean, the message [is like this]: This is a chronic illness that you can live with, that it's not going to absolutely kill you." This variation in perspectives was common among all participants and not attributable to specific participant characteristics.

Perceived inability to make treatment decisions

All the women faced numerous treatment options and felt unable to make their treatment decisions because they did not fully understand their treatment options. Four subthemes emerged to describe the phenomenon of perceived inability to make treatment decisions: (1) inability to fully understand

TABLE 1. DEMOGRAPHICS OF PARTICIPANTS

<i>Demographics</i>	<i>No. of participants</i>	<i>Percentage</i>	<i>Demographics</i>	<i>No. of participants</i>	<i>Percentage</i>
Age, years			Receiving treatment		
40–49	2	16.67	Yes	12	100.00
50–59	4	33.33	No	0	0.00
60–69	5	41.67	No. of chemo lines		
70–79	1	8.33	<3	2	16.67
Race			5	4	33.33
White	10	83.33	6	2	16.67
African American	2	16.67	7+	4	33.33
Marital status			No. of surgeries		
Married	7	58.33	1	3	25.00
Divorced	3	25.00	2	4	33.33
Widowed	1	8.33	3	2	16.67
Single	1	8.33	4	0	0.00
Children			5+	3	25.00
Adult	9	75.00	Drains		
Young	2	16.67	Yes	2	16.67
No	1	8.33	No	10	83.33
Education			Working		
HS	1	8.33	Yes	5	41.67
Some college	2	16.67	No	7	58.33
College	4	33.33	DNR		
Masters	3	25.00	Yes	0	0.00
MD/PhD	2	16.67	No	12	100.00
Religion			Currently alive		
Protestant	4	33.33	Yes	9	75.00
Catholic	6	50.00	No	3	25.00
Jewish	2	16.67			
Spiritual	1	8.33			
Years with cancer					
<2	1	8.33			
2–3	4	33.33			
3–4	2	16.67			
4–5	1	8.33			
5+	4	33.33			

HS, high school; DNR, do-not-resuscitate order.

the information on treatment options, (2) perceived lack of professional training to make treatment decision, (3) wanting doctors to make treatment decisions, and (4) perceived failure as being a partner in making treatment decisions. These four subthemes highlight the complexity and multidimensionality of this theme.

Inability to fully understand the information on treatment options. Universally reported was that conversations with their doctors were critical in helping them understand their disease and treatment options. They did not, however, think that they understood everything that was presented to them. Emily stated, “I wouldn’t say I got it, that is, I understood completely everything, but I kind of got the gist of what they were saying about.” Fay felt that she did not understand what was told to her about her treatment, “I think I learned things after the fact, not before. And I’d like to know before, good or bad. At least, I know what’s going on.” When participants felt they did not have enough information, they went on the Internet, although sparingly. Diane stated, “The main reason to look on the internet...you don’t hear everything, like you’re sitting there and like half of it doesn’t register.” Despite this, many of the women were not doing

online research because it is “depressing,” “disheartening,” “negative,” and “scary.” Table 3 has additional supporting quotes.

Perceived lack of professional training to make treatment decisions. Overall, patients expressed their lack of professional qualifications in making treatment decisions. Patty stated that she did not think she was qualified to make the decision, “Well, in the beginning, I was a little surprised. I’m thinking, well, these are my doctors. They should tell me what to do, you know? They’re the doctors.” Renee agreed that she did not have the credentials, “I don’t think that I had the credentials. I mean, they’re the experts, not me. And this is not my area of expertise.”

Wanting doctors to make the treatment decision. The perceived lack of information and qualifications provoked the desires to have their doctors make treatment decisions for them because they trusted that their doctors were professionally trained to do so. Jessica, who faced similar difficult treatment decisions like other participants, stated, “Something that I think, is...if it would be helpful of giving patient options. It’s kind of like, you know, I don’t go to the auto mechanic and say, ‘Okay,

TABLE 2. DEMOGRAPHICS OF INDIVIDUAL PARTICIPANTS

Pseudonym	Age	Ethnicity	Marital status	Children	Education level	Religion	Years with ovarian cancer	No. of chemo lines	No. of surgeries	Working	DNR	Alive
Anne	61	White	Married	2 Adult	College	Catholic	2.7	5	1	No	No	No
Diane	57	White	Married	2 Adult	Masters	Lutheran	4.7	6	2	Yes	No	Yes
Emily	60	AA	Widowed	2 Adult	2 Years college	Methodist	2.8	7	1	No	No	No
Fay	61	White	Divorced	2 Adult	College	Jewish	1.6	2	2	No	No	Yes
Heidi	65	White	Divorced	1 Adult	3 Years college	Catholic	3.3	8	2	Yes	No	Yes
Jessica	44	White	Married	2 Teens	College	Catholic	3.5	7	2	No	No	No
Lindley	74	White	Separated	2 Adult	PhD	Jewish	5.2	3	3	Yes	No	Yes
Mary	56	White	Married	1 Adult	College	Spiritual	2.5	7	1	No	No	No
Melissa	45	AA	Married	2 Young	DO	Episcopal	2.5	5	5	Yes	No	Yes
Patty	50	White	Married	1 Adult	HS	Catholic	6.5	5	6	No	No	Yes
Renee	55	White	Married	3 Adult	MBA	Catholic	7	5	5	Yes	No	Yes
Sarah	65	White	Single	No	Masters	Catholic	8	6	3	No	No	Yes

AA, African American; DO, doctor of osteopathic medicine.

should I use this wrench or that wrench or that wrench?" Like that's your job, which one's going to fix the problem better?" Her frustration, like other participants, was apparent: "Okay here are your choices, your chemotherapy drug choices. There's this, pros and cons. There's this, pros and cons. There's this, pros and cons. How the hell am I supposed to pick which one I should get? Which one is best for me? It's options and more options. I don't know if that's terribly helpful. I don't know *per se* what the outcomes are." She later explained that, "I felt like there should be somebody that's a lot more qualified than I am to make the choice. Well I see that that's why it is done that way. I get that, but I don't know, I guess, it just still seems a little absurd to be a part of that. I think there should be options and a recommendation."

Trusting in their doctors was one of the most important factors in making treatment decisions. As Emily stated: "I trust my doctor...I'm going along with what she said." Heidi mirrored this sentiment: "I was very confident in my doctor, so if he said okay, you're off this...then we'll try this one. Fine. Fine with me. What do you recommend? Okay, that's it. Then we'll do this one." The combination of trust and informed decision making became important aspects of their overall experience.

Perceived failure of being a partner in making treatment decisions. The perceived lack of information and qualifications impacted participants' perceptions of themselves as "partners" in decision making. When asked to explain their role in the collaboration, Mary stated, "I don't want to feel like I'm in the driver's seat because I just don't have the knowledge to earn that position on the bus, you know—but I do feel like it's a partnership." Heidi expressed a similar sentiment: "A partner? Well, I'm not a doctor, I don't have a degree, and I can read all about it all the time. How can I know one's better over something else, exactly—you know, the drugs or whatever." Lindley agreed that it was ultimately the doctor's decision, "Okay, doc, what do you recommend? Because I haven't been to medical school." A lack of clarity about the extent of their partnership role with the physician or its boundaries seemed to contribute to the sense of failure they experienced.

Enduring Emotional Distress

The presentation of a treatment choice also became a source of stress and anxiety for many of the participants. This is because the participants found themselves wanting to be able to make decisions, yet feeling that they did not have the information and qualifications to do so. Mary expressed her frustration with the decision-making process, "Every now and then I have a frustration that when it's time ... when it's decision-making time, we don't sit down and go, okay, here's all the options, and here's why I'm recommending this one. He generally comes in with, 'here's the situation, I think it's time to change, and here is my decision about it.'" Moments later she further explained this point by stating: "Okay, what am I supposed to do, like argue with him about is this one is better than gemcitabine or carboplatin, you know, it's kind of hard." Fay also expressed her stress about making treatment decisions:

"If I had the information, 'cause I probably would say, okay, listen this is what it is, you're an expert, not me. This is

TABLE 3. ADDITIONAL SUPPORTIVE QUOTES

Perceiving recurrent ovarian cancer as chronic illness	Fay: "It's like me having diabetes, you're not going to wake up one morning and it's gone." Lindley explains to people "it's a chronic disease like some people have diabetes or arthritis, and it's something that cannot be cured. But it can be kept on under control."	Mary: "you know, you've got mold in your basement, chemo is the bleach, but if you don't put a dehumidifier in, you know, after you've bleached the place, it just will come back. So his treatments are designed to kind of help the body be that dehumidifier."	Heidi: "there are days when I feel like, yeah, there's stuff that can be done to knock these tumors out and put me in remission for a while."	Renee: "I understand that this disease is not great. But you know what? I've been riding the wave of every new treatment. It's worked, so I'm being optimistic it will continue."	Melissa: "Something that you're diagnosed with that there's no cure for it. But it could be managed clinically."
Perceived inability to make treatment decisions	Jessica: "I have not been one to research everything and because that to me was extremely depressing. Everything I looked up about ovarian cancer, its viable rates and recurrence rates, I would be in a funk for a week..."	Patty: "I never researched anything on the computer. I don't think I had it in me to do that because I know and, and I don't mean this way I say it, but I don't want to hear other people's bad experiences, their sob story."	Fay: "You know, again, they give you the pamphlets. They give the printout. You read it. Everything is horrible. I means you go through and you read everything and a 'fatal event can occur', next line. What is the point? You say 'why am I reading this? I need it. It has to be done.'"	Melissa: "Well, you don't have any control. You're not the expert. And you have to have trust and go with the flow... Maybe there aren't options; well we could go this way, we could go that way. I don't know. Maybe this is what we have to do and that's it."	Sarah: "I'm not in charge because I don't think I have enough information about things. It's limited information. And I don't feel like I'm being given any options so that I can actually make a decision."
Enduring emotional distress	Mary: "Okay, what am I supposed to do, like argue with him about is this one is better than gemcitabine or carboplatin, you know, it's kind of hard."	Fay: "If I had the information, 'cause I probably would say, okay, listen this is what it is, you're an expert, not me. This is what's working and if it's not, there's other things you try. I probably wouldn't change it, but maybe I would have less anxiety if I knew what the steps were."	Patty: "If I would have thought of it as death or the side effects of menopause, what's worse? But I wasn't thinking of it that way back then. And that's what bothers me."	Diane: "And when they [doctors] describe extending life in terms of months, it's very depressing."	Emily: "Sometimes I'll say, okay, now if this doesn't work, what's the next step? And usually the answer is, don't worry. I'm a worrier. So if I know what the steps are and I can handle it better than if I am in the dark. Because then I concoct all kinds of things and I worry a lot more. But if I have specifics, I'll deal with the specifics. But the unknown is what gets me crazy."

what's working and if it's not, there's other things you try. I probably wouldn't change it, but maybe I would have less anxiety if I knew what the steps were...It's limited information. And I don't feel like I'm being given any options so that I can actually make a decision."

Their awareness of their disease status and overall comprehension of what it meant for their long-term survival therefore intersect to contribute to their perceived levels of emotional distress.

Discussion

The participants perceived their disease as chronic and did not think death was imminent, despite being diagnosed with a disease without a cure. They conceptualized recurrent ovarian cancer as a chronic disease only in the context of having more treatment options available to them. Such perception of recurrent ovarian cancer as a chronic illness is distinctly different from the existing conceptualization of the awareness of disease status from the health care providers' perspectives in terms of curability and survivability.^{10,14,15,19-32} Findings of the study suggest that it would be useful for researchers and clinicians to incorporate concepts of chronicity into their work with ovarian cancer patients. Furthermore, research is needed to provide comprehensive understanding of this phenomenon from perspectives of health care professionals (e.g., physicians and nurses).

As science continues to advance and more treatment modalities for cancer continue to develop, patients with recurrent ovarian cancer are facing the challenge of making more and more treatment decisions along the disease trajectory even in the terminal disease stage. The 12 women discussed their perceived inability to make treatment decisions because of lack of professional qualifications and lack of ability to understand treatment information. The combination resulted in stress and compromised well-being. The women in this study described their experience with being aware of disease status within the context that they had options today because of advances in treatments and could live longer with stable disease. Their perceived inability to make treatment decisions because of lack of information and professional qualifications resulted in enduring emotional distress.

This study's findings suggest three avenues for future research that could generate a short-term impact on the population and improve care overall in the long term. First, replication studies in various cancer patient populations and centers to further confirm the consistency and trustworthiness of the findings is critical. Another priority area for future research would focus on the understanding of the concept and process of shared decision making from the both perspectives of patients and providers. Participants in our study expressed that they had difficulty with the notion of "shared decision making." Yet, our participants did not provide data regarding the process of shared decision making. This line of research would ultimately help to develop and test interventions that would help patients make decisions in ways that would ease distress and reduce the perceived gap in partnership with physicians and their cancer care team. For example, a nurse-led intervention designed to assist patients become more informed and feel more comfortable with the decision-making process using dedicated time with a nurse would present the most efficient option given current constraints on clinical practice. Finally, because of the quality of the qual-

itative data and findings from this study, the development of a quantitative instrument that measures the concept of awareness of disease status in cancer patients—which includes the patient perspective of chronicity and disease management—would help providers adapt their communication and practice styles accordingly.

Limitations

There are limitations inherent in this approach and consistent with those found in all qualitative studies. Deeper understanding is the objective of a phenomenological study, not generalizability. Only through replication can the applicability of these findings to other individuals with metastatic cancers be determined. The participants in this study were also largely white middle-class women. More studies with patients from different racial, ethnic, and socioeconomic backgrounds are needed to address this limitation and determine where findings are consistent and diverge based on these factors. Furthermore, findings of the study were based on patients' experience from one cancer center; patients treated in different hospitals may have different perceptions regarding the phenomenon of being aware of disease because of availability of treatments, clinical trials, or the organizational culture of each cancer center.

Conclusions and Implications

The results of this study reveal how 12 women with recurrent ovarian cancer experience awareness of their disease status. The findings will help clarify conceptual and operational definitions of the concept of awareness of disease status in patients with recurrent ovarian cancer. Our study showed that patients had difficulties in making treatment decisions despite health care providers' efforts to promote shared decision making between patients and health care providers. Research and clinical practice should focus on developing interventions that provide patient-centered treatment information and effective patient-centered treatment decision-making skills and processes.

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Author Disclosure Statement

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