

STORIES OF TEAL: WOMEN'S EXPERIENCES OF OVARIAN CANCER

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ABSTRACT

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This dissertation explores the lived experiences of ovarian cancer. I used feminist ethnographic methods of in-depth interviews and focus groups to collect data from 28 ovarian cancer survivors in Northwest Ohio and Southern Michigan. The concepts of social support, uncertainty in illness, and intersectionality are used to understand women's experiences of the disease and their quality of life post-treatment. My grounded theory analysis shows the ovarian cancer experience as a process involving three phases including (not)making sense, owning the experience, and becoming a survivor. The phases are neither linear nor distinct, and each presents unique challenges to survivors, helping shape how they make meaning and communicate about their experiences. I identify managing uncertainty as the core variable in the ovarian cancer experience; uncertainty is high at diagnosis, plateaus during treatment, heightens again at the end of treatment, and remains in the backgrounds of women's lives as they navigate treatment aftereffects and/or recurrences. The ovarian cancer experience is influenced by women's age, religion, socioeconomic status, level of available social support, stage of disease, and treatment protocol. These factors work through and with each other to impact women's meaning making about the disease. This research helps demystify the ovarian cancer experience and puts human faces on the disease. It also provides a deeper understanding about the factors that influence women's experiences of ovarian cancer and the communicative strategies they use to determine their experiences.

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CHAPTER I. INTRODUCTION, BACKGROUND, AND RATIONALE

Women's health is a broad, complex, and an evolving topic whose understanding is shaped by economic, political, social, cultural, religious, legal, and medical issues. In the United States, the definition of women's health continues to expand with advances in research and technology to include all factors that directly and indirectly affect women's wellbeing (Office of Women's Health, 2002). The health of women is influenced by factors that impact population health and also by sociocultural norms, practices, and expectations. The multiple roles women play in society as wives, partners, daughters, mothers, and caregivers increase their vulnerability to stressors that adversely impact their health and general wellbeing (McDonough & Walters, 2001; Simon, 1992). Similarly, the value placed on the female body and societal pressure on women to look flawless to be considered attractive and beautiful burden the health of women and influence how we come to understand women and their health (Ellingson, 2004).

Social and cultural values attached to the female body lead to the seeming overvaluing of certain women's health issues (such as breast cancer) and undervaluing of some issues (such as ovarian cancer) (Holmes, 2006; Sulik, 2011). For instance, the position of the breasts on the female body and notions of the breasts as symbols of sexuality and womanhood have heightened anxiety about breast cancer, culminating in awareness, education and advocacy efforts (Holmes, 2006; Sotirin, 2004; Sulik & Zierkiewick, 2014). Critics argue, however, that the majority of such advocacy and awareness efforts aim to restore dignity to the feminine body or normalize its appearance instead of advocating for women empowerment and highlighting the embodied experience of the disease (Sulik, 2011). On the other hand, the position of the ovaries in the interior of the female body invokes less public attention about the organs and ovarian cancer (Holmes, 2006). Thus, feminist scholars and others consider an understanding of the "politics of women's body knowledge" including notions of health, illness, beauty, disability and aging as

essential to understanding women's health and related issues (Sotirin, 2004, p. 123). This is because knowledge about women's bodies shapes attitudes and beliefs about women's health and consequently, steps taken toward addressing issues that affect the totality of women's lives.

In this vein, it is pertinent that research that seeks to address issues and/or disease conditions related to women demonstrates an understanding of the broad issues impacting women's lives to enhance the perspectives offered. Thus, my aim in this dissertation project is to shed some light on how social, economic and medical issues, women's age, and characteristics of ovarian cancer influence women's experiences of the disease and their meaning making process. Such an analysis is important in not only validating the experiences of those affected by the disease, but also in providing survivors the space to challenge and address misconceptions about women's health. Additionally, this project aims to let the experience of ovarian cancer be narrated from the perspectives of survivors, as they have lived through it, to help demystify the disease, increase public awareness about it, and offer alternative narratives about the disease. This requires an investigation into the embodied experiences of ovarian cancer. It may be that the stories of ovarian cancer as told by survivors will be different from prevailing stories available in the public sphere; the stories may be upsetting to some people and can challenge normative notions about women's health and illness. But this can lead to advocacy, education, and awareness because then, people will understand what it "is like to have ovarian cancer" (DeShazer, 2003; Holmes, 2006).

Explaining Ovarian Cancer

Ovarian cancer is not a single disease; it refers to different types of tumors involving the ovary² (Alvarez, Karlan & Strauss, 2016). Ovarian cancer is the deadliest of all gynecologic

² Recent research indicates that many ovarian cancers do not originate in the ovary (see Alvarez, Karlan, & Strauss, 2016).

cancers³. Advanced epithelial ovarian cancer has the lowest survival rate and high recurrence and mortality rates (National Cancer Institute et al., 2012; Schink, 1999). Ovarian cancer is considered a chronic illness given the increasing number of women living with recurrent disease (Markman & Malviya, 2008). It is the fifth leading cause of cancer-related deaths in women in the United States (Centers for Disease Control and Prevention; CDC, 2010).

There are three main types of ovarian cancer including epithelial, germ cell, and sex cord (also known as stromal, or ovarian low malignant potential tumors, or borderline tumors, or atypical proliferative tumors). Of these, epithelial is the most common, accounting for 90 percent of all ovarian malignancies. Germ cell ovarian tumors are rare and affect mostly younger women (Matei, Brown & Frazier, 2013; Ng, Low & Arunachalam, 2012). Common risk factors for ovarian cancer include a family history of ovarian and/or breast cancer (for epithelial ovarian cancer), delayed childbearing, late menopause, early menstruation, and some environmental factors (Fleming, Beaugié, Haviv, Chenevix-Trench & Tan, 2006; Lalwani, Shanbhogue, Vikram, Nagar, Jagirdar and Prasad, 2010). Tests performed to diagnose and stage ovarian cancer include physical exam, pelvic exam, ultrasound, CT scan, CA 125 blood test, and biopsy; treatment options include surgery, radiation, and chemotherapy, depending on the type and stage of the tumor and whether or not patient wants fertility to be conserved (American Cancer Society, 2014).

Symptoms of the disease include swelling and/or pain in the abdomen and/or pelvis, vaginal bleeding after menopause, constipation, flatulence, and bloating; however, there can also be no obvious symptoms prior to diagnosis (American Cancer Society, 2014; Brain et al., 2014).

The majority of women with ovarian cancer are diagnosed at an advanced stage of the disease

³Gynecologic cancers are cancers that begin in female reproductive organs including the cervix, uterus, ovary, vagina, and the vulva.

due to inability of survivors and physicians to accurately read the early signs of the disease, contributing to the high recurrence and mortality rates (Bankhead et al., 2008; National Cancer Institute et al., 2012). Thus, the disease has long been described the “silent killer” because it supposedly presents no obvious symptoms until it has advanced; its growth is often slow and uncomplicated. However, many survivors claim the disease actually presents “shouting” symptoms such as bloating, flatulence, and abdominal swelling and pain even at its early stages; but symptoms are often attributed to other conditions, such as menopause, yeast infection and indigestion due to their generality (Bankhead et al., 2008; Gubar, 2012; Holmes, 2006). Ovarian cancer, thus, actually speaks through its symptoms but the “speech of ovarian cancer” (Gubar, 2012, p. 16) is often muted by both survivors and physicians. For instance, Holmes (2006) recounted retrospectively that prior to her diagnosis with ovarian cancer she had symptoms which she could not accurately interpret. Gubar (2012) also talked about how her “body yelled out repeatedly, loudly and clearly” (p. 56) with symptoms such as constipation and diarrhea for close to three years before her diagnosis. Similarly, Bankhead and colleagues (2008) found that ovarian cancer survivors experienced symptoms including postmenopausal bleeding (PMB), nausea, vomiting, and abdominal pain for about 12 months prior to diagnosis but “the terminology used by women to name their symptoms did not always accurately describe the symptoms they experienced” (p. 1012). Thus, ovarian cancer is often experienced in retrospect and there is never a complete resolution to the ovarian cancer narrative because of the possibility of a recurrence (Stacey, 1997); a situation that makes survivors feel a lack of control over the disease and their health. In the midst of this lack of control and uncertainty, ovarian cancer survivors turn to support systems including family members and friends to navigate the challenges posed by the disease (Arriba, Fader, Frasure & Gruenigen, 2011; Cesario, Nelson,

Broxson & Cesario, 2010; Howell, Fitch & Deane, 2003). A lack of support, however, leads to increased anxiety, depression and low quality of life (Hipkins, Whitworth, TARRIER & Jayson, 2004). Hence, I argue that a study of (ovarian) cancer should include a study of social support as well.

There is no cure for ovarian cancer, and treatment for the disease is often grueling and seemingly endless. Survivors have compared treatments for ovarian cancer with torture or war, a war between doctors and the disease fought using the female body as battleground (Gubar, 2012). Gubar (2012) described the side-effects of her ovarian cancer treatment as follows:

Not just the weight loss but also a floater in my left eye, hearing problems in the right ear, aching holes in my buttock, cramps under the small drain on the left side of my belly, the weight and heat of the bag against my right groin, and extreme exhaustion. . . . Should I attribute my fatigue and soreness to the advanced cancer, the suboptimal debulking, the three rounds of chemotherapy, the radiologists' drains, or the ileostomy operation? (pp. 159-169).

Treatment for ovarian cancer (and other forms of cancer for that matter) have lasting destructive physical and psychological effects on survivors including depression, anxiety, changes in women's sexuality and sexual health, and quality of life (Gubar, 2012; Howell et al., 2003; Taylor, Basen-Engquist, Shinn & Bodurka, 2004; Stead Fallowfield, Brown & Selby, 2001). Many survivors spend a major part of the rest of their lives managing these treatment aftereffects in addition to the constant fear of a recurrence (see Gallelli, 2014). These issues occupy survivors' attention, leaving few of them with the desire to make their experiences public (Gubar, 2012). Hence, the limited public discourse and knowledge about the disease.

Ovarian Cancer Research. Research about ovarian cancer from both the humanities and social sciences is minimal (e.g., Bowes, Tamlyn, & Butler, 2002; Hallowell, 2006; Holmes, 2006; Howell et al., 2003; Lancaster, Brain & Phelps, 2011); also, there are limited personal accounts of the disease (e.g., Gallelli, 2014; Gubar, 2012). This has created a disconnect between how the disease is experienced by survivors on the one hand and public understanding and perceptions about it on the other (Holmes, 2006). Existing psychosocial analyses of ovarian cancer focused on memoirs (e.g., Gubar, 2012), metaphors and public perception of the disease (e.g., Holmes, 2006, 2011; Jasen, 2006), ovarian cancer risk and treatment choice (e.g., Hallowell, 2006), quality of life in ovarian cancer survivors (e.g., Arriba et al., 2010; Mirabeau-Beale et al., 2009; Schulman-Green et al., 2008), ovarian cancer and sexual health (e.g., Stead et al., 2001; Taylor et al., 2004), and other survivorship issues (e.g., Bowes et al., 2002; Lockwood-Rayermann, 2006; Reb, 2007). These studies used autoethnography, interviews, historical and critical analyses, and quantitative methods. While these studies have contributed to the understanding about the disease, they are limited in that specific consideration was not given to how communication influenced and was influenced by women's experiences of the disease. Further, these studies gave limited attention to how the support ovarian cancer survivors received from their social networks influenced how they navigated issues related to diagnosis, treatment, and treatment aftereffects, and how women's avowed identities in terms of age, religion, socioeconomic status and their multiple social roles intersected to shape their experiences of the disease. Also missing in these previous studies is how women challenged and redefined normative notions about health, illness, and cancer survivorship and exercised agency during the illness experience. It is this gap in research that my dissertation project hoped to fill by providing feminist and communication perspectives to the study of ovarian cancer.

Conceptual Framework

I used the concepts of social support, uncertainty in illness, and intersectionality to ground the understanding of women's experiences with ovarian cancer diagnosis, treatment, and treatment aftereffects. Social support in the context of health and illness explains how social networks and the functions they perform impact emotional, psychological, and physical wellbeing by protecting the individual against stressful conditions, allowing him/her access to more social resources, regulating thoughts and feelings, and promoting healthy behaviors (Brashers, Neidig & Goldsmith, 2003; Callaghan & Morrissey, 1993; Cohen & Wills, 1985; Uchino 2004). Social support seems appropriate in this project to help understand the complexities and nuances of the experience of ovarian cancer, describing the experience as shared, influenced by, and influencing other facets of women's lives. The concept helps elucidate women's voices in the illness experience and the motivations for the mindset with which each woman approached the disease. Similarly, theorizing about uncertainty in illness (Babrow, Kasch & Ford, 1998; Babrow, Hines & Kasch 2000; Brashers et al., 2000; Mishel, 1988, 1990, 1999) is important in making clear how uncertainties about the disease manifest and are communicated and negotiated by survivors. Intersectionality also examines how factors, such as gender, race, sexuality, and other marks of identity combine to simultaneously produce privilege and oppression (Crenshaw, 1991; Hankivsky & Cormier, 2009). Feminist intersectional scholars argue that the multiple forms of oppression experienced by marginalized groups, including women, have cumulative effects on their lives and general wellbeing. The effects of these forms of oppression are not additive but multiplicative, and they affect not only a person's internal self, but also his/her access to resources and evidently his/her health outcomes (Crenshaw, 1991; Rogers & Kelly, 2011).

Together, social support, uncertainty in illness, and intersectionality help provide a comprehensive understanding of ovarian cancer. Working in complementary ways, the concepts explain how and why the disease is experienced and communicated differently by each woman, how women navigate and negotiate the varied support needs, uncertainties, and fears at various stages of the illness trajectory, and how successful and effective intervention initiatives should address these variations in the illness experience. The confluence of these concepts suggest a re-conceptualizing of notions about sexuality, sexual health, health, illness, and women's knowledge of their bodies in relation to ovarian cancer given the unique characteristics of the disease.

Methodology

I used feminist ethnographic methods of in-depth interviews and focus groups to collect data from ovarian cancer survivors in Northwest Ohio and Southern Michigan. In-depth interviews help understand the subjective experience individuals bring to an issue (Hesse-Biber, 2014), and focus groups place control over group interactions in the hands of participants and allow for a deeper understanding of the communication codes they use to talk about their experiences (Carey & Smith, 1994; Kitzinger, 1995; Morgan, 1996). These feminist methodologies highlight survivors' agency through the focus on their definitions of their own experiences and center their voices in the knowledge co-created (Hesse-Biber, 2014; Jaggar, 2013; Staller & Buch, 2014). A feminist ethnographic approach encourages formulation of research questions, data gathering, interpretation of evidence, and presentation of findings to be guided by feminist ethical principles, including giving accurate representation to women's (and marginalized group's) voices and embodied experiences and challenging dominant ways of knowing that value things that are symbolically masculine over the symbolically feminine

(Hesse-Biber, 2014; Jaggar, 2013; Staller & Buch, 2014). The feminist research approach helped give agency to women in this project to name their own experiences and present alternative narratives about the disease, illuminating how each made sense of her experience in her own way. Women's voices are loud and clear in the direct quotes I used to illustrate the findings.

Participants. Twenty-eight women with ovarian cancer (median age was 58.5 years; range 23-84 years) participated in the study. Twenty-seven of the participants identified as Caucasian and one identified as Mexican-American. Six participants (21.4%) were diagnosed at stages I and II each, 11 (39%) were diagnosed at stage III, three (11%) were diagnosed at stage IV, and two (7%) were unsure. At the time data were collected, six of the women (21.4%) were in treatment or about to begin treatment due to recurrence, and one participant was terminal and had stopped treatment. Five (17.8%) of the women had some graduate education or master's degree; 18 (64%) had some college education, associate degree, or bachelor's degree; and five (17.8%) had a high school education. The majority of the women were married (64%), and all of them were heterosexual. Eleven (39%) of the participants were pre-menopausal at the time of diagnosis and 17 (61%) were post-menopausal. The majority of the women described their socioeconomic status as "upper class" or "upper-middle class" and a few described themselves as "struggling" or as "living from paycheck to paycheck." See the complete demographic information in table 1.

Table 1
Demographic Information

Description	Number	% (N=28)
Stage of Disease		
Stage I	6	21.4
Stage II	6	21.4
Stage III	11	39
Stage IV	3	11
Unspecified	2	7
Age ⁴		
20-29	2	7
30-39	2	7
40-49	3	11
50-59	10	36
60-69	7	25
70-79	2	7
80-89	2	7
Marital Status		
Married	18	64
Not Married ⁵	10	36
Number of Children		
Biological Children	17	60.7
Adopted Children	1	3.6
No Children	10	35.7
Level of Education		
High School	5	17.9
Some College/Associate	10	35.7
Bachelors	8	28.6
Some Graduate/Master's	5	17.9
Menopausal Status ⁶		
Pre-menopausal	11	39
Post-menopausal	17	61
Recurrence Status		
Recurred ⁷	8	29
Never Recurred	20	71

⁴ Age range=23-84; median=58.5

⁵ Includes women who were divorced and widowed.

⁶ Menopausal status at the time of diagnosis.

⁷ Women whose disease has recurred at least once. Out of this number, three have died.

Procedures. Approval for the study was granted by the BGSU Human Subject Review Board. Participants were recruited with the assistance of (ovarian) cancer support organizations in Northwest Ohio. The organizations sent email notices about the study to people in their mailing list and interested women contacted me to set up interviews. Interviews took place at the convenience of participants who each received a \$20 grocery gift card as compensation. I obtained written consent from each participant prior to the interviews and also provided oral explanation of the study before the interviews took place. The semi-structured, in-depth interviews ranged in length from 45 to 120 minutes and took place face to face, over the telephone, or via FaceTime. After the interviews, I informed participants about the focus group discussions and those who agreed to participate were contacted at a later date to set up the meetings. When participants met for the focus groups, I again explained the aims of the study and obtained written consent from each of them before the discussions took place. I moderated the discussions and listened to women comment on and expand each other's views about the lived experience of ovarian cancer. A total of four focus groups were conducted; participation ranged from two to four women per group. Thirteen women participated in both the interviews and focus groups.

I audio-taped the interviews and focus groups and transcribed the data verbatim. I also took notes during both the interviews and focus groups. I asked participants questions such as: How have ovarian cancer and its treatments affected your life as a woman, mother, or wife? How have your age, religion, marital status, and socioeconomic status influenced your experience with ovarian cancer? What does it mean to be an ovarian cancer survivor?

Analysis. I analyzed the data using grounded theory methodology (Charmaz, 2014; Strauss & Corbin, 1990). I chose the grounded theory approach because it allows for describing

procedures/processes. The approach involves initial coding where the researcher interacts with the data to understand what is happening and focused coding where s/he develops initial codes to synthesize and organize the data and develop theory. In this study, initial analysis consisted of my reading through each interview transcript in its entirety to gain a general understanding of the data. Line-by-line coding for processes and actions helped to separate the data into categories and identify key concepts (Charmaz 1990, 2014; Glaser & Strauss, 1967; Strauss & Corbin, 1990). I critically analyzed the key concepts while asking questions about the data (e.g., how did women process diagnosis; how did women live through treatment; how did women negotiate identity and role expectations during treatment; and how did women conceptualize survivorship?). I used the constant comparison method (Charmaz 1990, 2014; Strauss & Corbin, 1990) to note differences and similarities in women's experiences. For instance, differences in the process depended on women's age, stage of disease and treatment regimen, socioeconomic status, and level of available support. At this point, the analysis transitioned into focused coding where I grouped codes into categories and examined relationships between them (Charmaz 1990, 2014; Strauss & Corbin, 1990). My analysis showed three phases in the ovarian cancer experience—(not)making sense, owning the experience, and becoming a survivor—and helped identify the core variable, managing uncertainty. The core variable explains the majority of the processes taking place in a data and it is related to many of the categories (Glaser, 2004). The core variable, managing uncertainty, was evident in women's narratives of their lived experiences of diagnosis, treatment, life post-treatment, and/or recurrences.

The analysis was both iterative and interactive (Charmaz, 2014; Morse et al., 2002); initial categories were modified as I interacted more with the data and categories were compared across groups. The analytic process of constant comparisons helped clarify how factors such as

age, stage of disease, treatment protocol, socioeconomic status, and level of available social support shaped women's lived experiences. For instance, I compared the experiences of women diagnosed early stage with those diagnosed late stage and also the experiences of younger women with older survivors (Charmaz 1990). I consulted a senior researcher and expert in the field as an audit trail and for confirmation of codes.

Trustworthiness is the umbrella term for issues of credibility, reliability, transferability, dependability, and authenticity in qualitative research. Trustworthiness is enhanced through methodological strategies such as member checks, peer debriefing, intercoder reliability checks, negative cases, and triangulation (Carlson, 2010; Morse et al., 2002). In this study, I determined trustworthiness through the expert review of audit trails, triangulation of data from the interviews and focus groups, and rigorous comparisons of themes with collected data. Participants were given pseudonyms to protect their confidentiality.

Entering the Field. As part of laying the ground work for this project, I volunteered with two cancer support organizations in Toledo, Ohio. This enabled me to build relationships with key gatekeepers of the population of women that I am interested in. My negotiation into these sites began in the spring of 2013 when leaders of the Cancer Connection of Northwest Ohio (CCONWO) visited the School of Media and Communication at BGSU to give a presentation at the invitation of a professor in the School. I informed the professor about my interest in working with CCONWO for my dissertation project, and she introduced me to leaders of the organization when they visited campus again at a later date. I maintained contact with the co-founder and president of the organization, Jean Schoen, via email and had our first meeting on June 13th, 2014 at her office in Toledo. At the meeting, I presented my research agenda to her, letting her know I wanted to be involved with the organization in providing support services to ovarian

cancer survivors. Jean was (and still is) very supportive and welcoming of my research ideas and said I could use her offices for any work. She later introduced me to Gini Steinke, president of the Ovarian Cancer Connection (OCC), another support organization in Toledo. I met with Gini on October 6th, 2014 in Toledo to discuss my research agenda, how I wanted to be involved with her organization, and how she could help me recruit participants for my project. Gini was also very encouraging and forth-coming with information and suggestions. After the project was approved by the BGSU Human Subjects Review Board, I met with Gini to discuss the way forward. She sent notices about the project to people in her mailing list and interested women contacted me to set up interviews. Also, with permission from Gini, I attended a survivors' luncheon organized by the OCC in April 2015 to talk about my project and recruit participants. I also participated in the Ellen Jackson Ovarian Cancer Walk in Toledo in September 2015. The walk is organized annually by the OCC to commemorate the national ovarian cancer awareness month of September and to raise funds. Disclosing this information about my negotiation into the sites of study is what Chiseri-Strater (1996) termed the researcher's *positionality* which is important in helping readers know what I was positioned to know and not know and why.

Reflexivity. Reflexivity requires the researcher to constantly examine and acknowledge how his/her sociocultural and educational background, identity, and location might influence the research process and outcomes, and be deliberate about limiting these influences (Hesse-Biber, 2014; Staller & Buch, 2014). Being reflexive is important for my project because I have not experienced ovarian cancer firsthand; all the knowledge I have about the disease is from secondary sources including books and research articles—sources that sometimes give limited representations of the disease (Gubar, 2012; Stacey, 1997). Secondly, I acknowledge that my identity as a researcher (e.g., I am relatively younger than many of the participants, and we come

from different sociocultural backgrounds) and as an outsider to the ovarian cancer community (i.e., I do not have any personal connection to ovarian cancer) might have impacted how women relate to me and how they choose to share their experiences. These differences could be advantageous in that I asked questions that participants and insiders would take for granted, but they could also present some challenges (Blythe, Wükes, Jackson, & Halcomb, 2013). Also, the format of data collection (i.e., telephone, FaceTime, and face-to-face interviews and focus groups) might have affected how women present their experiences and my interpretation and representation of these experiences. For instance, lack of physical contact in telephone interview might have enhanced or inhibited women's comfort level to candidly share their experiences

I achieved reflexivity by keeping a memo about my research experiences and reflecting on how I could improve the research process and outcome. For instance, I came to the realization that women cared more about the research project and how they could use their experiences to help bring awareness than they cared about knowing specific details of my life. Thus, unless specifically asked, I did not self-disclose. The majority of them wanted to know how and why I became interested in the topic for this project. I explained to them that I wanted to educate myself about the disease and to help increase public awareness and education. Women agreed this was an important task; thus, this common aim became the ground connecting me with women. I bonded with women not because of a common experience or background we shared, but because of a common purpose to bring ovarian cancer to the public radar. Women were eager to get their stories out and discuss how they survived despite the challenges; and I was ready to learn from them. I was willing to learn "what it is like to have ovarian cancer," including the

meaning of phrases such as “out-cancer someone⁸” and “chemo someone to death⁹.” I listened more than I talked; active listening was my way of making women feel comfortable and assuring them that I cared deeply about their life-stories. Women acknowledged this in responses such as “Thank you for making me comfortable so I could talk to you so easily” (Ruth, 55 years, stage IV) and “I was a nervous-wreck coming here because I was not sure what to expect, but you have made it very comfortable and easy to share” (Juliet, 59 years, stage II). Atkins (2016) described being reflective in the research process as “empathic engagement;” we learn the most when we enter a research site with an open mind. I was cognizant of this and regularly assessed my positionality.

I drew on my knowledge of feminist research ethics to navigate how to empathize with women without presuming to understand what they were going through. I listened effectively to women’s narratives and quickly learned and adjusted to how they wanted their stories to be received/responded to. For instance, women mentioned that they did not want to be pitied. I recognized this was important if I were to forge a relationship of trust and respect with women in the co-creation of knowledge about the disease. It was difficult for my facial expressions to not reveal that I felt sorry for a woman who had five recurrences or for the one who had learned of a recurrence and would be beginning treatment; but I learned to respect women’s feelings by constantly stepping back and mirroring how they wanted their stories to be received—as stories of hope.

Another significant observation was the difficulty I had in balancing the aims of this project with the reality of women’s experiences. It was eye-opening and humbling to realize that

⁸ This is to say that no cancer experience is better than the other. A stage I cancer diagnosis is as devastating as a stage III or IV.

⁹ This was how women described doctors who consistently prescribed chemotherapy even when their patients were sick and weak and the treatment was unnecessary.

this project was not merely to satisfy a requirement for a Ph.D.; I was invited by women to share their experiences with life and death. This gave me deep appreciation and respect for women, somehow making it hard for me to probe into personal aspects of their experiences including their sexual health. I was overly respectful that I came across as fearful (none of the women mentioned this; this was my own observation). I was not fearful; I was trying to understand what it meant to have ovarian cancer. I was humbled by the strength women showed in the face of adversity such that I felt unqualified to probe deeper. For instance, I could not ask one woman who was dealing with terminal ovarian cancer about her sexual health. I felt this issue was insignificant in light of the possible death she was facing. Instead, I allowed this woman to be in control of the discussion and narrate aspects of her experience she wanted to share. This was significant to my aim of centering survivors' voices and knowledge and in line with feminist research ethics and principles of legitimizing women's subjective knowledge.

Further, I achieved reflexivity by examining my adherence to ethical principles in the research conduct. I weighed the importance of women's lives against my aim to complete this project when asking them to participate in focus groups. I exercised great judgment about whether to make additional demands on women who were about to begin treatment (i.e., asking them to participate in focus groups). I had to draw a line between being respectful and being inconsiderate; in many instances, I chose to be respectful. To me, honoring women's lives and their experiences and considering them partners in this project (Gorelick, 1991; Hesse-Biber, 2014) meant that I had to factor the nature of the disease into the research process. Women's lives were interrupted by ovarian cancer thus, I did not expect my research to be without interruptions; I made space for these interruptions.

I embarked on this research project with a novice researcher innocence that was stripped away bit by bit with each woman I interviewed. I expected to meet ovarian cancer “survivors” in the context of how the term is widely understood in the present culture and environment. That is, “survivors” as people with minimal physical evidence and thus, reminders about cancer; “survivors” as people who have fought, beaten cancer, and are on the other side of the experience. But women’s experiences made me realize how narrow and biased my understanding of the term cancer survivors was. Thus, in this project I describe every woman diagnosed with ovarian cancer as a survivor because they all continue to battle this horrible disease on a daily basis.

By the time I finished collecting data, I was enlightened about the disease but also bruised psychologically. I was sorely grieved upon learning that three of the women I interviewed had passed away. I found out about two of them by searching the Internet when they did not reply my emails and about the other woman when her daughter replied to my email that “I’m sad to tell you my mom passed away March 8th. The cancer came back rather aggressively and she went downhill fast. Sorry to share this with you via email but I thought you should know.” I was sad and felt powerless to stop ovarian cancer from claiming the lives of women, beginning with those I have come to know through this project. To me, these women are not statistics; they are people whose voices I have heard and whose faces I have beheld.

Significance of Study

This project adds to the scholarship about women’s health, social support, uncertainty in illness, and intersectional analysis. This study adds to the research on women’s health by highlighting how women’s age, religion, socioeconomic status, level of available support, stage of disease, and treatment protocol combine to shape women’s lived experiences of ovarian

cancer. This is particularly important given calls for increased public awareness and education about ovarian cancer but limited focus on how social constructions of the disease influence how it is experienced and preventative efforts. Thus, this project aims to provide a comprehensive understanding of the interrelatedness of factors that directly and indirectly influence women's health while bringing an under-studied women's health issue to the public radar. Also, this project will help increase public discourse about ovarian cancer as a way of giving visibility to a disease hard to visualize because of its position in the female body (Holmes, 2006). It is by documenting and talking about the lived experience of a disease we would rather not imagine, think or talk about (Holmes, 2006) that we open up discussions about the disease and possibly increase public awareness and advocacy efforts.

This project is beneficial not only to ovarian cancer survivors, but to women in general and anyone who is related to a woman as a wife, mother, sister, daughter, aunt, sister-in-law, mother-in-law, niece, grandmother, partner, among others. Additionally, this project is for scholars, researchers, students and others who are interested in issues related to women, health, social support, and feminist research. Particularly for those in academia, this project indicates areas that need further research and the important role academicians can play in bringing to the public radar issues which have thus far received less research and public attention. For women, especially ovarian cancer survivors, this project acts as a conduit to letting their voices to be heard; this project allows for the narrative of what "it is like to have ovarian cancer" (Holmes, 2006) be told by those who have experienced it. This in itself can be empowering to survivors, can attract public sympathy, and lead to activism for the disease. Further, this project offers an alternative narrative about sexual health, health, and illness in the context of ovarian cancer. Survivors' experiences challenge normative views about how sexual health is experienced and

expressed in the context of a serious illness and the factors that impact women's meaning making process.

Organization of Chapters

In the chapters that follow, I draw from relevant literature to provide context for the findings from this project. I organize the chapters according to the phases in the ovarian cancer trajectory (i.e., (not)making sense, owning the experience, and becoming a survivor). Chapter two discusses issues with diagnosis including women's interpretation of symptoms (or lack thereof) and decisions about disclosing their diagnoses. Chapters three, four, and five are organized consistent with the format of a journal article. I reviewed literature related to the specific findings, presented the findings, and discussed the implications of the findings. This helps provide detailed insights into specific aspects of the project while explaining how each part contributes to illuminate the lived experience of ovarian cancer. In the concluding chapter, I summed up the findings, presented a model describing the ovarian cancer experience, and discussed the research and practical implications of the findings.

CHAPTER II. (NOT)MAKING SENSE

Introduction

In this chapter, I discuss events leading to women's diagnoses and the factors that influenced how they received the news and communicated it to others. Diagnosis came as a surprise to women, many of whom were misdiagnosed and/or diagnosed late because they and their doctors could not interpret symptoms of the disease. I name this phase in the ovarian cancer trajectory "(not)making sense" because the diagnosis often did not make sense to women.

The (not)making sense phase describes the period between diagnosis and start of treatment for ovarian cancer survivors¹⁰. The period spanned weeks or months during which women lived on the borderlines of health and illness, hopeful and doubtful, questioning if changes in their bodies amounted to anything significant. Women were "shocked," "numbed," "frozen," "stunned," and "surprised" by the diagnosis because some of them were young, healthy and active, and had no family history of cancer. Below, I explain the process of diagnosis for survivors.

The majority of women had symptoms; when they mentioned these to friends, their friends encouraged them to go to the hospital and have them checked out. After several tests at the hospital, some women were diagnosed and treated for pre-menopausal symptoms, urinary tract infections, indigestion, or back/hip pains. When their symptoms did not get better, women persisted until they finally received a diagnosis of ovarian cancer. Other women had ovarian cysts, which were monitored before they developed into cancer. Also, many of the women received clean bills of health at their annual medical check-ups months before diagnoses were

¹⁰ I adopt the National Coalition for Cancer Survivorship (NCCS)'s definition of a cancer survivor. NCCS defines survivorship as "from the time of diagnosis and for the balance of life" (<http://www.canceradvocacy.org/about-us/our-mission/>).

made, making diagnosis unsettling for women. Suspicion of cancer from ultrasound and pelvic examinations were later confirmed through surgery. Thus, most women went into surgery without knowing for sure that they had cancer. This added to the uncertainty and distress women experienced; women had hoped and prayed their symptoms would not be cancer.

Surgery helped doctors to stage the disease. Women for whom the disease had spread to other organs in the body worked on treatment plans with their doctors and began treatment (mostly chemotherapy or radiation). It was a matter of days or weeks when scans showed tumors and when women had surgery and started treatment. This gave women little to no time to process a diagnosis as they had to begin treatment immediately following their diagnoses. Thus, many of them took time to process what had happened when treatment was underway and they were sure they had the disease under control.

Women exercised great care and control over how and to whom they disclosed their diagnoses. Some of them waited until after surgery to inform loved ones who were not present when diagnoses were made, while others explained the situation to loved ones after tumors were found. Women's approaches depended on the maturity level of their children, proximity to loved ones, and other family and/or health issues going on at the time of diagnosis (e.g., death in the family or health problems with other family members; one woman's husband had open-heart surgery at the same time as her chemotherapy treatment); they disclosed out of obligation and need to receive social support. Women maintained a strong front for their loved ones, with many of them failing to openly show emotions. The process is illustrated in the figure below.

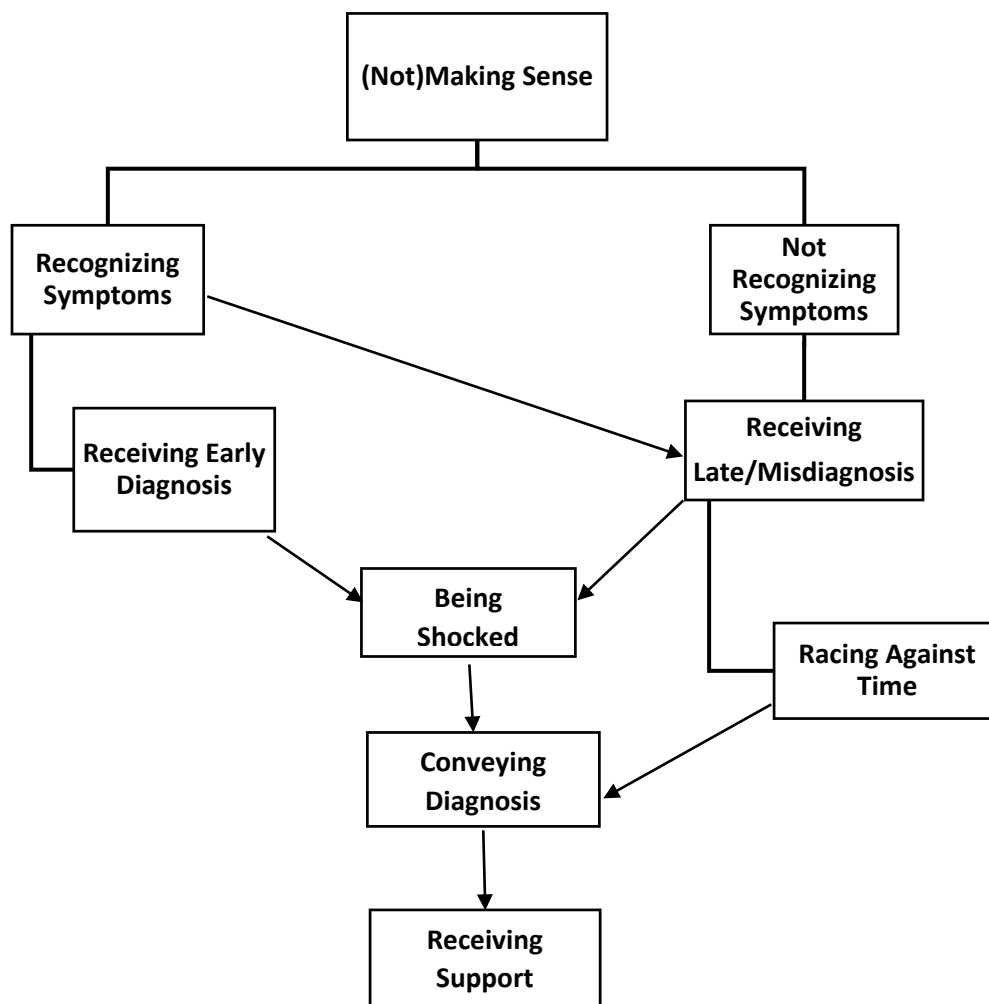


Figure 1: The Process of (Not)Making Sense of Ovarian Cancer Diagnosis

Not/Recognizing Symptoms

Women's age, overall health status, family history of cancer, and the generality of symptoms contributed to how they and others responded to symptoms. Women experienced symptoms such as bloating, flatulence, lack of appetite, spotting between menses, back pain, and pain in the lower abdomen, but could not connect these to ovarian cancer. Hence, diagnosis came

as a shock to the majority of them. For instance, Lyne (60 years, stage II) remarked, “when I got news of my diagnosis, I was like, “okay, what do you mean by ovarian cancer? We do not have ovarian cancer in my family.” Other women’s views are exemplified in the following quotes:

I certainly would not have considered myself a likely candidate for ovarian cancer because I had no family history of breast or ovarian cancer. I ate very healthy within my ideal body weight; I ran a few days a week. I was overall in good health; I had no health issues going on. It was a very big surprise, the diagnosis (Esther, 48 years, stage III).

It was really a shock because you never think something like that will ever happen to you. I have been really healthy and active all my life. I have been doing sports so you do not think something like that is ever going to happen (Christie, 59 years, stage III).

I have been very healthy my entire life. I was called a gym rat; I was at the gym a lot, lifting weight and walking. I do not smoke; I never drank much. So when I found out I had this [ovarian cancer] everyone was shocked. All my friends could not believe it; they said, “if you can get it, we can get it too” (Patricia, 67 years, stage III).

Further, some women had had their annual medical check-ups and were told everything was fine. They, thus, could not correlate symptoms they were experiencing with ovarian cancer because they did not expect to be healthy and at the same time have ovarian cancer developing in their bodies. The women now know that a pap smear does not detect ovarian cancer, but they did not know this fact prior to their diagnoses. For instance, Juliet (59 years, stage II) noted that:

I went to my gynecologist in August for my annual exam and everything came back fine and six weeks later, I was in surgery [for ovarian cancer]. That was how fast it all happened. It was never explained to me that the annual pap smear does not detect ovarian cancer; and the symptoms of the disease were also not explained to me so when I was having the symptoms, I did not know what they were.

Similarly, Gifty (50 years, stage I) explained:

I had gone for my regular pap test and everything was fine then I started having some abdominal pains, which I thought was a urinary tract infection, so they put me on antibiotics. I took that for a whole 24 hours and my pain was getting worse and worse so that was when I knew something was wrong and came to the emergency room.

Women mentioned exercising, watching symptoms, and complaining casually about symptoms before consulting their healthcare practitioners. Some women followed their intuition and went to the hospital while others were encouraged by loved ones to do so. For instance, Ann (65 years) noted that she complained about her symptoms to a friend who encouraged her to seek medical care. She said, “I started to have some spotting, and I asked a friend who was a nurse and she said that happens sometimes after menopause. Then I told another friend and she said, “no, go to the doctor.” Grace (26 years, stage I) also narrated her situation thus:

I kept noticing that my stomach was getting bigger and I would tell my friends how I was losing weight but my stomach was protruding and it was rock hard. And my friends would say “no, you are fine; it is just your stomach.” When I would work out, I would lay on my stomach ready to do push-ups, I could not lay on my stomach because it hurts. And I was like something is wrong but no one believed me.

These examples highlight the vague, yet complex, nature of symptoms for ovarian cancer. Symptoms were hard to pinpoint by women. There is still a lot to learn and understand about the disease because recognizing symptoms early did not always lead to early diagnosis. Also, the CA 125 test¹¹ came back normal for some women, providing false assurance that their symptoms could not be cancer. This was distressing to women and heightened their fear of lack of control over the disease. Also distressing was failure by healthcare workers to heed women's complaints about symptoms, leading to late diagnoses and misdiagnoses.

Receiving Late/Misdiagnosis

Several of the women in this study were misdiagnosed; some reported consulting up to 11 different doctors before receiving a diagnosis. As experts of their own health and bodies, women knew something was not right and kept pressing for answers until diagnoses were made. Many women's complaints were brushed aside for a long time, resulting in late diagnoses. For instance, Mercy (58 years, stage I), who had breast cancer years earlier, explained that she was misdiagnosed for ovarian cancer and was given false assurances by her gynecologist that everything was okay. She was eventually diagnosed stage I when she switched to a different doctor. She stated:

They found a benign ovarian cyst in 2006. [The doctor] followed me every year for five years; I had the CA 125 blood test and transvaginal ultrasound every year. At the time, my breast cancer oncologist thought that the cyst should be removed but my gynecologist explained that so long as it was clear and stable, there was no need to take it out. Then in June 2011, I went in for my annual exam and [the gynecologist] did transvaginal ultrasound and that cyst had changed dramatically. [After numerous tests] I was

¹¹ CA 125 (cancer antigen 125) is a biomarker for ovarian cancer.

diagnosed with stage 1A ovarian cancer. I was told I did not need chemotherapy because the cancer was in early stages. Then in June 2014 I noticed a lymph node on my leg and I asked my doctor if he thought it was the ovarian cancer returning and he said “no;” so we should watch it for a while. Fortunately, two days later I had my six-month appointment with my [breast cancer] oncologist and she was concerned about the lymph nodes. So a biopsy confirmed that I had a recurrence [of ovarian cancer] in two places. . . . I finally found a new doctor, and I wrote to the one whom I had seen for 14 years that I could no longer work with him because I did not trust his judgment anymore concerning my health.

Mercy’s ovarian cancer recurred again and she began treatment shortly after our interview. Similarly, Rose (55 years, stage III) mentioned that the only symptoms she had were pains in her hips and in the groin area, which two pain specialists blamed on her medical history of back pain. She said, “I knew this was not right and I was getting pissed. I knew something was not right but I had no clue it was ovarian cancer.” When Rose was finally diagnosed six months later, she stated, “when [the doctor] told me I had cancer, I did not cry because I had cancer, I cried because I was right and I knew something was wrong.” Rose’s cancer recurred a few months after our interview. Gena (79 years, stage III) also experienced a similar situation with her diagnosis. She narrated her story thus:

I was not feeling good and I was diagnosed as having an autoimmune disease. . . . I saw about 11 different doctors who kept giving me anti-depressants because they were treating me as depressed hysterical woman. . . .When I got the diagnosis, I was like “I am not crazy; I know there was something wrong.” When you do not feel good for so long

and nobody can find anything and suddenly they find something, you are like “hey, I am not crazy.”

Lyne (60 years, stage II) also shared a similar story of late/misdiagnosis:

I went to the doctor and explained the pain I was having on my upper side below my ribcage. She checked me and said I had a bladder infection and gave me some medications that got rid of the bladder infection, but I was still having the pain. So I went back to her, and she said maybe I was building up on gas. But nothing worked. She ordered an MRI and she found the tumor and said it could be in my ovaries so she did the CA 125 test and those came back elevated and she said, “I think we might be looking at ovarian cancer.”

And Esther (48 years, stage III), who lives with recurrent ovarian cancer, said:

In the fall of 2009 I had started to notice some bloating in my stomach. After a few weeks I went to my doctor and she did exams and some laboratory work and everything came back normal and she said “I think that you have signs of gluten sensitivity so you should try and eat gluten-free diet.” So I tried doing that for a couple of months but it did not work. In March 2010 during my annual gynecological visit, [I mentioned my symptoms] and the doctor’s response was that he thought I was perimenopausal. So I decided I just needed to increase my physical activity and run that bloating away. But by June of that year I could not get through an 8-mile run any longer and I went back to my general practitioner and said, “I am still not feeling well; I am still bloated.” So he ordered a CT scan and the results showed fluid in the abdomen. They tested the fluid and it came back

cancerous and they sent me to a gynecologic-oncologist for surgery. It was a nine-month long process and by the time I was diagnosed it was stage 3C.

These stories show that ovarian cancer is still highly misdiagnosed, a situation that leads to high recurrence rates. As shown by the examples in this study, women have intimate knowledge of their health but their complaints were often unheeded by medical practitioners who assumed to know more about women's bodies than women themselves. I argue that listening to women and considering them partners in their own health could lead to early diagnosis, which consequently improves chances of survival. One goal of this dissertation is not only to gather the stories of women, but to also use these stories to highlight the reality of the disease and bring about changes in the way the disease is approached. Statistics backed by the lived realities of women are telling, but will the medical and academic research community listen?

Communicating Diagnosis

Women explained that the hardest part of the diagnosis was disclosing the news to their loved ones. Ellen (42 years, stage I) noted that “the hardest part of the whole experience is telling my kids [about the diagnosis]” and Esther (48 years, stage III) said “I would say telling them [my children] when I was first diagnosed was awful; everybody cried. And when a child hears “cancer” they automatically think “are you going to die?”” Despite how hard this was, women configured ways to present their diagnoses in a non-threatening way to loved ones. For example, Andrea (43 years, stage III) explained:

[When the doctor gave me the diagnosis], I thought more about my children than I did myself because they were all at home and I was thinking “we need to get home and have a conversation with them. This conversation has to happen tonight.” When we got home,

we did not want to call it cancer in front of my smallest child who was 9 years old. We told him that I just had some infections in my stomach and I am going to have surgery and it is going to make mom's hair fall off. We did not call it "cancer" so we thought of something that I really do not like and I hate peas so we called it "peas". Mom has peas.

Stella (63 years, stage II) also explained how she communicated her diagnosis to her children.

She said:

[My children] knew I was seeing a physician for my hip pain but I knew I had to call them and tell them when they found the tumor. I did not call them right away; I waited until I had the CT scan [results]. So I asked them to call me when they were able to talk and not driving and they all called me eventually.

When disclosing their diagnoses many women's goal was to protect their loved ones. As explained by Nora (59 years, stage II), "As a mother you are protecting till you are gone." This also meant that when women recognized that disclosing their diagnoses would do more harm than good to their loved ones, they chose not to tell. For example, Rose (55 years, stage III) did not tell her mother about her diagnosis because her mother was not in a position to understand. She explained, "My mom has Alzheimer's disease so she still does not comprehend cancer." Ann (65 years) also stated that she did not disclose her diagnosis to her mother who had Lewy body disease and was still grieving the loss of her brother. She noted:

I never told my mother that I had [cancer] because she was still grieving the loss of my brother. I explained to her that I was going to do D&C [dilation and curettage]. Until the day she died I never told her I had cancer; I just did not see any point in giving her that.

The labor involved in telling others about their diagnoses was intense for many of the participants in this study. Women disclosed the news first to those in their immediate families out of relational obligation and also to receive support; some later used social media and other sources to disclose diagnoses to other people. Women mainly received emotional¹² and tangible¹³ support to process their diagnoses. For example, Marie (54 years, stage I) explained that when her sister heard about her diagnosis, “she got on a flight right away to come stay with us for two weeks.” Grace (26 years, stage I) also stated that her father rushed from his business trip to visit her at the hospital and her brother “came to stay with me at my apartment after we got off from the hospital and he helped me out. He drove me to my doctor’s appointments and cleaned up after me and did my dishes.” Similarly, Chelsea (56 years, stage I) mentioned that her friend and cousin were her “calming factor” during her diagnosis. She said, “I remember my friend sitting there and saying ‘God has got this and everything is going to be okay’ and my cousin told me he would try to be here with me as much as possible.” Patricia (67 years, stage III) stated that her “daughter who lives in Toledo moved in with me to kind of watch me and help cook and check on me to make sure I was okay.” And Andrea (46 years, stage III) explained how her friend helped her process her diagnosis in the following quote:

A childhood friend came over and we were sitting on the bed and I asked “why me? Am I being punished or something?” And she looked at me and said “why not you?” You are one of the strongest people I know who can get through this. Why not be an example?” And I said “okay, I guess that make[s] sense to me.”

¹² Emotional support is the “communication behavior enacted by one party with the intent of helping another cope effectively with emotional distress” (Burlinson, 2010, p. 179).

¹³ Tangible support includes providing direct/material aid or services for people in need (see Cohen & McKay, 1984; Uchino, 2004).

Women exercised judgment and great control over how diagnoses were communicated. Family members who were too young to understand or had other health problems that prevented them from comprehending and helping women to process the diagnoses were spared the news or had the news broken down for them. For example, Andrea described her cancer as “peas” for her nine-year-old son to understand. This situation added to the complexities women navigated as they tried to make sense of their diagnoses, and presented ovarian cancer diagnosis as involving more than just women receiving the news from their doctors. In disclosing their diagnoses, women considered not only their own emotions but also how their loved ones would react to the news (Charmaz 1991).

Racing Against Time

Women revealed that the circumstances surrounding their diagnoses and the nature of ovarian cancer as aggressive and deadly influenced how they and their team of doctors responded to diagnoses. Women jumped into action and aggressively went after the disease as soon as diagnoses were made. This was necessary given that many of them were diagnosed late. Women mentioned lacking time to process their diagnoses until treatment (i.e., chemotherapy or radiation) was underway. For example, Andrea (43 years, stage III) explained her experience as follows:

It happened so fast; it came and went before I even knew it. I do not even know if I have had time to process everything. Because you are given that diagnosis and you are like, “okay, let us act now; let us do it.” So you do it and you just keep going and you do not give yourself the time to think about it.

Christie (59 years, stage III) also mentioned lacking enough time to process her diagnosis and explained that that helped her not to think too much about her prognosis as that could have increased her uncertainty and fear. She stated:

It was really quick from when I had my diagnosis and had to go into surgery; it was very quick and I did not have much time to think about it, which is not a bad thing because when you got time to think about it, it is very scary.

Women had to quickly figure out how they were going to arrange their work and family situations, among other things. Grace (26 years, stage I) mentioned that she had to arrange for leave from work while planning for surgery. She said, “It was so fast that I literally had no time to process it. I had to figure out my work situation and how to get on medical leave.” Chelsea (56 years, stage III) also said she was told her prognosis was not good and should “put her affairs in order.” She described how she processed the news below:

The doctor told me to get my final affairs in order and I should not waste time doing that. So I was thinking “I am going to die within a few weeks.” I sat in my home crying as I met with the funeral director; it was traumatic. First, you just received the diagnosis that you have cancer, then you hear that you needed to get your final affairs in order, and it is not that I have a husband or a mother living that was going to take care of my final affairs. That sent me into a state of shock.

Chelsea’s situation highlight how women’s shock pertained not only to news about diagnosis but also to the task of processing potential death and lack of social support to provide the needed buffer.

Conclusion

The initial phase in the ovarian cancer trajectory entailed experiencing symptoms which would later be interpreted as cancer, receiving misdiagnosis for several weeks and months, getting into a state of shock and disbelief when diagnosis was finally, quickly putting one's self together and using tact and judgment to disclose news to loved ones, and getting into action to treat the disease. The process lasted weeks and months for women and was construed differently by women depending on the circumstances of their lives at the time. The diagnosis did not make sense to women because it came unexpectedly particularly, many of them were healthy, young, and had no family history of cancer.

Approaches women used to communicate their diagnoses mirrored similar findings about motives for disclosing health information (see Charmaz, 1991; Donovan-Kicken, Tollison & Goins, 2012; Faulkner, 2016; Greenberg & Smith, 2016). Women disclosed out of relational obligation and to receive social support. There are risks associated with disclosing health information (Charmaz, 1991; Faulkner, 2016) and in this study, women considered the risks not only to themselves but also to their loved ones before deciding how to tell others about their diagnoses.

Findings from this study support previous studies that ovarian cancer is misdiagnosed or diagnosed late (Gubar, 2012; Holmes, 2006). Women in this study could not interpret symptoms of the disease because of the generality of the symptoms and lack of knowledge about the disease. There is, thus, a need for increased education about the disease. Additionally, it is important that healthcare workers recognize that knowledge women have about their own health and bodies could help with early diagnosis. Rejecting and/or undermining women's subjective knowledge works to the disadvantage of both women and the advancement of knowledge about

women's health. There is still a lot that is unknown about ovarian cancer thus, it is important that the voices of women who have lived with/through the disease are considered critical to unlocking the puzzle about the disease.

CHAPTER III. OWNING THE EXPERIENCE

Introduction

The second phase in the ovarian cancer experience is what I termed “owning the experience.” This is the stage where survivors are in treatment and are trying to make sense of all that had happened. In this chapter, I examine the communicative strategies women used to make sense of their experiences in their own ways. Owing the experience characterizes adjustment to diagnosis and treatment where women set the terms to define what their experiences mean to them and eliminate interfering messages and actions to manage their own uncertainties and those of others. I reviewed the literature about meaning making to provide context for the findings. My grounded theory analysis revealed that at the mid-point in the ovarian cancer trajectory, women distanced themselves and also experienced distancing from loved ones as they tried to make sense of how the diagnosis and treatment could impact their lives and the lives of others. Other strategies for making meaning included the assumption of different identities and roles and setting boundaries to manage interfering influences. Overall, women aimed to protect their loved ones and other survivors and to forge inner security to overcome their uncertainties with ovarian cancer.

Setting Boundaries and Distancing Selves: Owing The Lived Experience of Ovarian Cancer

When I was first diagnosed I sent a letter to my [work] colleagues letting them know that I would answer any question about ovarian cancer they needed to know; I just do not want questions about prognosis because I do not know what my prognosis was. So I set those boundaries and I think that was helpful to people because I let them know right

away what I was most comfortable talking about and what I was not (Esther, 48 years, stage III).

The above quotation exemplifies the quagmire many (ovarian) cancer survivors face in their desire to determine their own experiences while concomitantly connecting with others. Esther is a registered nurse living with recurrent ovarian cancer. She was diagnosed when she was in the middle of finishing her master's degree. She did not consider herself at risk for ovarian cancer, because there was no history of cancer in her family, she lived a healthy lifestyle and was in good health overall. Esther explained she had no problem sharing her experience with others but noted it was also important for her to set the parameters within which the discussions took place. Esther set those boundaries in order to foster meaningful conversation about the disease and to protect her sense of security in knowing she would survive the disease. The ovarian cancer experience is wrought with uncertainties (Fitch, Gray & Franssen, 2001; Hipkins, Whitworth, Tarrier & Jayson, 2004; Lockwood-Rayermann, 2006); thus, it is significant that some survivors are upfront about their feelings and weed out behaviors, messages, and other influences that threaten their inner strength to fight the disease. Also significant is the need for research about how survivors maintain their inner balance and construct their lived experiences.

The cancer experience is a process that begins with the onset of symptoms and continues through diagnosis, treatment, and life after treatment (Salander, 2001). Most of the time, ovarian cancer survivors are unable to immediately grasp the implications of their diagnoses; a situation influenced, among other things, by lack of knowledge about the disease (Gubar, 2012; Holmes, 2006; Reb, 2007). Most women learn about the disease after diagnosis, and this affects how they process the diagnosis and other experiences in the illness trajectory. This is because ovarian cancer presents vague symptoms and diagnoses are often made at advanced stages (i.e., stages III

or IV) (Bankhead et al., 2008; Fitch et al., 2002; National Cancer Institute et al., 2012). The process of receiving a diagnosis is intense and wrought with a roller-coaster of emotions. It proceeds quickly, leaving most survivors with no time to take a breath and make sense of everything (Ekman, Bergbom, Ekman, Berthold & Mahsneh, 2004).

Cancer changes the lives of survivors and others in their social networks (Howell, Fitch & Deane, 2003; McKenzie & Crouch, 2004). In the midst of the unexpected and sometimes sudden changes brought by a cancer diagnosis, survivors are forced to search for meaning to re-define their identities, roles, and perspectives on life. Meaning making is important to adapting to and coping with cancer (Fife, 1994) and to keeping hope alive (Bowes, Tamlyn & Butler, 2002). However, the ability to search for and find meaning depends on factors including existing worldviews, goals, and beliefs (Thompson & Pitts, 1993), and it may be futile and distressing for most people (Kernan & Lepore, 2009). Many women are devastated and have a hard time coming to terms with a cancer diagnosis and the threat the disease poses to their health and life (Fitch et al., 2002; Reb, 2007). However, others find the diagnosis less surprising especially if they had symptoms that pointed to cancer (Ekman et al., 2004; Fitch et al., 2002). While there is variability in how women react to an ovarian cancer diagnosis, the immediate concerns of the majority of survivors relate to managing decisions about treatment and treatment side effects; it is after this stage that the reality of the prognosis begins to sink in (Reb, 2007).

There are phases in the ovarian cancer trajectory and each phase poses different concerns/challenges to women (Hamilton, 1999; Reb, 2007). Reb (2007) developed a model to explain the phases of the ovarian cancer experience. She identified “shock,” “aftershock,” and “rebuilding” as the phases women go through to transform the death sentence of ovarian cancer; women’s progression through the phases was influenced by their faith and communication with

healthcare providers about disease prognosis and treatment outcomes (Reb, 2007). While Reb's model is useful in explaining the process of transforming the seeming death sentence of an ovarian cancer diagnosis into a story of hope, it fails to capture in detail how survivors navigate diagnosis and treatment to make meaning of their experiences in their own ways. This study takes up this challenge by explaining how survivors take charge of their experiences as they navigate the identity and role changes that accompany the ovarian cancer experience in three phases [(not)making sense, owning the experience, and becoming a survivor]. In this chapter, I explore the second phase in the ovarian cancer trajectory post-diagnosis—owning the experience—where women adjust to the uncertain diagnosis. I describe the communicative strategies they use to make sense of their experiences by taking an intersectional approach and examining how factors including age, stage of disease, treatment protocol, and the level of available social support shape the process for each woman. Owning the experience characterizes adjustment to diagnosis and treatment where women set the terms to define what their experiences mean to them and eliminate interfering messages and actions to manage their own uncertainties and those of others. I present the actions women took to protect themselves and those they love to forge a sense of security in the midst of the uncertainties the illness brings, exemplified in the quote at the beginning of this article. This work extends feminist and communication scholarship on women's experiences of health and illness and women's right to name their experiences.

Making Meaning of Cancer

The concept of “meaning” has been widely researched in the context of stressful life events, including cancer diagnosis. Some researchers define the concept in terms of the processes of making sense of stressful events (i.e., meaning making or sense making) while others focus on

the outcome of the search for meaning (i.e., meaning made or outcome meaning) (Fife, 1994; Park, 2010; Lee et al., 2004). The general understanding inherent in these approaches is that stressful life events challenge people's general worldview (i.e., global meaning) and cause distress; thus, in an effort to reduce the distress and regain control, individuals search for meaning. In her *Meaning Making Model*, Park (2010) explained that the meaning making process begins when a stressful event is appraised to be at odds with one's subjective belief systems and sense of meaning (i.e., global meaning). However, a lack of discrepancy between the stressful event and one's global meaning leads to successful adjustment to the situation (Park, 2010). The process is influenced by faith, social support, perceived control over the situation, and an appraisal of the effects of the event on one's functionality, relationships, and life goals (Fife, 1994; Lee et al., 2004; O'Connor, Wicker, & Germino, 1990; Thompson & Pitts, 1993). Although the process may be endless, futile, and distressing for some people (Kernan & Lepore, 2009), meaning is found when individuals change their worldviews to accommodate the stressful event or when they appraise the event in a way that poses less threat to existing beliefs and values (Thompson & Pitts, 1993).

In searching for meaning, cancer survivors use strategies such as attribution (i.e., searching for answers), illusion (i.e., perceiving the situation different than what it is), positive reappraisal, and problem-focused coping (Park, 2010; Lee et al., 2004; Skaggs & Barron, 2006). For example, Coward and Kahn (2005) found that social support and inner strength were significant to how breast cancer patients constructed meaning of their diagnoses and treatments. Women found meaning by seeking information about treatment and threats of the disease, and focusing on a hopeful future (Coward & Kahn, 2005). Availing themselves of resources in their communities and from other survivors also helped women reappraise their condition, realizing

that they did not have to go through the cancer episode alone (Coward & Kahn, 2005).

Communicating about the cancer experience can enhance social support and feelings of control over the disease (Badr & Taylor, 2006; Charmaz, 1991; Donovan-Kicken, Tollison & Goins, 2011). But it can also negatively impact survivors' positivity and how well they adapt to the experience (Badr & Taylor, 2006).

Adjustment to cancer depends on the phase of the disease because some phases, such as the diagnostic phase, can be more stressful than others (Hoskins & Haber, 2000). Adjustment also extends beyond the end of active treatment because of issues with recurrence and fears about ending treatment (Ekman et al., 2004; Hoskins & Haber, 2000). In the case of ovarian cancer, the unique characteristics of the disease including high recurrence and mortality rates and increased uncertainty about the future (Howell et al., 2003; Reb, 2007) fuel survivors' search for meaning. The search for meaning is contingent on survivors' physical well-being and their ability to keep hope alive (Bowes et al., 2002; Reb, 2007), and includes self-reflection, reappraisal of life, and setting short-term goals (Bowes et al., 2002). Self-reflection also helps survivors to become resilient and to learn from their experiences (Lee et al., 2004, 2006). Thus, subtle as it may seem, the search for meaning following a diagnosis with ovarian cancer is significant to the overall quality of life of survivors and the meaning they construct of their lived experiences. Hence, the focus of this chapter on how ovarian cancer survivors define what their experiences should mean for them. Based on the review of literature, the following research questions guided the study reported in this chapter:

RQ1: How do ovarian cancer survivors construct their post-diagnosis lived experience?

RQ2: How do factors including age, religion, stage of disease, treatment protocol, and level of available social support influence the lived experience of ovarian cancer?

Findings

For many of the participants, the process of owning the ovarian cancer experience began shortly after diagnosis. Women entered into a phase of the illness trajectory where they critically assessed their experiences and took specific steps to make meaning in their own ways. In the first phase, women were still recovering from the shock of the diagnosis, learning about the disease, and trying to position themselves in relation to their new roles and identities (e.g., as sick people and receivers of care instead of caregivers). Given that their sense of self was challenged by the diagnosis, women actively negotiated their new identities and managed influences as a way of owning their experiences. The process of owning the ovarian cancer experience is described in figure 2.

The process began during active treatment which included combinations of surgery, chemotherapy, and/or radiation. Women reflected on the diagnosis and what it could mean for their lives once treatment was underway and they were sure they had the disease under control. They tried to put the diagnosis into perspective by distancing themselves physically and/or mentally from people and belief systems. Women explained needing to “find” themselves again because the diagnosis shook the core of their being. Women also put on strong fronts to coordinate their inner voices and protect their loved ones. Some indicated “forcing” themselves to look strong and healthy while others stated assuming different identities during treatment including becoming docile and compliant. Women did these things to manage their own uncertainties and those of their loved ones.

Further, women actively managed contradictory messages, actions, and thoughts when they were in treatment. This meant that women delayed joining support groups, did not inquire about other survivors’ experiences with treatment, and controlled sharing and seeking

information online. Women set these boundaries to manage their uncertainties and to make meaning of their experiences in their own ways. The process of owning the experience was influenced by women's age, level of available social support, stage of disease, treatment protocol and recurrence status.

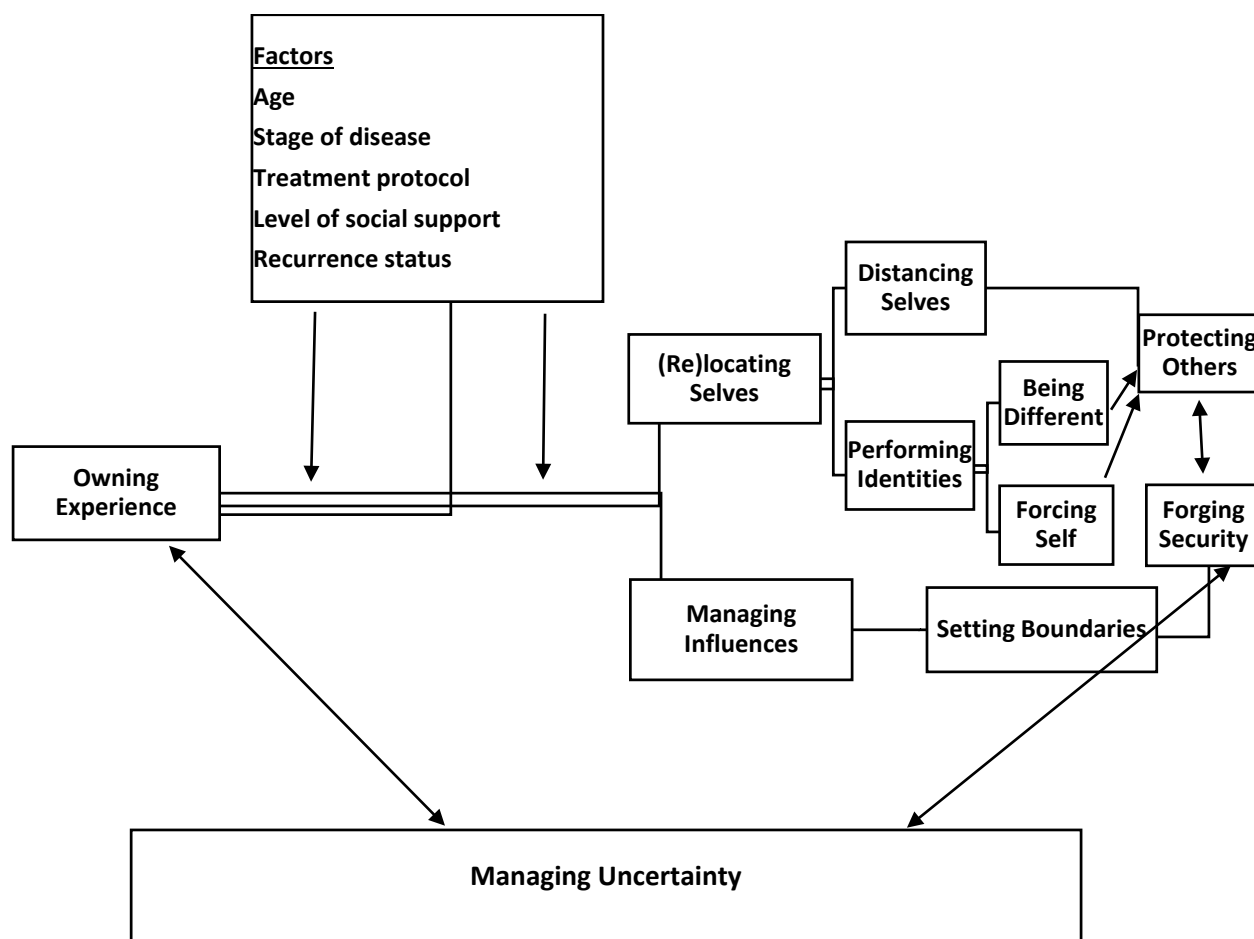


Figure 2: The Process of Owning the Ovarian Cancer Experience

(Re)locating the Self

Women indicated they needed to pause after the roller-coaster of emotions following the diagnosis to reflect on what was going on and decide how to handle the situation. Women's desire to make the ovarian cancer experience their own began with locating themselves in what

was happening. Women processed how and why they got cancer and how the diagnosis and treatment could impact their lives, health, and the lives of their loved ones. Participants explained it was important to understand this process to prepare physically and psychologically for the “long haul.” Survivors experienced distancing of/from the self and performed roles and/or identities in an effort to reconcile who they were and who they were becoming. These sub-themes are discussed below.

Distancing Selves. Women noted they withdrew physically and/or mentally from people and/or their own belief systems in the process of (re)locating the self in the ovarian cancer event. The timing and approach of this distancing differed for women depending on age, stage of disease, religious background, and level of available social support. Some women experienced distancing during treatment, others experienced it at the end of treatment, while others still experienced it upon recurrence. For instance, some participants mentioned distancing themselves from their faith or God following diagnosis; while others regained their faith, others were yet to do so. Rose (55 years, stage III) noted she quit believing in God as she sought justification for her diagnosis. She explained, “Once I got cancer, I quit believing in God. I [reasoned], ‘I do not deserve this.’” Becca also stated that she distanced herself from God but eventually regained her faith. She said:

I was so annoyed with God; I was angry, disappointed, surprised and just could not believe God would put me through this. I kept saying “this is not possible, God will never let this happen to me.” So when it happened, I was completely astonished and I went into total silence for a month (Becca 57 years, stage III).

Further, some survivors distanced themselves from friends and loved ones in the process of making sense of their diagnoses. This stemmed from uncertainty about the course of treatment

and whether or not they would be treated differently by others. Patricia (67 years, stage III) explained that she asked people not to visit her because she needed time alone to heal. She said, “I turned into a hermit. I told my friends, ‘do not come and see me. You can call me but I may not pick the phone.’” Similarly, Andrea (43 years, stage III) mentioned distancing herself from her mother because she wanted “to be me again.” Andrea explained that her mother was being overly protective and that made her uncomfortable. She stated:

I had to distance myself [from my mother] for a little bit. She was calling 3-4 times a day asking, “Did you eat?” “How are you feeling?” “Did you get sick today?” One day she came over and we were making dinner and every once in a while I would catch her staring at me and I said “mom, I am not dead yet; I am right here, stop staring at me.” And she was like “sorry.” So I had to distance myself from her.

Importantly, women explained that they distanced themselves and thus, their experiences, from others because they wanted to protect these people. For example, Katie (23 years, stage IV) mentioned being “distant” from her family and friends because she did not want to bother them. Nora (59 years, stage II) also noted, “I would not tell [my parents] a whole lot about what was going on because I know how bad it hurts them. I felt bad that I was the one who was ill so I tried to protect them.”

Other participants also distanced themselves because their level of strength had waned following treatments and thus, were not able to do activities they previously engaged in. For instance, Patricia (67 years, stage III) explained, “I did not want to be around my grandchildren because in the past I was running around with them, playing football; but I was not that person anymore. I was a sitter, docile, and not cheerful.” Patricia was still trying to find herself and make sense of the new identity forced on her by ovarian cancer; thus, she claimed the space she

needed to re-know herself before she could reach out and have meaningful engagements with others.

Reciprocally, women also experienced distancing from those around them. Survivors stated friends kept their distance because they did not know how (or did not want) to deal with the notion of someone having cancer. For example, Christie (59 years, stage III) explained how friends avoided her because of a misconception that cancer had to be subject of their discussions. She said, “There have been very few people who have distanced themselves from me. I think they have this idea that when they see me, they have to talk about [my battle with ovarian cancer], which could not be more opposite.” Patricia (67 years, stage III) also explained her experience with friends distancing themselves as follows: “I have friends that I have not heard from. I am thinking they probably did not know what to say. What do you say? I am sorry? They do not know how to respond.” Ruth (55 years, stage IV) also noted how rejection from friends hurt her self-esteem:

I have friends, life-long friends, who walked away from me because they could not take it. And it hurts my heart. I asked my sister, ‘What cannot they take? I am the one going through it?’ and she said ‘Sissy, you are slapping them in the face with their own morality and they cannot take it.’ I was in a relationship; he walked away. And if that does not hurt your heart it beats the hell out of your self-esteem.

Additionally, Lynn (60 years, stage II), who was terminal at time of the interview, explained how her father could not stay in the same room with her because he could not stand the idea of her dying. She said:

There are some people that do not know how to deal with you because you are dying so they do not want to deal with you at all. My own father has a hard time dealing with me; he cannot stand being in the same room with me. It is easier for him to get up and go to the other room or go outside and do something than to sit down and talk to me, because he cannot deal with my death.

Evident in these examples is the frustration women faced dealing with distancing from loved ones at the height of their fight with ovarian cancer. While many of the survivors were understanding of the reaction of loved ones, the situation nonetheless was stressful and further heightened women's uncertainties about the illness. This distancing from/of others was crucial in helping women locate themselves in the whole experience, further providing the drive to make the sense making of ovarian cancer their own. Women came to the realization that this was *their* life, experience, and ordeal and they had to make it their *own*.

Performing Identities. Further, women experienced identity changes going through treatment and afterwards. These changes occurred as part of managing the uncertainties of treatment and in a bid to foster security for themselves and their loved ones. Importantly, many of these identity performances were consistent with normative expectations of the ill and women as mothers to be compliant.

Becoming Different. Women indicated assuming identities different from their usual selves during treatment. For example, Grace (26 years, stage I) noted that "I changed after my surgery. I was a different person. It felt like I had a new life." Patricia (67 years, stage III) also explained how she became a different person during treatment in the following quote:

When I received news of my diagnosis until I was done with treatment, I became very docile and very quiet and compliant and would pretty much do whatever anyone told me to do. So while I had cancer, I was a different person; I changed into a totally different person.

These changed personalities happened because participants were uncertain about their health and lives at that point; they were navigating unknown territories. They were also still (re)locating the self and trying to make sense of the diagnosis.

Forcing the Self. In a similar vein, women stated becoming ‘strong,’ ‘healthy,’ and ‘normal’ in an effort to make the diagnosis and treatment less severe for their loved ones. Many of the survivors recounted “forcing” themselves to look healthy during treatment, and it was to protect loved ones and forge inner balance. Particularly, women with children acknowledged the fears of their children and tried to make life as normal as possible for them. Andrea (43 years, stage III) said she negotiated the threat posed to her identity as a mother by her illness:

I did not want my children to see me sick; so I never allowed it. I made sure that I got up every day and took a shower and put make-up on. It was hard but I did it. It was tough. There was only two times of the last nine months that I could not get up; the rest of the time, I forced myself to get up.

Ellen (42 years, stage I) also mentioned performing strong in order to protect her family. She stated, “I found that the stronger I was on the outside the calmer things were with the people around me. So I had the tendency to be strong for everybody.” Also, Pattie (38 years, stage III), who was diagnosed at age 19, had a complete hysterectomy and thus lost her ability to have children, said she acted “strong” to make grieving her lost fertility less obvious to her family.

She explained, “During treatment I tried to be strong for family members and not show a whole lot [of grieving]”.

Similarly, Katie explained she:

Did not want [friends] to feel that there was something wrong with me. I [argued] “I am fine, there is nothing wrong with me; I want to be normal again, treat me like anyone else.” I felt like I was trying to force myself to be myself. . . . By the end of the year [when I was cleared of cancer], I felt like I had put all my energy into trying to trick myself into feeling normal again that I was so tired and sick of having to try to be myself. I kind of hit a wall (Katie, 23 years, stage IV).

Gena also stated performing “strong” in an effort not to be treated differently. She remarked thus:

Once I was through with the treatment, I wanted to prove to myself and the world that I was still Gena. I was going to do what I could to help others; no sad stuff. I always made sure I looked good because I did not want people to think, ‘oh, she has cancer, look at how she looks’ (Gena, 79 years, stage III).

These quotes highlight reasons survivors performed identities. Performing these identities and roles was a way for women to protect their loved ones, avoid being treated differently, and cement their hope of beating the disease. For many of the survivors, it was important that how they felt and acted in the face of uncertainty matched how they were treated by those around them, hence a need to “perform” in order to score the desired reaction from those around them. As noted by some of the participants, this identity/role performance came at a price—“hitting a wall.” These findings support previous studies that survivors perform identities to seek validation

for their views about their preferred identities (Donovan-Kicken et al., 2011; Ekman et. al., 2004) and to protect their loved ones (Atkins, 2016).

Managing Influences

As part of making sense of the cancer experience in their own ways, women also set the parameters to define what their experiences meant for themselves and others. Managing influences describes steps women took to determine how their experiences unfolded, solidify their inner voices, and minimize interfering interferences. Women were in the process of adjusting to the diagnosis and treatment and desired consistency in the messages of hope they told themselves and other messages in their environments. They actively managed messages, actions, and thoughts that sought to interfere with how they wanted their experiences to unfold for them. Women were aware that negativities and misconceptions about ovarian cancer could exacerbate an already difficult experience for them; thus, they actively filtered out negative influences as much as possible. Participants chose when and how much to know about the disease, when and whether or not to join a support group, and how much of their experiences was disclosed on social media. They set these boundaries to protect their own lived experiences and that of other survivors and to regain the control seemingly lost to cancer.

Setting Boundaries. Some survivors considered a diagnosis with ovarian cancer tough enough that it was unwarranted to add additional stresses by knowing details of their particular cancer cell, for example, or the specifics of their treatments. For instance, Mercy (58, stage I) explained she did not inquire about the standard treatment for ovarian cancer because she wanted to experience treatment in her own way. She stated:

When I was going through chemo, I did not want to hear other people's experiences; I just wanted to go into it blind and experience whatever was going to happen. I wanted it to unfold for me personally. I did not know how many treatments people typically have; I did not know that I was having that much chemo. I just did not want to know.

Nora (59 years, stage II) also chose not to know her cancer cell. She said, "I have had women ask me 'what cancer cell do you have; what are they treating you with?' I do not know what cancer cell I have because I do not want to know." Similarly, Kylie (65 years) had no desire to know her prognosis and stage of cancer for fear that that information might interfere with her psychological preparedness to fight the disease. She remarked:

My whole philosophy was to fight and it did not really sink in to me that I only had 30% chance of survival. I did not even remember [the doctor] saying [I had 30% chance of survival] until after I was declared cancer-free and then all those memories came back. [My poor prognosis] probably registered but I did not want to acknowledge it.

Significantly, women who were living with recurrent ovarian cancer noted how important it was to control how much information about their lived experience was shared on social media as a way of protecting other survivors and honoring their memory in the event that they passed away. For instance, Nora asked her daughter to take down a Facebook page created to share her experience because:

I do not want to be known just because of ovarian cancer. I think the more the cancer comes back, the more you become a little inward because there is a feeling that 'it has got me; it is going to take my life eventually.' So I am going to go inward with myself; I will

still let friends and family know what is going on, and that is all. Because at that point, it becomes extremely personal (Nora, 59 years, stage II).

Esther, who also was living with recurrent disease, narrated how she managed her presence online in the following quote:

I do not share my story and what is going on [on social media] because I do not want anybody to pity me. So often people hear stage III-C ovarian cancer and they go, ‘oh, she is a goner;’ ‘oh, poor thing, she is gone’. Another reason is as a survivor, I have gone online and searched other people’s pages and lots of them have died. That is hard especially if you are newly diagnosed and you are trying to find women who have survived and you find that they were really active and posting and then nothing and a family member comes in to say they have passed away. So I figured if I start a Caring Bridge page and I die it must be hard for someone to see (Esther, 48 years, stage III).

These quotes suggest how women actively owned their experiences by controlling messages and behaviors that interfered with how they wished to be remembered and what they wanted their experiences to mean to them. Women had significant knowledge about ovarian cancer to be uncertain about the future of their health and the impact treatment could have on their identities and on their loved ones. It was important for many of them to not make their uncertainties public because that could contradict how they carried themselves and the strength they showed in the face of the adversity. Women were aware that recurrent disease meant imminent death but for them, succumbing to the disease would not mean that they did not “survive” it. Thus, it was important that memories they had created for and with others were protected. This is consistent with previous research which suggests that controlling information was a way for survivors to regain some of the control lost to cancer (Charmaz, 1991; Donovan-

Kicken et al., 2011) and to manage the uncertainties about the illness (Brashers, Goldsmith, & Hsieh, 2002; Miller, 2014).

Discussion

In this chapter I examined the second phase in the ovarian cancer trajectory—owning the experience. The results support previous findings that there are stages in the ovarian cancer trajectory and each phase presents unique challenges for survivors (Hoskins & Haber, 2000; Reb, 2007). The second phase in the ovarian cancer experience described the process of women taking steps to make sense of their experiences in their own ways. Women distanced themselves from others and also experienced distancing from loved ones as they tried to make sense of their diagnoses and treatments. Women also assumed different identities and roles and actively managed behaviors, information, and actions that sought to interfere with their lived experiences (Atkins, 2016). They aimed to manage the uncertainties associated with the disease (Hipkins et al., 2004; Lockwood-Rayermann, 2006) to foster an inner sense of security and to protect others.

Factors influencing how women made sense of their conditions and actively negotiated their lived experiences included the stage of disease, age, level of available social support, and recurrence status. Consistent with previous findings (Atkins, 2016; Donovan-Kicken et al., 2011; Ekman et al., 2004) women in this study performed “healthy” and “strong” so as to protect their loved ones (mostly children, parents, and partners) and also to avoid being treated differently. In the process, women were stressed out with some reportedly “hitting a wall”. Besides protecting loved ones, women also acted “healthy” and “strong” to bolster their sense of security in fighting the disease; this identity performance fostered consistency in how survivors wanted to fight ovarian cancer and how they acted to achieve this goal. Similarly, women who did not have partners and children also performed these identities as a survival mechanism: they needed that

sense of inner balance to fight the disease. For many of the women in this study, having loved ones protected from the effects of ovarian cancer was necessary for their own meaning making process. Women were also not afraid to keep a distance as they (re)located themselves in the process.

Further, women set boundaries to control what and who influenced their lived experiences of the disease. This was to manage uncertainties and take attention from the illness (Brashers, 2001; Brashers et al., 2000; Miller, 2014). This finding is significant in showing ovarian cancer survivors as active participants in the process of owning their experiences (Charmaz, 1991). Women were actively involved in shaping their understanding of the disease, naming what counted and what did not. Feminist scholars advocate for the rights of women to name their experiences (Anzaldúa, 1992; Collins, 1986, 1990); this study showed how women did this. Previous studies explained the process of making sense of cancer and strategies survivors used to cope (e.g., Bowes et al., 2002; Park, 2010; Lee et al., 2004; Reb, 2007). This study extends those findings and adds that women did not use these strategies to only cope; they used them to own their experiences outside of medical and relational expectations. Women used these strategies to negotiate how they experienced the illness and how others came to understand ovarian cancer.

This study has implications for scholarships in communication studies, women's and gender studies, and cancer research. Highlighting the *owning the experience* phase of the ovarian cancer trajectory may enhance understanding about ovarian cancer from the perspectives of survivors and the active role they play in naming their experiences. The factors that influence the process of owning the ovarian cancer experience suggest a need for individualized approach when considering the impact of the disease and treatment on women. Further, findings of this

study imply that ovarian cancer survivors aim to manage the uncertainties about the disease and also use their experiences to educate and bring awareness. Education efforts, therefore, should be directed at supporting this goal. Spaces should be created for women to determine their experiences while also educating about the disease.

Conclusion

The results of this study support previous studies that there are phases in the ovarian cancer trajectory. The results also point to the mid-point of the ovarian cancer experience — owning the experience — as crucial to how women adjust to the diagnosis and treatment, the meaning they construct of their lived experiences, and their quality of life post-treatment. I argue that women do not only use active communicative strategies to make meaning of their experiences in their own ways; they use these to protect loved ones and other survivors and to foster a sense of inner balance to manage the uncertainties about the disease.

CHAPTER IV. BECOMING A SURVIVOR

Introduction

A stressful phase in the ovarian cancer trajectory is the end of active treatment when women experience significant anxiety and uncertainty as they leave active medical care and navigate life after treatment. In this chapter, I reviewed the literature on uncertainty in illness and cancer survivorship to help explain the process of becoming an ovarian cancer survivor. Ovarian cancer survivorship began at diagnosis and continued through treatment and life after treatment; the process was marked by uncertainty as women encountered treatment aftereffects including changes in their finances. The construction of survivorship was distinct for each woman and influenced by her socioeconomic status, stage of disease and treatment protocol, recurrence status, and level of available support. Women felt guilty if their experiences did not reflect normative understanding of ovarian cancer including advanced disease, long, grueling treatment, and recurrence. I argue that women in this category have alternative narratives about the disease to offer and they need to be supported to voice these narratives.

Becoming an Ovarian Cancer Survivor: Managing Uncertainty And Survivor's Guilt

When I was done [with treatment] and put in remission, that scared me more than the whole time being in treatment because I knew the cancer was being killed off because I was in treatment. And then you stop [treatment] and you go, "well, now what? Is it [cancer] going to come back? Where is it going to come back at?" This guessing game of "oh my gosh, now what am I going to do?" I will keep doing treatments, I do not care (Andrea, 43 years, stage III).

The period following the end of active treatment is critical to the overall health and quality of life of cancer survivors (Arnold, 1999; Garofalo et al., 2009). Quality of life for many survivors is generally low at this stage because of uncertainty about health status, heightened stress about returning to normal life, and experiences with treatment side-effects including insomnia, fatigue, medically-induced menopause, and altered sexuality (Duffey-Lind et al., 2006; Garofalo et al., 2009; Knobf, 2007; McKenzie & Crouch, 2004). It is at this phase that losses suffered during treatment, including loss of hair, strength, or other body parts are communicated, negotiated, and dealt with outside the healthcare setting (Hewitt et al., 2006). Thus, this phase in the cancer experience warrants increased research attention because how survivors respond to diagnosis, treatment, and the transition to survivorship can influence long-term adjustment to the experience (Garofalo et al., 2009). Further, it is worth investigating how uncertainty at the end of active treatment influences the path to survivorship for ovarian cancer survivors.

Andrea's reflection (quoted above) on ending active treatment for ovarian cancer shows this uncertainty. She is a 43-year-old mother of three who went aggressively after the disease with nine weeks of chemotherapy, a radical hysterectomy during her 6 weeks off, and then another nine weeks of chemotherapy. Andrea, like many women affected by ovarian cancer, was anxious about going into medical remission after enduring months of treatments and becoming used to, and somehow trusting, the treatment to get rid of the cancer cells. Once treatment is over, then what? Even though Andrea anticipated the end of treatment, she became vulnerable and ill-prepared to face life without/after treatment. This uncertainty makes women almost wish treatment would never end because being in treatment and feeling tired and worn-out means they are actively fighting the disease.

Ending active treatment is not the end of the cancer journey. It is the beginning of the transition from cancer patient to survivor, and it can be a moment of both uncertainty and anxiety, and joy and psychological healing for survivors depending on the site and stage of disease (Costa-Requena et al., 2011; Ferrell, Smith, Cullinane & Melancon, 2003; Garofalo et al., 2009). This phase in the cancer experience is usually dominated by fear about recurrence and treatment aftereffects (Armes et al., 2009; Arnold, 1999; Hewitt, Greenfield & Stovall, 2006; Ferrell et al., 2003; Lethborg, Kissane, Burns & Snyder, 2000; Ozga et al., 2015). During active treatment, survivors are certain (through visible effects of treatment on their bodies) that they are actively battling the disease—a proactive involvement in their health that is empowering and can lead to improved coping outcomes (Arnold, 1999). Further, survivors have constant access to high-level medical and social support during treatment. However, these forms of support recede once active treatment is over, leaving survivors feeling vulnerable, lost, scared, and uncertain about the future (Arnold, 1999; Duffey-Lind et al., 2006; Garofalo et al., 2009; Hewitt et al., 2006; Knobf, 2007; Lethborg, 2000; McKinley, 2000; Mishel & Braden, 1987; Reb, 2007).

The ovarian cancer experience is wrought with uncertainty because treatment does not guarantee cure and because of the high recurrence rate which makes the experience seemingly unending for many survivors (Gubar, 2012; Howell et al., 2003; Markman & Malviya, 2008; Reb, 2007; Stacey, 1997). Further, the disease presents vague symptoms providing no “safety signals” that it will not recur; a situation that leads to increased anxiety and uncertainty at the end of active treatment (Ekman et al., 2004; Hipkins, Whitworth, Tarrrier & Jayson, 2004; Ozga et al., 2015). The level of anxiety, fear, uncertainty, and depression experienced by ovarian cancer survivors is impacted by factors including age, stage of disease, and length of time living with the disease (Arden-Close, Gidron & Moss-Morris, 2008; Lockwood-Rayermann, 2006). I argue

that the characteristics of ovarian cancer (i.e., vague symptoms, late diagnosis, and high recurrence and mortality rates) have significant implications for the process of becoming a survivor and women's constructions of their lived experiences. Thus, this chapter explores women's constructions of the lived experience of ovarian cancer following the end of active treatment, and investigates the process of survivorship, factors that influence the process, and the consequences for the totality of women's lives.

Uncertainty in Illness

Uncertainty is a cognitive state that occurs "when an event cannot be adequately structured or categorized because sufficient cues are lacking" (Mishel & Braden, 1987, p. 48). Individuals cannot make meaning of events or determine the outcomes of situations because of insufficient cues to make such prediction. Uncertainty is characteristic of the illness experience, and it increases as specific information for meaning making is missing (Neville, 2003). Uncertainty in illness is impacted by factors including unpredictability about the illness's cause, duration and treatment outcomes, changing self-concept, and lack of social support (Babrow, Hines & Kasch 2000; Brashers, 2001; Mishel, 1999). Uncertainty is multilayered and connected to other facets of one's life. Particularly with illnesses, which have possibility for recurrence, uncertainty is exacerbated due to difficulties in distinguishing between bodily changes survivors may be experiencing and symptoms of disease recurrence (Mishel, 1999). It varies across persons, type and stage of illness, decisions about treatment, and at the end of treatment (Brashers, 2001; Brashers et al., 2000; Hoskins & Haber, 2000; Mishel, 1988, 1990, 1999; Reb, 2007). For instance, uncertainties about chronic illnesses (such as cancer and HIV/AIDS) span the illness trajectory and change as the illness progresses; whereas uncertainties about acute illnesses are short-term (Brashers et al., 2000; Mishel, 1990). Similarly, phases in the illness

experience incur varied forms of uncertainty including concerns about accuracy of symptoms, diagnosis, and decisions about disclosure and treatment (Brashers et al., 2000; Hoskins & Haber, 2000; Reb, 2007). Some people find uncertainty unsettling while others find hope and contentment in uncertainties (Brashers, 2001).

Just as there are differences in the experience of uncertainty, so are there variations in strategies for managing uncertainty (Brashers, 2001; Mishel, 1999). People manage uncertainty by regulating information and interaction with others (Brashers, Goldsmith, & Hsieh, 2002; Babrow, Hines & Kasch 2000; Brashers et al., 2000). For example, people with HIV/AIDS avoid or seek information about the disease to manage their uncertainties (Brashers et al., 2000), and cancer survivors manage disease-related uncertainties by managing involvement in support groups (Atkins, 2016; Ussher et al., 2008). Hence, communication is significant to how uncertainty is understood, expressed, and managed (Babrow, Kasch & Ford, 1998; Babrow et al., 2000; Brashers et al., 2000).

Uncertainty is high among cancer survivors because of fluidity of disease characteristics, treatment aftereffects, and possibility of recurrence. For instance, in the case of ovarian cancer, uncertainty about treatment progression and outcome can influence how survivors experience the disease and transition to become survivors, which can also increase uncertainty in other areas of survivors' lives including finances and relational wellbeing. There is, thus, a critical need for research about how survivors navigate and communicate their psychological concerns as they complete active treatment. This will help illuminate the concerns and support needs of survivors and aid in intervention initiatives.

Cancer Survivorship

Social constructions of the cancer survivor label imply cure from cancer and a notion that the label is earned through fighting and beating cancer (Kaiser, 2008; Zebrack, 2000). This narrow meaning ascribed to the label has impacted an understanding that some cancer experiences are worthy of the survivor label while others are not — a notion contested by survivors and researchers alike. Consequently, cancer survivors accept, reject, or modify the survivor label to reflect their experiences and understanding of the term and to challenge dominant discourses (Deimling, Bowman, Wagner, 2007; Documet, Trauth, Key, Flatt & Jernigan, 2012; Kaiser, 2008; Park, Zlateva, Blank, 2009; Zebrack, 2000). Those who adopt the label feel they have conquered the disease or consider the disease a permanent part of their lives while those who reject the label find inconsistencies in constructions of the term and their own experiences (Kaiser, 2008). Adopting the label is not static; it shifts relative to changes in survivors' understanding of their experiences (Morris, Campbell, Dwyer, Dunn & Chambers, 2010).

Cancer survivors who adopt the survivor label do so at various periods in the illness experience. For instance, some come to the realization that they are survivors when their lives are back to normal, when treatment is over, or as they connect with other survivors (Documet et al., 2012; Morris et al., 2010). Adopting the label is influenced by factors including age, experience of symptoms, type and/or number of treatment, level of treatment aftereffects, and involvement in cancer-related activities (Deimling et al., 2007; Documet et al., 2012; Morris et al., 2010; Park et al., 2009). Claiming the cancer survivor identity can positively impact psychological wellbeing. For instance, it can improve adjustment to other stressful life events

and boost health-enhancing behaviors such as compliance with medical recommendations (Deimling et al., 2007; Documet et al., 2012; Park et al., 2009).

However, the survivorship orientation creates expectations about cancer and how survivors ought to experience the disease. Identifying as a cancer survivor comes with expectations to embody behaviors, responses, and norms consistent with social constructions of the label including being grateful, normal, and heroic (Little, Paul, Jordens, Sayers, 2002; Zebrack, 2000). This alienates and produces feelings of guilt in people who do not embody the expected ideals due to recurrences or severe treatment aftereffects (Deimling, Bowman, Wagner, 2007; Kaiser, 2008; Zebrack, 2000). For instance, breast cancer survivorship is associated with optimism, advocacy, and feminine attributes (Michel, 2014; Sulik, 2011); a situation which causes distress in women who do not feel their experiences reflect these attributes (Kaiser, 2008; Sulik, 2011). A recent study found that cancer survivors refused to claim the survivor label because they felt they had not earned the label as used to describe people who have overcome high-risk life events (Khan, Harrison, Rose, Ward & Evans, 2011). Kaiser (2008) also explained that some breast cancer survivors rejected the survivor label because “they believed they were not sick enough to be a survivor” (p. 84). These perceptions about survivorship are derived from the social environment which influences constructions of the label and associated role expectations (Kaiser, 2008)—what Sulik (2011) termed “feeling rules¹⁴.” Thus, how the public understands and talks about cancer survivorship have implications for survivors’ lived experiences (Deimling et al., 2007).

Ovarian Cancer Survivorship. The situation is not different with ovarian cancer where survivorship is equated with advanced disease, grueling treatment, and/or recurrences. This view

¹⁴ Feeling rules are social expectations of how survivors should react and respond to cancer.

is influenced, to a large extent, by social constructions of the disease including its public representations and lack of “happily-ever-after” survival narratives (Holmes, 2006; Gubar, 2012, p. 23). Images and symbols of the disease in the public realm are unsavory and metaphors associated with the disease, including “silent killer” and “whispering disease,” decrease public awareness. There is limited public knowledge about ovarian cancer (National Ovarian Cancer Coalition, n.d.); the disease remains visible to medical eyes only (Holmes, 2006). This produces some form of disconnect between how the disease is experienced and public understanding and perceptions of it (Holmes, 2006). Added to this, ovarian tumors can be “monstrous and fascinating;” they are usually very large and can contain bodily parts such as teeth, hair and nails (Stacey, 1997). Ovarian cancer survival narratives are limited and often describe grueling treatments and side-effects (see Gubar, 2012). Relative to this understanding about the disease, women diagnosed at an early stage and those whose disease has not recurred feel inadequate to claim the survivor label; they feel guilty that their experiences with the disease are less than what most survivors experience.

This chapter aimed to address the following research questions:

RQ1: What is the process of becoming an ovarian cancer survivor?

RQ2: What does it mean to be ovarian cancer survivor?

Findings

Every woman affected by ovarian cancer is a survivor¹⁵. However, the process of becoming a survivor was more intentional at the end of active treatment. The process differed for each woman based on stages in their post-treatment experiences: some had been out of treatment

¹⁵ The National Coalition for Cancer Survivorship (NCCS) defines cancer survivorship as “from the time of diagnosis and for the balance of life” (<http://www.canceradvocacy.org/about-us/our-mission/>).

for a long time (i.e., 17 years) while others had recently finished treatment (i.e., four months), and some had not experienced any recurrences while others had multiple recurrences. For each woman, the process of becoming a survivor was deeply personal and involved sorting through life at different paces and phases depending on age, socioeconomic status, level of available social support, and treatment aftereffects. For instance, women with high socioeconomic status did not experience some of the financial stresses other survivors faced, and women who did not have lingering treatment aftereffects such as neuropathy were able to get their lives back together more quickly than those who experienced these aftereffects. As indicated by Kylie (65 years old), the transition from cancer patient to cancer survivor was a long, rough process. She stated: “I struggled for three years to become a cancer survivor. My struggle with becoming a cancer survivor was longer and far more intense than fighting cancer.”

Ending Treatment

The process to becoming a survivor began after treatment ended. Women explained that the end of active treatment represented hope and optimism. They looked forward to returning to work, taking part in sporting activities, getting their lives back on track again, and putting the ovarian cancer experience behind. At the same time, women were uncertain about what to expect life- and health-wise post-treatment. They were aware of the possibility of recurrence and of regular hospital check-ups for several years to come but felt they had some time to bask in surviving the grueling treatment before worrying about recurrence. At this stage in the process, women had the support of close friends and/or family members to assess their lived experiences and to forecast a hopeful future; some of them would join support groups later. Women explained the need to reappraise their lives and priorities because when they were in treatment their focus was on living through each day.

As part of sorting out their lives, women assessed the impacts of treatments on their finances, relationships, and lives. They discussed changes they made in their lives including dietary changes and exercise routines. Women also mentioned negotiating changes treatments had made to their sexual self-concept. At this point, some of the women indicated psychological readiness to “go public” with their experiences by joining support groups, participating in programs to educate medical students about ovarian cancer, and participating in ovarian cancer fundraisers and annual walks. Meeting other survivors through these public events gave women a currency against which to evaluate their own experiences: the experiences of other survivors. Women who were diagnosed early stages felt their experiences did not measure up—an evaluation that produced guilt in them: they felt guilty that they had it easy while others struggled. Women who experienced recurrences had their process of survivorship interrupted as they went back into treatment.

Survivors stated that finishing treatment was one of the difficult stages in the ovarian cancer experience. It was a period filled with mixed emotions including excitement, relief, hope, and optimism, on the one hand, and fear and uncertainty, on the other. Women used words such as “thrilled,” “happy,” “thankful,” “scared,” and “concerned” to describe how they felt about finishing treatment. Women expressed awareness and fear about the disease recurring but tried not to dwell on the thought. For instance, Andrea (43, years stage III) explained: “Do I think I will get cancer again? Probably. I think I will probably get it again. I do not know if it will be in my breast or somewhere else.” Kara (70 years, stage II) also mentioned the constant fear she had about recurrence. She said: “Even though I have been cured, it is a little monster that is behind you all the time. It is like ‘what is next; could it come back?’ Yes, I guess. You do not have

control over that.” Similarly, Mercy (58 years, stage I) was aware of her chances of recurrence but felt she had some time before starting to worry about that:

Because I just finished chemo, I do not think it is going to recur right away. I feel like I have some time before I have to worry about it recurring again. But obviously I am very concerned because I know I have a 50% chance of recurrence.

As these quotes indicate, uncertainty was very high in women post-treatment. The process of becoming a survivor was enmeshed in subtle, constant fear of what to expect next. Women were not in denial of the chances of the disease recurring; they were informed and educated about that. However, they chose to focus on things they could control including closely monitoring their diet and exercise pattern as they work on getting their lives back together.

Putting the Pieces Back Together

To many survivors, the path to becoming a survivor was stressful because there were no explicit rules to help navigate life after treatment. As observed by Mercy (58 years, stage I): “the difficult thing is what your life is like afterwards: losing your job and trying to figure out insurance and issues about disability. It is the afterwards that you do not know. Nobody tells you that.” During treatment, women had put their lives on hold to live and manage immediate side-effects of treatment thus, it was after treatment that they could refocus and reappraise their lives. Kylie (65 years old) explained that: “You cannot deal with it [ovarian cancer] as it happens to you. When I was dealing with my chemo, I was trying to deal with how to live today; I did not have time to deal with anything else”. Mercy (58 years, stage I) also echoed a similar sentiment in the following quote:

I am still trying to sort out what my life is going to be afterwards because right now I am not in a position to work because of my hands and feet [neuropathy] and I do not know if I would be considered disabled by social security.

For each woman, re-assessing life post-treatment began on a personal level and gradually unfolded to include close friends, family members, and other survivors based on level of interest and ability. The majority of survivors experienced increased anxiety and uncertainty as they grappled with treatment aftereffects including disability, job loss, neuropathy, sexual health concerns, and weight loss/gain. They highlighted the toll treatment took on their finances and the concomitant impact on their lived experiences.

Navigating Financial Stressors

All the women acknowledged the financial toll the disease could take. While some of them did not experience financial difficulties first-hand, the financial security of many others was threatened and/or wiped out by the disease. The majority of the women had stopped working, worked part-time, or took early retirement to focus on treatment—changes that affected their finances. Additionally, health insurance co-pays and out-of-pocket payments were “difficult” and “stressful” for women, with some of them explaining the disease had put them in financial “holes” they could not come out of. Andrea (43 years, stage III) explained her situation thus:

The treatment takes a huge financial toll; we are about half a million now [in debt]. Will I be paying it for the rest of my life? Absolutely. If anyone ever told you that there is no price to life, yes, there is a price—I am proof of it.

Similarly, Chelsea (56 years, stage III) noted that:

The cancer has changed my finances drastically. It took away my part-time position that was my supplemental income and bombarded me with bills that I have no idea when I would be out from under them. I am still paying my hospital bill and I will be paying that for quite some time. It probably put me in a financial hole I never dreamt possible.

Ruth (55 years, stage IV) also stated:

I make very little money every month since I have had this sickness. I am lucky if I make \$300 - \$400 a month; and that is to buy grocery and other things. I have had to file bankruptcy; they foreclosed [my house]. I now live in the basement in the home of my sister and her husband.

And Esther (48 years, stage III) mentioned “financially, it has been more difficult because when I took medical retirement I had to take about 45% reduction in my wages so I am on social security disability now and that makes a difference financially.”

To these survivors, the financial stresses were another issue they needed to contend with as they put the pieces of their lives back together after treatment. The financial stresses were acknowledged by all women; however, these influenced the experiences of some women more than others. Women who had limited available support in terms of strong family systems and relational partners and those with limited financial buffers expressed more concern about the financial consequences of treatment. Women in this category appeared more disturbed about their financial situations and seemed doubtful about getting their finances straightened. Among these women were Ruth, Chelsea and Mercy who lived alone and had limited family support. With the limit on her finances, for instance, Ruth was unable to follow medical advice to eat healthy because she could not afford it. Chelsea explained that she constantly “fights” with her

insurance company over unpaid medical bills. She said, “insurance companies expect everybody to have families and for the family to jump in and take care of things; but not everybody does have family. I have family but they are all deceased.” Mercy also echoed similar frustrations when she stated that “every day a mail comes in I am like ‘am I going to have a crazy afternoon or a quiet afternoon?’ because I am dealing with healthcare bills that have come in.” These women had to bear the financial stresses single-handedly; this heightened their fears and uncertainties about the future and impacted their experiences of the disease.

On the other hand, women with strong financial and family systems had the stresses from the financial fallouts of treatment ameliorated by their support systems. For instance, Andrea was able to secure the financial future of her family by putting her “house in a trust so that if something would have happened my children can have a home to grow up in.” Andrea was able to return to work after treatment, her husband had a job, and her family and friends were willing to help out; over 700 people showed up for a fundraiser organized for Andrea. Thus to Andrea, the financial burden of ovarian cancer might be daunting but she knew she had people to fall back on; this reflected on how she lived through the illness. Similarly, Patricia mentioned that though it “cost a little more to pay out of pocket” for her treatment, she was able to afford it because “I put away a lot of money for retirement and I have a very good pension. I have never been worried about [the cost of treatment].” Patricia was divorced but she was financially stable going into treatment and had grown children who were doing well in life.

These situational factors highlight how the financial toll of the disease was experienced by each woman and the concomitant impacts on their lived experiences. Coming out of treatment and feeling optimistic about the future and their health, women were faced with yet another hurdle in their battle with the disease; however, the financial hurdle was experienced and

expressed differently by each woman depending on her life conditions at the time. Many of the women were unprepared to deal with the financial issues. This situation increased their uncertainties, making real the fact that there is a price to life for some.

Confronting Change

Finishing active treatment meant women also had to navigate changes treatments made to their physical, psychological, and social selves. Treatments impacted women's perceptions of their sexual self-concept, an understanding that they integrated into the meaning they constructed of their lived experiences¹⁶. In a similar vein, survivors mentioned making changes in their lives to manage uncertainties. Women explained that while certain aspects of the disease including recurrence and gene mutations were out of their control, they tried to control what they could in order to lessen the chance of recurrence. This included making dietary changes, such as eating organic food and exercising more. For instance, Esther (48 years, stage III) mentioned that: "I have not bounced back from the second treatment. My stamina is not what it used to be and that is why I am trying to exercise 15-20 minutes four times a week. I also try to eat healthy." Again, Andrea (43 years, stage III) who has the BRCA gene mutation and was at risk of breast cancer explained the changes she made in her life. She said:

My family switched to more organic food; we cut off on sugar and processed foods. I take probiotics and immune boosters. Most breast cancer tumors are hormone-driven so I am careful about what I put in my system that has even natural hormones. I did not do hormone replacement therapy after my hysterectomy; I just deal with having hot flashes.

Patricia (67 years, stage III) also mentioned cutting out sugar from her diet. She stated:

¹⁶ These changes to women's sexual self-concept are discussed in chapter 5.

I have changed my diet. I just drink water, no sugar. I do not eat the candy, cookies and pies that I used to eat. I eat organic fruits and vegetables. I eat hormone-free and preservatives-free chicken. I wanted to do everything I could to give me as long life as possible.

Other women, however, could not afford to make the recommended dietary changes. As stated earlier, Ruth (55 years, stage IV) could not make changes in her diet because she did not have the means. She explained, “The doctor would say ‘I want you to lose weight; I want you to eat more fresh vegetables and fruits.’ Yeah, really? When I have \$100 a month for grocery, I am going to buy pasta. What do you want me to do?” Thus, to the extent that women were able to confront the changes they needed to make and incorporate these into their lives depended on the availability of financial and social resources. This suggests socioeconomic status as an important element in the ovarian cancer experience.

Another area where having ovarian cancer changed women was in their perceptions about spending. Women indicated increased willingness to spend money on themselves as a result of uncertainties about the future. For example, Esther (48 years, stage III) explained that:

For our 25th wedding anniversary I got a new diamond for my husband, and we would never have spent money like that; that would have been something we would have waited till we are married 50 years. But that may not happen.

Stella (63 years, stage II) also said that she had developed more flexibility in her spending: “We are more willing to spend money on travelling and projects we are working on. We were more careful with our spending previously. This [cancer experience] has made us a little free to spend our money.”

These differences in women's negotiation of the changes that come with the disease highlight the intricacies of the ovarian cancer experience and the multiplicative effects of all facets of women's lives on their experiences. For instance, lower socioeconomic status impacted women's ability to exercise control and choice over aspects of their lives that impacted their experiences, including their diet. This helps elucidate the varied issues women were dealing with that had a rippling effect on their experiences. As I would explain below, level of financial stability and available social support also affected the extent to which women were able to connect with other survivors through support groups. Thus, it is important that the cumulative effects of these factors on the ovarian cancer experience are examined to better understand women's meaning making processes.

Going Public

When women felt ready psychologically, they shared their experiences with other survivors and society; women who were through with treatment needed to connect with other survivors and to raise awareness about the disease. Some of them had strong support systems in family and friends but wanted to meet other survivors who understood what they were going through. Women joined support groups, participated in programs to teach medical students about ovarian cancer, and took part in fundraisers and cancer walks.

Sharing the Cancer Journey. Joining support groups was a way for survivors to identify with the disease, draw strength and hope from other survivors, and process their experiences by talking through it with others. For some survivors, support groups acted as a reality check and a reminder that their experiences were real, tough, and worth taking about. Women who did not join support groups either felt no need for additional support, lacked logistics to attend group meetings, or believed support groups would be detrimental to their psychological wellbeing.

However, those who joined support groups explained that they were at a point in the illness experience where they felt ready to talk about their experiences and needed the help of other survivors in the transition. Women's views are illustrated in the quotes below.

I think as time went on I was more ready to deal with things. I had done everything I needed to do and now I am at the other side of the experience. It was at the point where you could talk about it because when you have cancer and you get through it, nobody wants to hear about it again. But [the support group members] understand. I do not think my main reason for joining was to use my experience to help others; it was more to talk about my experience with people who understand (Rose, 55 years, stage III).

I joined that group because I felt disconnected in a way. Nobody understood me and I felt only the group would understand me better because they can relate. Even though your family is very loving, they hear cancer-free and they are like "oh okay, that is it." Unfortunately that is not it because your mind cannot go from a cancer patient to being a cancer-free person; it does not work that way (Kylie, 65 years).

By going to the support group, I was making myself realize that "I have got this cancer." I needed those reality checks because otherwise now that I am feeling better, I would think I am fine and I might go back to my bad habits (Patricia, 67 years, stage III).

Other women also joined support groups to be an encouragement to those recently diagnosed. They explained:

I love going to the support group meetings; that is my way of helping. When women who had been newly diagnosed could look across the table and see several people that are alive, it is very encouraging to them (Jenny, 84 years, stage II).

I tell the people at the support group that I do not need to be coming anymore because the treatment and plans for ovarian cancer have changed so much that my 17 years' experience is not necessarily viable; but they tell me that newly diagnosed women need to know that people can survive so long. So I keep going (Carrie, 84 years, stage IV).

These examples make clear the different reasons and motivations why women joined support groups. These were influenced by women's recurrence statuses, length of years living with the disease, and level of available social support.

Facing Own Mortality. Survivors acknowledged that joining support groups also meant being willing to be exposed to the realities of the disease, including witnessing the passing of group members and receiving stark reminders about their own mortality—reminders often hard to take. This aspect of connecting with other survivors was difficult for many women. As explained by Nora (59 years, stage II), the support group was sometimes counter-productive to her psychological wellbeing yet she felt it was needed. She said:

In some ways the support group scared me because I would hear stories that were so horrible. I was doing okay; I was working and I did not want to think that it [cancer] could come back. Seeing the look on some women's faces, you knew they were stage 4 which I am stage 4 now because it has metastasized to my liver. Women would be very quiet and they would tear up a little bit but you could see that they just did not have hope.

Ruth (55 years, stage IV) also explained her experience of loss in support groups as follows:

We had a lot of members that died. It is hard because you are with them and they are bearing their souls to you on an intimate level; you know what they have gone through and they also know what you have been through. You are even forging a friendship and

puff, they are gone. And it starts again and then another one is gone. It is really hard because you see it more in an ovarian cancer group.

And, Kylie (65 years old) mentioned, “In my journey from 2010 to today I have three very good friends who lost it to ovarian cancer. That affects your thinking and mortality because you realize it is right in front of you.”

These examples suggest that women had to learn to balance not only changes in their lives in the transition to becoming survivors but also differences in others’ experiences of the disease. To become the survivor they wanted, women had to learn to quickly sort out encounters at support groups and other public events that were meaningful to their own lived experiences and leave out those that were counter-productive. This required some level of psychological stamina. Others’ life stories helped women put their own lived experiences into perspective but also increased women’s uncertainty as they saw other survivors’ turns, twists, faces, and phases; their own battle with the disease could be like that. While each woman’s situation was different and the experience of ovarian cancer was never the same for everyone, seeing the struggles of other survivors sent women on an imagination journey to figure out “what could be” of their future selves—a situation that exacerbated uncertainty.

Feeling Guilty

By connecting with other survivors through support groups, cancer fundraisers, annual walks and other programs, women assessed their experiences and coping mechanisms against those of other survivors and against normative constructions of the disease. Their assessment, particularly those diagnosed at early stages (i.e., stages I and II) and those whose disease had not recurred, rated their experiences as less worthwhile. Women in this category reported feeling

“guilty” comparing their experiences with those of other survivors. They termed this “survivor’s guilt” as explained in the following quotes:

Sometimes I feel guilty being a survivor because so many people passed away. It is called survivor’s guilt. Having survived so long you feel bad that others are not surviving as long as you are and you wish that there was more you could do for them or that the medical community could do (Pattie, 38 years, stage III).

I feel guilty saying I am a survivor when I have all these women around me [at the ovarian cancer luncheon] who are really struggling. I only had 3 chemotherapy treatments and there are other women fighting for their lives and I question myself: “am I really that much of an example when I have had it so much easier than they have had it?” When I am in the general public, I do not really have a problem, but when I am among other [survivors], that is when I am hesitant to use the word “survivor”. I feel that maybe I should have suffered a little more (Lucy, 60 years, stage I).

There had been times I leave the group meetings feeling very, very guilty because ladies come and they have had recurrences or they come and they are struggling with side-effects [of treatment] and they ask how things are going with me and I say, “well, everything is going fine; 12 and a half years, no reoccurrence.” I feel a little guilty sometimes (Juliet, 59 years, stage II).

Juliet mentioned being very guarded when talking about her experience in the support group so as not to hurt the feelings of other survivors. She said: “I do not want to come across as self-righteous; I do not want anybody to feel bad when I talk about my experience. I try to be open about it but I am more careful about how I word it.”

Implicit in these quotes is an expectation of what ovarian cancer should feel and look like: advanced disease, weak bodies, long, grueling treatments, and imminent death. Thus, women who felt their experiences did not conform to the normative “look” of ovarian cancer underrated their experiences, describing them as less adequate. This guilty feeling contributed to shape women’s lived experiences and could affect the strength they drew from their experiences and the extent to which they communicated about and used these to help other women. Also worthy of note is how this guilty feeling was profound when women were in the midst of other survivors. This suggests that fellow survivors became the elements of comparison for women; a comparison based on the not-too-pleasant social constructions of ovarian cancer (Holmes, 2006; Stacy, 1997). Because of the unpleasant images and metaphors associated with ovarian cancer in their social environments (Holmes, 2006; Gubar, 2012), women went into treatment expecting it to be harsh and difficult. When they construed their experiences as less than the ideal, it produced guilt. For instance, Stella (63, stage II) mentioned that she expected her treatment to be worse than what she experienced: “the chemotherapy was hard but I was expecting it to be harder. It was not a walk in the park but it was not as bad as I expected it was going to be.” Women who harbored this guilty feeling had alternative narratives about the ovarian cancer experience that is often not available to the public and they need to be supported and encouraged to embrace and construct these narratives.

The “Becoming a Survivor” Model

The preceding discussion explained the process of becoming an ovarian cancer survivor and the factors that influenced the process for each woman. The process is illustrated in figure 3.

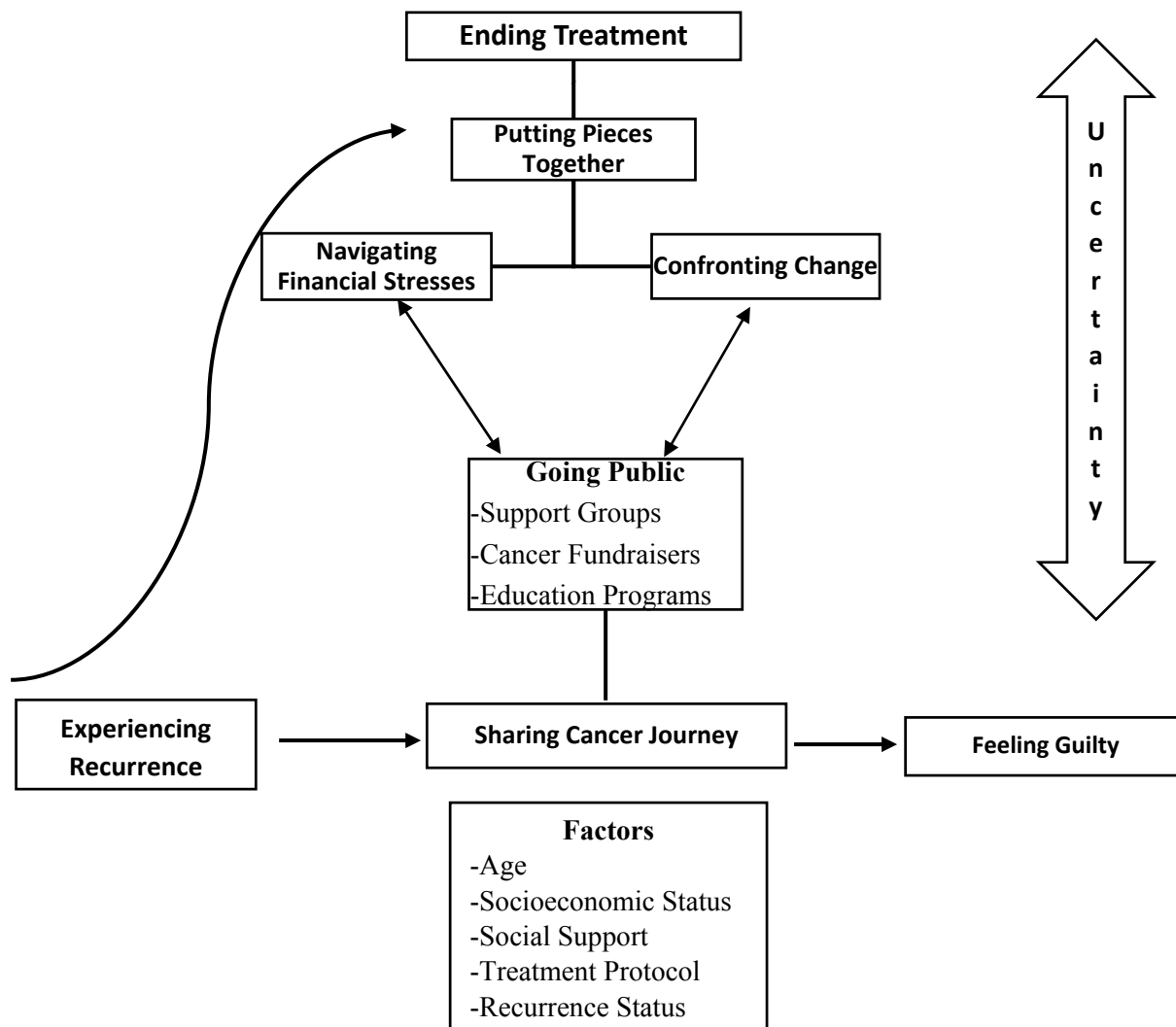


Figure 3: The Process of Becoming an Ovarian Cancer Survivor

The process of becoming a survivor becomes more intentional at the end of active treatment and it is significant to the total lived experience of survivors. The period following end of active treatment is marked by increased uncertainty in survivors; they faced separation anxiety as they left constant supervision of medical care. Survivors were unsure about what to expect in terms of changes in their bodies, finances, relationships, and the long haul of putting the pieces of their lives back together. There were no books or explicit rules guiding the path to survivorship, but there are women willing to write and narrate their own stories and lived

experiences and to use these to benefit womankind. Women's stories were constructed through layered experiences of financial stresses, visible and invisible changes in their bodies, guilt, pride, and social support. The process of becoming a survivor was unending for survivors and shrouded in uncertainty; uncertainty marked the entire process. For women whose disease had recurred, they had yet finished putting the pieces of their lives together when they had to begin treatment again. The process was not linear as women experienced some of these post-treatment issues concurrently.

The process was influenced by factors including women's socioeconomic status, level of available social support, intensity of treatment aftereffects, and recurrence status. Lower socioeconomic status limited some women's ability to maintain health-enhancing behaviors such as keeping a healthy diet and the logistics to attend support group meetings, and increased the financial stresses they experienced along with the disease. Further, limited social support in terms of close family members and relational partners meant that women negotiated the financial stresses and other changes alone. This lack of buffer increased women's uncertainties about their health and future. Also, intensity of treatment aftereffects and recurrences impacted the process of becoming a survivor for some women. For instance, it was a long process for women who had severe neuropathy to get their lives back together, and recurrences caused some women to quit their jobs which adversely impacted their finances. Also significant was how social constructions of ovarian cancer affected some women's experiences of the disease. Thus, the ovarian cancer experience is different for each woman, and every woman's experience is worth celebrating. Ruth (55 years, stage IV) explained this better when she narrated her experience in the support group. She said:

I have heard women tell other women that stage 1 is not cancer, that stages 3 and 4 are the real ones. You cannot tell somebody that. I always tell them, “ladies, you cannot out-cancer somebody”. You want to tell me that you getting cancer was any less devastating at stage 4 than at stage 1? That your stomach did not hit the floor and your jaw dropped? No, you cannot do that. It is not a competition; there is no winner.

Discussion

This chapter explored the process of becoming an ovarian cancer survivor following the end of active treatment and how that contributed to women’s lived experiences of the disease. Interview and focus group findings with ovarian cancer survivors showed that even though becoming a cancer survivor begins with diagnosis and continues through the rest of women’s lives (National Coalition for Cancer Survivorship, n.d.), the process becomes more thoughtful, intense, and deliberate at the end of active treatment. The construction of survivorship differed for each woman and was influenced by factors including socioeconomic status, stage of disease and treatment protocol, recurrence status, and level of available support. Similar to previous findings (Armes et al., 2009; Arnold, 1999; Ozga et al., 2015), results of this study showed that stress, anxiety, and uncertainty heightened at the end of active treatment. Uncertainty remained with women; aches and pains in their bodies, routine hospital check-ups, and the conditions of other survivors reminded women of the possibility of a recurrence. These reminders contributed to the increased uncertainty in survivors (Lockwood-Rayermann, 2006).

Further, results of this study highlighted the important roles support groups play in helping women navigate the transition to becoming survivors. Support groups served varied purposes for women depending on how far away they were from active treatment; for some, support groups provided encouragement, strength, and hope while for others, they provided an

avenue to become symbols of hope to others. This is consistent with previous findings about the roles of social support in the cancer experience (Dubois & Loiselle, 2009; Kreps, 2003). Joining a support group is a more advanced form of sharing the lived experience of ovarian cancer because of the challenges of communicating in face-to-face settings including limited control over exposure to information and the actions of others (Schneider, Kerwin, Frechtling & Vivari, 2002). Thus, once women chose to connect face-to-face with other survivors, it indicated a certain level of readiness to fully embrace the ovarian cancer experience and identify with the disease and other survivors. This process took time and varied for each woman. Hence, length of time since treatment is significant to the impact of support groups on women's lived experiences of the disease.

Additionally, connecting with other survivors through support groups and other public events helped women process their experiences and enriched the process of becoming survivors. However, it also introduced women to stressors that were counter-productive to their lived experiences, consistent with previous research (Ussher et al., 2008). Fear of recurrence increased anxiety and uncertainty in women, robbing them of the strength to focus on current events (Arnold, 1999; Cesario et al., 2010). It is, therefore, important for scholars, practitioners, and advocates to continue to remind survivors of how the experience is unique for each woman so as to maximize the potentials of support groups and public events as sites of support for women with the disease.

The findings related to survivor's guilt is a unique contribution of this study to scholarship on ovarian cancer, women's health, uncertainty management, and social support. It appeared women had expectations of what ovarian cancer should feel and look like—expectations acquired from constructions of the disease in the public realm. Social constructions

of ovarian cancer include advanced disease, high recurrence and mortality rates, and unsavory symbols and images in the public (Gubar, 2012; Holmes, 2006; Stacy, 1997). The disease is portrayed as un-survivable as there are limited survival stories and as public discourse around the disease often takes place following the death of a public personality or someone close to them (e.g., Angelina Jolie). There is no human face on the disease in the public realm. Women drew on these constructions of the disease to make sense of their lived experiences, leading some to form the notion that they needed to “suffer more” for their experiences to count. This indicates how conventional understanding about the disease may be influencing women’s interpretations of their lived experiences. Women who experienced “survivor’s guilt” were unknowingly reinforcing beliefs about the disease (e.g., that some cancer experiences are worth more than others, and that ovarian cancer has to be tough); beliefs they should rather be challenging because their own experiences contradicted these. Women undermined their own experiences to make true erroneous beliefs; they had a narrow understanding about their experiences and failed to consider the effects of diagnosis and treatment on the totality of their lives. By this, women embraced a survivor-blaming mentality instead of a victor/survivor identity; they made surviving ovarian cancer seem uncustomary.

I argue that women who felt guilty for surviving ovarian cancer have alternative narratives about the disease to offer. These narratives are not popular and may be in the minority regarding the general understanding about the disease; but they are needed nonetheless. We need these alternative narratives to help demystify the disease and give an accurate representation of the continuum of women’s lived experiences. While issues with recurrences are out of the control of survivors, women who did not experience recurrences do not have to penalize themselves for their conditions. This calls for efforts to increase public education and awareness

to help correct the erroneous perceptions. Research and social support efforts are also needed to encourage women to celebrate their individual survival stories; women who felt guilty need to be supported and encouraged to voice, write, and live these alternative narratives. Herein lies the significance of the present study which helps put human faces on ovarian cancer and supports alternative narratives and experiences of the disease.

Conclusion

There are some limitations of this work. First, I could not verify whether the changes women made in their lives, including dietary changes and exercise routines, were sustained. A follow-up study would be necessary to determine the effectiveness and sustainability of these changes. Also, women were at different stages post-treatment; thus, the number of years away from active treatment without a recurrence could have impacted women's constructions about becoming a survivor. Future research should consider the views of women who recently finished treatment and long-time survivors separately to better understand the factors impacting the path to survivorship.

These limitations notwithstanding, this study has significant implications for scholars interested in women's health issues, cancer, and communication. The findings offer unique perspectives on women's lived experiences of ovarian cancer and their paths to becoming survivors.

CHAPTER V. “I FEEL DIFFERENT”: OVARIAN CANCER AND SEXUAL SELF- CONCEPT

Introduction

As a gynecologic cancer, ovarian cancer and its treatments affect women’s sexuality and sexual health. The disease affects a core element of womanhood and femininity—the ovaries. Scholars and others argue that the position of the ovaries in the interior of the female body and the prognosis of the disease contribute to limited public awareness. In this chapter, I reviewed the literature and discussed findings about the effects of ovarian cancer and its treatments on women’s understanding of sexual self-concept. Women’s understanding is influenced by life conditions at the time of diagnosis, the treatment regimen, and factors such as age and level of social support. I argue that sexual self-concept in the context of ovarian cancer needs to be reconceptualized to account for how the disease presents itself.

The effects of cancer and its treatments on the sexuality and sexual health of survivors have been well documented in the literature. Cancer treatments including surgery, chemotherapy, radiation, and bone marrow transplant can have long-term physical and psychological effects on survivors including changes in sexual functioning and the structure of sexual organs, body image, and relationships (Parton, Ussher & Perz, 2015; Krychman & Millheiser, 2013; Andersen, 2009; Gilbert, Ussher & Perz, 2010a; Anderson & Johnson, 1994). These post-cancer sexual health concerns cause worry and anxiety and negatively impact women’s sexual self-concept, relationships, and overall quality of life (Krychman & Millheiser, 2013; McCallum et al., 2012; Gilbert, Ussher & Perz, 2011; Vaz et al., 2007; Schultz & van de Wiel, 2003).

Even more profound are the effects of gynecologic cancers and/or treatments on women's sexual health because these cancers affect organs considered to be indicative of womanhood and femininity including the ovaries, uterus, fallopian tubes, and cervix (Parton, Ussher & Perz, 2015; Sekse et al., 2013; McCallum et al., 2012; Gilbert, Ussher & Perz, 2011; Wilmoth & Spinelli, 2000; Price, 1998). "Intra-psychic" effects of gynecologic cancers and/or treatments can negatively impact women's psychological wellbeing as a result of changes in their individual and social identities and body image (Gilbert, Ussher & Perz, 2011; Reis, Beji & Coskun, 2010). These changes may not affect women's sexual functioning per se, but can affect their sexual sense of self, which is a component of sexuality and sexual health. Sexual health comprises sexual function (including desire, arousal/excitement, and orgasm), sexual self-concept (including body image, sexual esteem, and sexual self-schema), and sexual roles and relationships (including communication and intimacy) (Cleary & Hegarty, 2011; Woods, 1987).

Scholars suggest that to improve the overall quality of life of women affected by gynecologic cancers, health practitioners need to understand sexuality concerns as an important component of quality of life and develop holistic treatment approaches that take into consideration the sexual health needs of survivors (Wilmot & Spinelli, 2000; Wilmoth, 2007). In line with that, numerous studies have examined women's sexual wellbeing related to breast cancer (Ussher, Perz & Gilbert, 2012; Avis, Crawford & Manuel, 2004), gynecologic cancers (McCallum et al., 2014; Sekse, Gjengedal & Råhem, 2013; Cleary & Hegarty, 2011; Bodurka & Sun, 2006; Juraskova et al., 2003; Schultz & van de Wiel, 2003), and from the perspectives of affected women and their heterosexual and non-heterosexual partners (Ussher, Perz & Gilbert, 2014; Gilbert, Ussher & Perz, 2011; Hawkins, et al., 2009). While some work has been done exclusively on ovarian cancer and sexual health (e.g., Taylor et al., 2004; Stead et al., 2001),

more research is needed on the subject, particularly research using a feminist intersectional approach. Intersectionality looks at how factors such as gender, race, sexuality, and other marks of identity intersect to shape the experiences of marginalized groups (Hankivsky & Cormier, 2009; Crenshaw, 1991). Thus, a feminist intersectional approach to ovarian cancer and sexual health recognizes differences in women's experiences based on their unique life circumstances and the conditions of their diagnoses and treatments, and offers a nuanced perspective on the disease. I argue that research that conflates ovarian cancer with other gynecologic cancers obscures the fact that advanced epithelial ovarian cancer is the deadliest gynecologic cancer and contributes to the public's lack of awareness of the disease and the supportive care needs of survivors (National Cancer Institute et al., 2012; National Ovarian Cancer Coalition, n.d).

Ovarian cancer is often diagnosed at an advanced stage because it presents vague symptoms, a situation which contributes to its high mortality rate (Schink, 1999). Symptoms of ovarian cancer include flatulence, bloating, constipation, and pelvic and/or abdominal pain (American Cancer Society, 2014; Brain et al., 2014). Ovarian cancer and its treatments can significantly impact the sexual health of women because the disease originates in the ovary, and treatments can have lasting effects including induced menopause in premenopausal women (Gubar 2012; Taylor, Basen-Engquist, Shinn & Bodurka 2004; Howell et al. 2003). Further, advanced ovarian cancer has a high recurrence rate (Schink, 1999), and research suggests that women's sexual health is affected more with cancer recurrence (Andersen, 2009). Thus, focused investigation into women's life conditions, stage of disease, and treatment regimen is warranted for further understanding of women's sexual health following a diagnosis with ovarian cancer. Hence, the significance of the present study which explores the effects of ovarian cancer and/or

treatments on women's sexual self-concept and how factors such as age, stage of cancer, and level of social support intersect to shape the meaning women construct of their experiences.

Sexual Health and Sexuality

Sexual health is an evolving multidimensional concept influenced by past and current political, social, and cultural events (Edwards & Coleman, 2004). Concerns about sexual health can be categorized into physical sexual concerns including pain during sexual intercourse (dyspareunia), vaginal dryness, or changes in the structure of the sexual organs; psychological sexual concerns including decreased interest in sexual activity and concerns about changes in body image and identity post-treatment; and social sexual concerns including decreased sexual interest by partners and partners distancing themselves emotionally (Abbott-Anderson & Kwekkeboom, 2012). These dimensions of sexual health are intertwined such that a change in one area can effect changes in another (Schultz & Van de Wiel, 2003; Woods, 1987). Thus, scholars suggest that for a fuller comprehension of sexual health, the interrelatedness among biological self, self-esteem, and social roles and relationships needs to be considered (Butler, Banfield, Sveinson & Allen, 1998). The present study focuses on women's sexual self-concept following ovarian cancer diagnosis and treatment (see, Woods, 1987).

Sexual health is a subjective construct measured by individual experiences (Schultz & Van de Wiel, 2003). Hence, this study discusses sexual self-concept in the context of ovarian cancer as experienced and expressed by affected women. This is based in the feminist belief that women have subjective and intimate knowledge of their experiences and thus, have the right to name these experiences (Anzaldúa, 1992; Collins, 1990, 1986). Importantly, women have a broad understanding of sexuality and sexual health beyond sexual functioning to include feelings and perceptions about appearance and fertility (Cleary & Hegarty, 2011; Wilmoth & Spinelli,

2000; Butler, Banfield, Sveinson & Allen, 1998). This understanding is influenced by life events including injuries, disease diagnoses and treatments, aging, gender roles, and sociocultural beliefs and practices (Johnson, 1996 as cited in Butler, Banfield, Sveinson & Allen, 1998; Woods, 1987). For example, Rubin Nemeroff and Russo (2004) found that women's appreciation of their bodies, their understanding of womanhood, and use of strategies to protect their self-concept were influenced by societal practices which objectify women and their experiences. Parton and colleagues (2015) also found that women's perceptions of their post-cancer bodies were impacted by their cultural contexts and normative notions about embodied femininity and sexuality.

Sexual Health and Gynecologic Cancer

A closer look at gynecologic cancers and sexual health shows a connection between the meaning survivors construct of their experiences and their evaluation of the (dis)satisfaction these bring them. Sekse and colleagues (2013) found that women affected by gynecologic cancers felt their bodies had changed so much that they had to learn to accept and understand these bodies in new ways. This led to a disconnect between women and their bodies on the one hand and women and their sexual partners on the other, consequently affecting women's sexuality and sexual health (Sekse et al. 2013). Thus, it is important that gynecologic cancer survivors are supported to accept their post-treatment bodies because failure to do so can present barriers to achieving optimum sexual health (McCallum et al., 2012).

Also worthy of note is research suggesting that few women who face challenges in their sexual lives post-gynecologic cancer treatments are bothered by the situation. Several factors including the sexual health of partners, individual factors such as coping styles, and concerns about recurrence influence the priority given to post-cancer sexual health issues (McCallum et

al., 2014). For example, women who had survived ovarian cancer for at least 2 years reported being satisfied with the appearances of their bodies even though treatments had left visible scars on them (Stewart et al., 2001). Most survivors “had changed or downgraded the meaning of sexuality after their illness” (Stewart et al., 2001, p. 541). Therefore, there is a need to appreciate how survivors define and embody sexual health based on their unique individual experiences. Such a nuanced understanding of sexual health, particularly sexual self-concept, related to ovarian cancer is what the present study offers.

Sexual Health and Ovarian Cancer. Unlike other organs in the female body such as the breasts which are visible and sexualized, the ovaries are hidden in the interior of the female body, almost forgotten and rarely mentioned in public discussions; they are considered irrelevant once childbearing is completed (Holmes, 2006; Crossen, 1942). Also, the position of the ovaries in the female body limits women’s knowledge about them; very few people think about the ovaries unless there is a medical reason to do so and even then, our view and understanding of the ovaries and ovarian cancer are mediated with the assistance of medical personnel or technology (Gubar, 2012; Holmes, 2006). This situation further promotes alienation from the ovaries and ovarian cancer. Thus, the connection between ovarian cancer and women’s sexual health is often not examined because society associates sexuality with vibrant, energetic, and physically attractive bodies and body parts. Unfortunately, this is not the image the ovaries, ovarian cancer, menstruation and menopause—which are functional products of the ovaries—create in the public’s eye (Holmes, 2006; Martin, 2001; Stacy, 1997). Ovarian cancer does not lend itself well to the “early diagnosis,” “overcoming,” and “war” rhetoric of cancer (Jasen, 2009). Further, the connection between ovarian cancer and women’s sexual health is often not made because ovarian cancer normally affects post-menopausal women to whom sexuality and

sexual health are thought to be of lesser priority (Bradway & Beard, 2015; Ussher, 1989).

However, studies indicate that ovarian cancer affects pre-menopausal women as well (Hensley et al., 2003). Indeed, many of the participants in the present study are pre-menopausal.

Research by Stead and colleagues (2006, 2001) showed that ovarian cancer survivors experienced physical and psychological sexual health issues, but whereas the physical problems receded with time, the psychological problems persisted, impacting women's self-esteem and relationships (Stead et al., 2001). Also, Taylor and colleagues (2004) found that ovarian cancer survivors' perception of their body image affected their sexual functioning. Based on the review of literature, this study was guided by the following research questions:

RQ1. To what extent do changes in women's bodies brought on by ovarian cancer and/or treatments affect their perceptions of sexual self-concept?

RQ2. What meaning do women construct from their experiences?

Findings

Feeling Different. Approximately 40% of women acknowledged that ovarian cancer and its treatments had affected their sexual self-concept including appearance and body image in significant ways. Women noticed changes in their sexual self-concept starting from the treatment stage—changes which became permanent for most of them. For most women, the changes began with the aftereffects of surgery including nausea, tiredness, and scars from the operation. Women stated feeling “different,” “insecure,” and “traumatized” by the disease and its treatment. Patricia, a 67-year-old woman diagnosed at stage III, noted that “when I was in treatment, I was insecure. I just felt like a fish out of water; I felt very vulnerable. I really was not myself.” Gifty also made a

similar remark about feeling different following treatment. She elaborated: “Losing your hair is hard. You look completely different; people look at you and the minute they saw you they ask “what happened? What is wrong?” [Gifty, 50 years, stage I]. Another participant also said:

It was one good year after I finished treatment before I started to feel like myself a little bit more. Even when I look in the mirror now, I feel that I am so old-looking; I really feel like it aged me [Marie, 54 years, stage I].

Evident in these quotes is the struggle ovarian cancer survivors faced in reconciling the conditions of their post-treatment bodies to their understanding of sexual self-concept. The appearances and functions of their bodies were in stark contrast with women’s notion of the “normal” body. While their bodies had gone through changes, women’s conceptualization of sexual self-concept had not yet changed, hence, they felt different.

Experiencing Difference. Depending on the stage of disease and treatment protocol, women interpreted the changes to their sexual self-concept differently. For instance, women who were diagnosed at an early stage (i.e., stage I) and had surgery but not chemotherapy did not feel different in terms of sexual self-concept. Pre-menopausal women in this category did not experience induced menopause and associated side-effects of hot-flashes and hair loss thus, there were minimal visible marks about their appearances that made them different. Even though the scars from the surgeries were present, these were not visible for public scrutiny so the women did not consider them a problem. One participant noted: “I did not have to do chemo. Most people lose their hair in seconds. But I did not have to go through any of that” [Grace, 26 years, stage I]. Another participant diagnosed at an early stage remarked that the disease and its treatment did not affect her sexual sense of the self. She said, “It did not change anything. I look the same, I feel the same” (Ann, 65 years, stage I).

On the other hand, women diagnosed at late stages of the disease (i.e., stages III or IV) explained that the treatments had affected their body image and self-confidence. Most women in this category went through the standard course of treatment for ovarian cancer including surgery and chemotherapy, had lost their hair, and live with the aftereffects of the disease—daily reminders too obvious to ignore. One participant who was diagnosed late stage and also had preventative double mastectomy described the effects of the multiple treatments on her sexual self-concept in the following way:

It affected the way I perceive myself. I feel so deformed and so ugly; I hate looking at my body in the mirror. I have no interest in having a relationship with a man. I would love to get married but I do not see it in my future. If I cannot stand to look at myself in the mirror, I cannot even imagine a man would (Ruth, 55 years, stage IV).

For Ruth, the combined treatments had left both physical and psychological marks on her life visible not only to herself but also to the public. Living in a society that places much emphasis on appearance and physicality (Holmes, 2006), women were compelled to rate their sexual self-concept according to normative standards. This is evident in the narratives of participants for whom the physical marks of the disease were visible to the public and those for whom the marks could only be seen by themselves and their partners. Thus, whether women are pleased and happy, or not, with their post-cancer bodies is dictated by societal standards including the emphasis on appearance and physicality. Whereas the physical marks serve as constant reminders of the disease, women's concerns with these were accentuated by whether the marks were visible or not.

Seeing Marks

Given the visible and invisible marks ovarian cancer and treatments had left on women's lives, women took measures to mask the marks and to protect themselves and those around them. Some of these measures included wearing scarves and wigs, putting on make-ups, or being careful about activities they engaged in. Of significance was how personal characteristics of women including age impacted how they interpreted the marks and thus, their approach to dealing with these.

Being Conscious. For the most part, younger participants were very conscious of the permanent marks treatments could leave not only on their bodies but their lives as well including the inability to have children once the ovaries were removed. Losing the ovaries at an early age meant women would likely not be able to have biogenetically related children, a notion that was hard for many young participants to come to terms with. Grace explained how she reacted when she was mistakenly informed that a hysterectomy had been performed on her. She said:

The nurses were there and I said, "Did they do a hysterectomy?" and both of them looked at me with this terrified look and said "yes, they did." I could not stop crying for over an hour. Even though I had someone come in [later] to tell me that it did not happen, it was still like the end of the world for me because I want to have a lot of kids [Grace, 26 years, stage I].

Additionally, the treatment protocol for many of the women included multiple surgeries which somehow limited them in terms of how much physical activity they could engage in. Women were aware of this limitation and constantly monitored the activities they participated in to protect themselves from further harm. This constant monitoring made women even more

conscious of their post-cancer bodies. For instance, Ellen (42 years, stage I) explained how the scars from her surgeries influenced her self-consciousness:

I had 25 staples on my stomach; I came home with drainage tubes because I was still draining. I have scars from my belly all the way down and scars from drainage; so anytime someone makes a motion around their stomach I feel that it is because my stomach is fat.

Another participant also explained her situation thus: “I have plenty of staples [from surgeries] on my stomach. . . . So now I have to be really careful that my stomach does not split open” (Victoria, 34 years, stage III). Similarly, women stated they were conscious not to present their post-treatment bodies in ways that threatened those around them, including their children.

Andrea [43 years, stage III] noted how she made conscious efforts to present herself in a non-threatening way to her children. Andrea was in treatment and wanted to make life as normal as possible for her children. She said,

It was really important for me to take care of myself because I did not want my children to see me sick. So I never allowed it. I made sure that I got up every day and took a shower and put make-up on. It was hard but I did it.”

Also, Stella (63 years, stage II) stated she covered her head whenever she went into the community so people would not be offended by her post-treatment body:

I would sit on the front porch with my bald head and it did not bother me. But I would wear a hat to the store simply because I did not want to offend anybody that might see me with a bald head and not like it.”

These comments showed the great care women took to adjust their physical appearances to meet societal standards of “normal” and “healthy”. This limited women in how they fully embodied the disease as they attempted to make life normal for those around them, a situation that impacted their sexual self-concept, added a layer of stress to their experiences of the disease, and highlighted the challenges of living with and communicating about the effects of a hard-to-visualize disease (Holmes, 2006).

Caring Less. In other instances, women acknowledged the permanent marks treatments for ovarian cancer could leave on their lives but considered these insignificant. They explained that they did not fixate on the physical changes and limitations brought on their lives by ovarian cancer. Older participants in this category explained, for instance, that they gave less thought to the loss of hair associated with chemotherapy because they knew the hair would eventually grow back. They noted: “I went through a lot of sessions of chemo. I lost all my hair, which was no big deal; it grows back” [Christy, 59 years, stage III]; and “When I lost my hair, I saw it as a minor thing; I knew it would come back. It is not a final thing. My hair did not come back the same color or texture but I am alive so who cares?” [Jenny, 84 years, stage II].

Further, post-menopausal women were bothered less by losing their reproductive organs during hysterectomy. They explained they were past the reproductive years thus losing these organs did not make any difference. In particular, some of the women had had hysterectomies prior to the ovarian cancer diagnosis. Women’s views are illustrated in the following quotes:

I did not mourn my ovaries and I think it is because I was done with what I needed to do with them; I would have felt a lot different if I still needed to have children. If you no longer need something, you are not going to mourn it if they get taken away [Ann, 65 years, stage I].

When the oncologist told me he had to take out the tumor, he also told me he might have to do a complete hysterectomy and asked if I was okay with that. And I said “I am in my 50s, I do not care, do it and make my life easier [Rose, 55 years, stage III].

The doctor suggested I get complete hysterectomy and I said “fine! I am not using that stuff anyway and I do not intend to use it again so take it away [Carrie, 84 years, stage IV].

Implicit in these quotations is how women had internalized dominant views about the female body including which body parts are essential to femininity and which ones are expendable. This understanding and the life conditions of individual women influenced their unique experiences of the disease. Social constructions of femininity suggest the ovaries are of lesser importance when childbearing is completed (Holmes, 2006; Crossen, 1942). Thus, in discussions about the connection between ovarian cancer and treatments and sexual self-concept, it is important that these issues are considered.

Moving Past the Scars

The final theme identified described how women found strength through their support networks to move past the scars and limitations placed on them by the disease. Significant to this transformation was the level of available social support which helped women put the aftereffects of treatments into perspective and thus, redefine their understanding about sexual self-concept. Support was given by women’s spouses, family members, friends, and support group members, and it helped women cope with the aftereffects of treatments and incorporate these into their individual experiences. For instance, one woman explained how being part of a group which

supports cancer patients with work-out trainings helped her regain her self-confidence and to find meaning in her experience. She noted:

[The support group] helped me gain my self-confidence back because with my chemo, no matter what I did I gained 10-15 pounds; and I just did not look like myself. I had no hair, I had no eye-lashes, I had no eyebrows [Mercy, 58 years, stage I].

Another participant, Andrea, talked about how losing her hair had affected her body image but the support she received from family and friends helped her not to feel strongly about the loss and instead take pride in the physical evidence of her disease. Andrea's parents, brother, and best friend all shaved their hair in support of her fight against ovarian cancer. The effect of this support on Andrea's sexual self-concept was profound as noted in the following quote:

For a long time, I did not want to leave the house; I did not want to put this [scarf] on because people are going to stare, they are going to look. Then, it got to a point where I go out with pride; it is like the scars that I have are just part of my journey [Andrea, 43 years, stage III].

When people were less supportive of women's post-cancer bodies, women interpreted that as indicative of the change/difference society needed to see to start rethinking general perceptions of "healthy" and "normal" because these standards lose their meaning when applied to ovarian cancer. One participant explained how having no hair made her cancer experience real to her brother who stared at her for the entire period he was there to visit. She stated:

My brother had a hard time sitting there looking at me with no hair because that made it very real to him. I could see it all over his face; he just kept looking at me and his lips

quivered and he had a very hard time because with the hair gone, it made it real to him [Patricia, 67 years, stage III].

For Patricia, the changes in her physical body was part of her ovarian cancer experience; she did not need to change anything about that. Rather, the onus rested with those who could not accept the ‘difference’ in her body to learn to appreciate it as presented to them; those people needed to acknowledge that following treatment for ovarian cancer, women’s strength is connected with looking different. Thus, it is not about how women affected by ovarian cancer see themselves without hair that impacted their sexual health, but how people around them react when they see women look different. Having no hair automatically communicates to society that there is something wrong with women; that women are different.

Discussion

This study examined the effects of ovarian cancer and its treatments on women’s perceptions of sexual self-concept. It extends understanding on how women manage and negotiate their sexual identities and wellbeing in the face of a life-threatening disease such as ovarian cancer, and highlights the factors that influence the meaning women construct of their sexual self-concept. Additionally, this study sheds light on how women integrate sexual self-concept into the meaning they construct of their experience with ovarian cancer. It fulfills calls for sexual health to be explored in specific gynecologic cancers (Rubin et al., 2014).

Overall, the results showed that ovarian cancer and its treatments challenged women’s sexual self-concept, consistent with previous findings about gynecologic cancer and sexual health (Parton, Ussher & Perz, 2015; Sekse et al., 2013; McCallum et al., 2012; Gilbert, Ussher & Perz, 2011; Wilmoth & Spinelli, 2000; Price, 1998). Women felt “different,” “insecure,” and

“traumatized” by the disease and its treatments. But whether this difference was visible and acknowledged by society or not, women nonetheless found strength in it and used it to shape their unique experiences. The differing perceptions women had about the effects of treatments on their sexual self-concept were impacted by their age, level of available social support, stage of disease, and treatment regimen. These factors work with, through, and against one another to shape women’s experiences of ovarian cancer and sexual self-concept.

The level of available social support significantly ameliorated the effects of treatments on sexual self-concept regardless of women’s age, stage of cancer, or treatment course. Younger and older women diagnosed at different stages of the disease appraised the effects of the disease on their sexual self-concept differently. But the level of support each woman received somehow leveled the playing field in the experience of ovarian cancer and sexual health. In the same vein, stage of cancer and treatment regimen impacted women’s sexual health; however, age of women mitigated how this was expressed as post-menopausal women did not recognize the effects of the disease and treatments on their sexual health whereas the impact was significant for pre-menopausal women.

These findings support previous research that the notion of altered body image is influenced more by patients’ circumstances, personality make-up, and level of available support and less by the presence of disease and its treatment (Schultz & van de Wiel, 2003; Price, 1995). Thus, in the experience of ovarian cancer, the disease and its treatments alone do not affect women’s understanding of sexual self-concept; instead, perceptions of sexual self-concept were influenced by the unique situation of each woman’s life at the time of diagnosis, her treatment regimen, and factors such as her age and level of social support. The damage of ovarian cancer and its treatments on women’s lives could be grounds enough to predict negative impacts on

their sexual self-concept. However, whether these changes concerned for women depended on how each woman interpreted the situation.

Women's concerns about their sexual self-concept had little to do with their physical appearance but with how they could not trust society to interpret the functions of their bodies. Women were conscious to make their post-cancer bodies measure up to societal standards for healthy and beautiful thus, took steps such as wearing scarves or wigs to normalize the appearances of their bodies. But as argued by feminist scholars (e.g., Butler & Rosenblum, 2001; Lorde, 1997), these societal standards and demands further rob women of their agency to embody their experiences. How society reacts to women who have no hair compels affected women to constantly explain their health status; women who want to avoid giving this explanation and to feel normal, choose to cover their scars and hair, as suggested by some of the participants in this study. The desire to feel "normal" post-cancer explains why most women choose to have breast reconstruction after treatments for breast cancer (Rubin & Tanenbaum, 2011). With ovarian cancer, the quest for normalcy causes women to cover their hair and scars.

In the case of ovarian cancer, it is in the image of a sick, worn-out body that women are assured they are well or are getting rid of the disease. This is because the disease may be lurking in women's bodies without them knowing because of the nature of the disease. It is when women look sick with no hair, that they are assured they are actually well and healthy (Gubar, 2012; Holmes, 2009; Stacey, 1997). Thus, to most ovarian cancer survivors, the end of treatment, which would normally be hailed because women's bodies get to rejuvenate, presents uncertainty and anxiety. This needs to be taken into consideration when discussing sexual health in the context of ovarian cancer and its treatments.

Conclusion

The results of this study support previous studies that gynecologic cancers affect women's sexuality and sexual health. The results of this study indicated that societal expectations of the female body including how it should be presented—with hair—and the unique circumstances of ovarian cancer survivors' lives including their age, stage of diagnosis, treatment regimen, and level of social support intersect to influence women's perceptions about sexual self-concept. The intersectional effect of these factors are best understood when the unique situation of each woman's life is taken into consideration.

One noted limitation of this study is that the disease had recurred at least once in one third of the participants; a situation which might influence the decreased concern they had about appearance and sexual health. Surviving ovarian cancer helps women to prioritize what is important in life and what is not (Stewart et al., 2001). This limitation notwithstanding, this study is important as it highlights the connection between ovarian cancer and women's sexual self-concept and the intersecting influence of individual- and societal-level factors on this relationship. I argue that sexual self-concept in the context of ovarian cancer needs to be conceptualized differently because the effects of treatments are mostly not visible compared with, say, mastectomy for breast cancer. Thus, the way the disease presents itself has to be taken into consideration. Western societies are very visual such that something has to be visible for it to gain attention (Holmes, 2006; Stacey, 1997), but because treatments for ovarian cancer do not change the appearance of most women, the impact of the disease and its treatments on women's sexual self-concept is often ignored. This is an issue that health communication and feminist scholars need to address to help gain a better understanding of women's experiences of ovarian cancer.

CHAPTER VI. CONCLUSIONS

In this dissertation, I explored the lived experiences of ovarian cancer through the life-stories of 28 survivors from Northwest Ohio and Southern Michigan. I examined the intersections of factors that influenced women's experiences of the disease and their quality of life post-treatment, including age, religion, and socioeconomic status. I also considered how the level of available social support, stage of disease, and treatment protocol impacted women's meaning making about ovarian cancer. My aims were to 1) enhance understanding about the lived experience of ovarian cancer through the lived realities of survivors; and 2) provide an avenue for survivors to challenge and clarify social constructions of ovarian cancer and educate about the disease. Broadly, I sought to answer the following research questions: 1) what does it mean to be an ovarian cancer survivor, and 2) what are the factors that shape women's lived experiences of the disease?

The results shed some light on significant aspects of the disease beginning from the onset of symptoms through treatment and life post-treatment. I described managing uncertainty as the core variable¹⁷ in the lived experience of the disease. Uncertainty was high at diagnosis, plateaued during treatment as women focused on actively battling the disease, heightened at the end of treatment, and remained in the backgrounds of women's lives as they navigated treatment aftereffects and/or recurrences. Available social support worked to both ameliorate and exacerbate uncertainty, and women used various strategies to manage uncertainty and take ownership of their experiences. Some women felt guilty for having a relatively easy battle with the disease; I argue that these women offer alternative narratives about the disease, which should be supported and encouraged. In this chapter, I provide an overview of the findings and present a

¹⁷ The core variable is the central idea/theme that runs through the data. It explains the majority of the processes taking place and is related to many of the categories.

model that describes the process of the lived experience of ovarian cancer. I also examine the contributions of this study to the communication discipline and discuss the limitations and directions for future studies.

Explaining the Lived Experience of Ovarian Cancer

My grounded theory analysis of the data showed the lived experience of ovarian cancer as a process comprising three phases: (not)making sense, owning the experience, and becoming a survivor. The process began with the non/experience of symptoms by women and continued through months of treatment and living with treatment aftereffects. Each phase in the process presented unique challenges to survivors—challenges that shaped how women came to understand and communicate about their experiences. The phases are not distinct or linear; they are part of a complex, not-by-choice journey. The journey meant different things to women and was experienced and communicated differently by each survivor depending on her life conditions at the time of diagnosis, treatment protocol, age, socioeconomic status, recurrence status, and level of available social support. These factors worked through, against, and with each other to shape the meaning women constructed of their experiences, helping provide a nuanced understanding of the disease.

The core variable of managing uncertainty permeated all phases of the illness trajectory and was significant to how women negotiated life roles, relationships, and challenges at each phase and their gradual progression toward survivorship. The nature of the disease including vague symptoms and high recurrence rates (American Cancer Society, 2014; Brain et al., 2014) caused uncertainty in women, and from the time of diagnosis and for the rest of their lives, women actively managed these uncertainties to coordinate their inner balance and voice to fight the disease. Uncertainty began with the onset of symptoms, heightened at diagnosis, plateaued

during treatment, heightened at the end of treatment, and persisted for the remainder of women's lives. Uncertainty pertained to concerns about outcomes of treatment, short- and long-term effects of treatments on women's identities, sexual self-concept, finances, social roles, and relationships. Below, I present the model of the lived experience of ovarian cancer and walk the reader through each phase and the implications for research and practice.

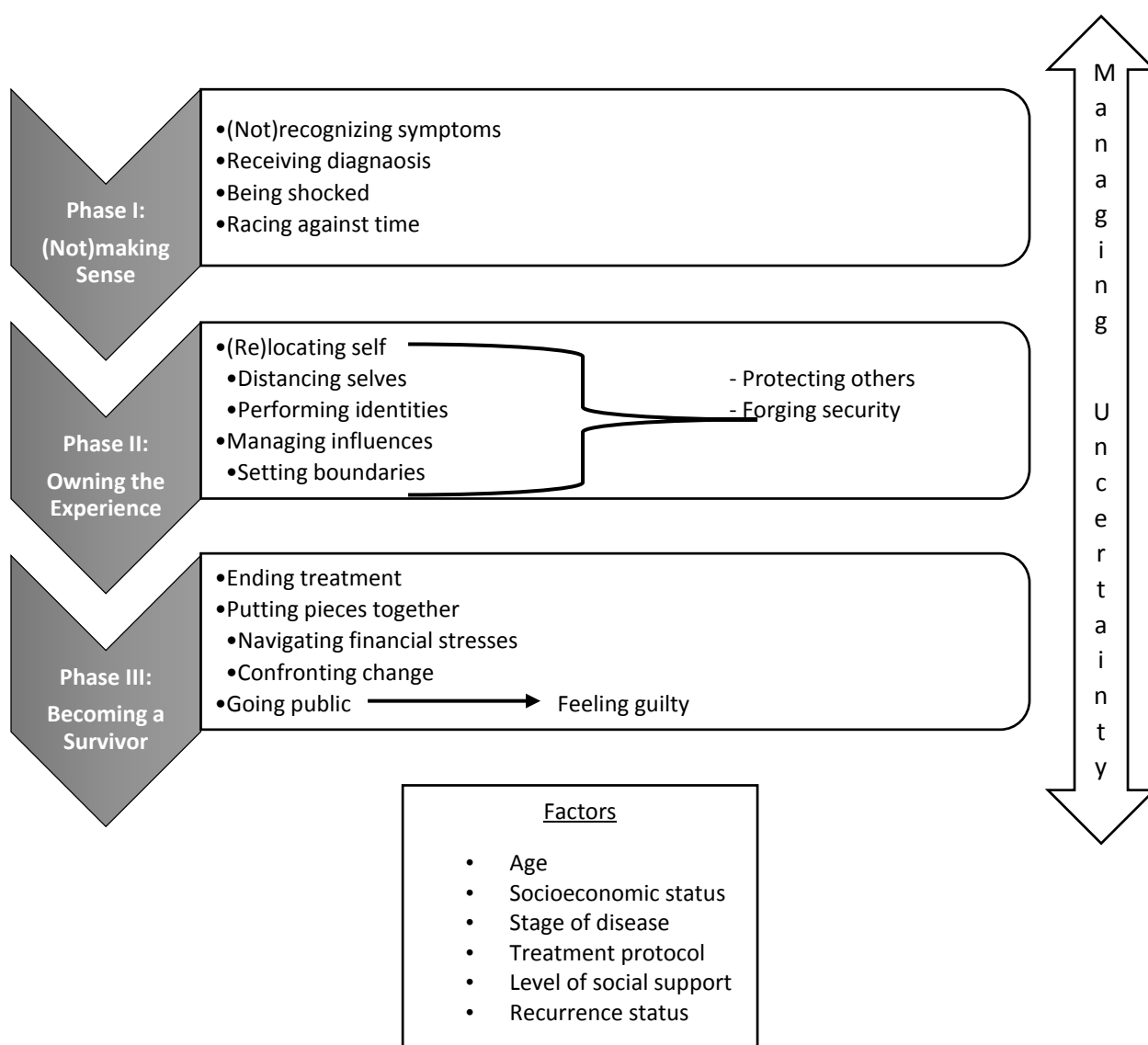


Figure 4: Model of the Lived Experience of Ovarian Cancer

Phase I: (Not)making Sense

I named this phase in the ovarian cancer trajectory “(not)making sense” because a cancer diagnosis never makes sense to anyone (see Faulkner, 2016). Women in this study reflected on their family histories and lives at the time of diagnosis to piece together how their diagnoses came about. When trying to make meaning of the diagnosis, it still did not make sense to women. Whether diagnosis was expected or it was by accident, it still came as a surprise to most women. Women who had symptoms could not connect them to ovarian cancer because they lacked knowledge about the disease; some doctors also could not interpret symptoms of the disease. This led to misdiagnoses and/or late diagnoses and consequently, recurrences.

Women were frustrated and angry that their complaints of symptoms went unheeded by healthcare practitioners. While this could be blamed on the nature of the disease as it presents less obvious symptoms (Gubar, 2012; Holmes, 2006), it also pointed to a disregard for women’s subjective knowledge of their health. For instance, Mercy (58 years, stage I), narrated how she noticed signs of disease recurrence and complained to her doctor who told her it could not be cancer because he was “usually right about these things.” True to her observations, Mercy’s cancer had recurred; she eventually broke ties with her doctor, and he never offered an apology to her. This, among other instances referenced in this study, indicated that issues concerning late/misdiagnosis and lack of knowledge and awareness about ovarian cancer still persist at the expense of women’s lives. Thus, there is a need for communication, health, and women’s studies scholars and practitioners to continue research into this topic to hammer home the realities of the disease and educate about how women’s voices are essential to the broad aim of finding reprieve from ovarian cancer. Scientific knowledge about ovarian cancer and knowledge generated

through women's lived experiences need not be considered as opposites but as complementary ways of learning about the disease and fighting to find a cure.

Further, the period between receiving diagnosis and starting treatment was a crunch time for several women. Women had little time to put themselves together before beginning treatment; women literally were in a race to save their lives as they began treatment. During this period, women carved strategies and time out of no time to communicate their diagnoses to those in their inner circles including parents, partners, and children. They disclosed out of relational obligation, to obtain support, and to manage their uncertainties and those of their loved ones. Factors that influenced how women reacted to diagnosis included family history of cancer, age, general health status, and level of available social support. This finding points to how diagnosis with a serious illness such as ovarian cancer changes people's orientation to time (Charmaz, 1991).

Findings from this study also suggest that ovarian cancer is increasingly being diagnosed in younger women who are otherwise healthy, and calls for a reconsideration of how we educate about the disease. These women had no family history of cancer and would not have considered themselves at risk of the disease. This trend where younger women are diagnosed needs to be highlighted more in education campaigns to sensitize the public about the risk each woman faces—this is a task for health communication scholars. Similarly, some of the women in this study had had complete hysterectomies years earlier before they were diagnosed of ovarian cancer. Thus, health communication and education campaigns need to emphasize that having a hysterectomy and/or oophorectomy¹⁸ does not preclude women from having ovarian cancer; it

¹⁸The surgical removal of ovaries.

reduces one's risks but does not take away the possibility of having the disease (Kauff et al., 2002).

Another issue worthy of consideration is the anxiety, fear, and uncertainty women experienced at diagnosis. Women were unsure what the outcomes of the diagnosis and treatment would mean for themselves and their loved ones. This caused distress in women. Many of them, however, did not openly express this fear and uncertainty. Women mentioned not crying when diagnoses were given. Continued research is warranted to fully understand how women expressed these suppressed emotions at other stages in the illness trajectory so as to design appropriate intervention.

Phase II: Owning the Experience

The second phase in the ovarian cancer experience constituted the period when women were in active treatment. Treatment included surgery, chemotherapy and/or radiation. Women who were diagnosed at early stages and the cancer was encapsulated did not go through chemotherapy or radiation treatment. For these women, treatment was relatively short, making some of them to question if they had cancer at all. This was because they associated cancer with chemotherapy, hair loss, and long hospital stays; many of the women in this category felt guilty identifying as cancer survivors—a situation that impacted their constructions of the ovarian cancer lived experience and how they used their experiences to benefit others. However, the treatment phase was long and grueling for women who had chemotherapy and/or radiation.

Women processed their diagnoses and at the same time managed treatment side-effects such as fatigue, pain, nausea, and other changes in their physical and social selves. They focused on basic issues at hand including what to eat and how to make it through treatment; bigger

concerns about insurance and the future were dealt with after treatment. This explained why uncertainty plateaued at this stage because women knew not to worry too much as that could interfere with the effectiveness of treatment; they were certain that treatment would get rid of the cancer cells. For example, women explained how they lived through treatment in the following quotes: “all you have to do is worry about how you feel that minute, and do you have enough food in the house, and what is your next appointment” (Mercy, 58 years, stage I); and “when I was dealing with my chemo, I was trying to deal with how to live today” (Kylie, 65 years). Support from loved ones and team of healthcare workers was also important in keeping women afloat. Cards, prayers, calls, meals, and visits were consistent for the majority of women during treatment.

Another significant finding was how social support during treatment served two ends for women: it provided women a reason to keep living and fighting; but it also burdened some women as they felt obliged to stay and look positive for their loved ones. Women with partners and children performed “strong” and “healthy” for the benefit of coordinating their inner voices and stability and also to give hope to those they love. However, women who had no partners or children remained “strong” and “healthy” as a direct survival mechanism. For instance, Mercy (58 years, stage I) explained the freedom she felt going through treatment alone. She said, “I went by myself [to treatments]. I wanted it that way. I wanted to go in, have chemo and come home and rest; I did not want to feel like I have to entertain anybody or worry about them.” This highlights the subtle emotional labor women felt obliged to provide when ill: to be responsible for the psychological and emotional wellbeing of their loved ones. This finding suggests that it is not always unhealthy when people choose to go through illness experiences alone or to receive support at a distance (i.e., through calls, emails, and cards); it relieves them of the burden of

having to perform immaterial labor. The finding also supports past research that relationships provide support as well as stress in times of illness (Goldsmith, 2009).

Equally significant were practical steps women took to make their experiences their own including claiming space from people around them and setting boundaries regarding how much information they took in and gave to the public. Women used these strategies to manage uncertainties associated with the disease. Factors that impacted how women experienced treatment and measures they took to make the experience their own included stage of disease and treatment protocol, age, level of available social support, and recurrence status. The process of owning the ovarian cancer lived experience was distinct for each woman and definitive of women's quality of life post-treatment.

I found that going through treatment was a way for women to be in control of their health and be actively involved in fighting the disease. They felt sick, weak, and tired yet this was evidence to them that the disease was being fought off. This helped lessen the uncertainty women felt. Treatments provided a safety net for women, explaining why uncertainty heightened at the end of active treatment when that safety net is taken away. Thus, with the lived experience of ovarian cancer, it is in the image a sick worn-out body that women are assured that they are well. It is therefore important that these issues are discussed with women toward the end of active treatment to foster security in women and lessen uncertainty. Here is where health communication can prove useful in helping reconstruct understanding of healthy and ill bodies as they pertain to ovarian cancer.

Phase III: Becoming a Survivor

Finishing active treatment marked another phase in the ovarian cancer experience. Many of the women felt ill-prepared to deal with the aftereffects of the disease on their own. Women had time to recuperate and sort through their lives before beginning regular check-ups with their doctors. This was the stage where women became intentional about survivorship as they managed treatment aftereffects including disability, job loss, neuropathy, sexual health concerns, and weight loss/gain. Uncertainty increased at this stage as women embarked on a journey to put the pieces of their lives back together. Women navigated financial stresses resulting from costs of treatment and being out of work, and negotiated changes to their bodies and sexual self-concept. They actively processed what it meant to be ovarian cancer survivors by connecting with other survivors through support groups, fundraisers, and other education events.

One significant treatment aftereffect women contended with was in the area of sexual health¹⁹. Visible and invisible effects of treatments on their lives challenged women's understandings of sexual self-concept. Some women struggled to reconcile the conditions of their post-treatment bodies, including scars from surgeries, to their understanding of sexual self-concept. They stated feeling "different," "insecure," and "traumatized" by the disease and its treatments. The differing perceptions women had about the effects of treatments on their sexual self-concept were impacted by their age, level of available social support, stage of disease, and treatment regimen. Women showed less concern about appearances of their post-treatment bodies—most of the scars from surgeries were not visible to the public; but they were worried more about how they could not trust society to interpret the functions of their bodies.

¹⁹ Sexual health comprises sexual function (including desire, arousal/excitement, and orgasm), sexual self-concept (including body image, sexual esteem, and sexual self-schema), and sexual roles and relationships (including communication and intimacy) (Cleary & Hegarty, 2011; Woods, 1987).

Many of the women had strong support systems in family and friends but joined support groups to talk through their experiences with others who would understand or to be an encouragement to those who recently finished treatment. Others also did not join support groups due to logistical and time constraints or because they felt guilty for having a relatively “easy” experience. Women in the latter category felt they did not have much to contribute to the lives of other survivors. I argue that these women have alternative narratives about the ovarian cancer experience to offer but feel their narratives do not fit into current understanding about the disease. Women in this category should be encouraged to embrace and voice these much-needed alternative narratives. These results point to survivor’s guilt as a complex aspect of the ovarian cancer experience needing further research. With improvements in research and increasing rates of survival (Markman & Malviya, 2008), survivor’s guilt is a reality many women would continue to grapple with. It is, therefore, important to recognize this issue as a problem in order to design intervention and support for affected women. Education about survivor’s guilt could be incorporated into public education materials about the disease; this will help raise awareness and provide caregivers with tools to assist survivors. Further, survivor’s guilt could be addressed in conjunction with support groups and other public education and awareness events. Strategies to help survivors better communicate this feeling of guilt with other women would be beneficial to ease discomfort in talking about the issue and open avenues for support provision. Creating spaces for women to embrace and voice alternative experiences and narratives about the disease would help address the notion of survivor’s guilt.

Joining support groups was a way for women to manage uncertainties about their health and future. Long-term survivors provided hope and comfort to others that the disease could be survived. Support groups provided a safe space for communication, healing, advocacy, and

community building; they were “like a safe harbor” as observed by Carrie (84 years, stage IV). Kara (70 years, stage II) also explained the value of support groups as follows: “when you have cancer and you get through it, nobody wants to hear it again; but these people [support group members] understand.” Support group members also advocated for one another and other women affected by the disease. For instance, women explained that they had rallied to the president of the Toledo Hospital when two of the three gynecologic-oncologists treating survivors had left the area under circumstances women believed were politically motivated. Also, women in the support group made quilts, which they placed at hospitals in the local area to encourage newly diagnosed survivors.

Conversely, women also experienced some downsides of support groups including coming face-to-face with others living with recurrent ovarian cancer. This was disturbing to many women as it contradicted their mental constructions of survivorship. They hoped to deal with the disease once and never had to face it again; thus, seeing recurrences was too real for some women to take. Women also witnessed the deaths of group members, and that made their own mortality very real. This situation aggravated the level of uncertainty women experienced. Women managed this uncertainty by regulating how often they connected with support group members. For example, Nora (59 years, stage II) stated, “I like [the support group] a lot but not enough to go too often”. These findings are consistent with previous research on the topic (Ussher et al., 2008).

Similar to research about the role of communication in managing uncertainty (Babrow, Kasch & Ford, 1998; Babrow, Hines & Kasch 2000; Brashers et al., 2000), results of this study suggest that communication, including managing how much information about the disease women received and shared, was significant to managing uncertainty about ovarian cancer.

Every woman who had ovarian cancer has some fear about the disease returning, and women chose different strategies and routes to manage this uncertainty.

Further, women also participated in programs where they used their experiences to educate medical students about ovarian cancer from the perspectives of survivors. Women found it worthwhile to use their lived experiences as a teaching tool. Some also participated in annual walks to commemorate the ovarian cancer month of September. These public events created an avenue for women, particularly those who recently finished treatment, to identify with the disease and connect with other survivors. For instance, Patricia (67 years, stage III) explained, “I went for the survivors walk because I needed to identify myself with [the disease]”. On display at the 2015 Ellen Jackson Ovarian Cancer Walk in Toledo were pictures of women who had survived the disease a couple of months, those who had survived for years (e.g., 19 years), and those who had died. This, women explained, helped put a human face on ovarian cancer. Because public discourse around the disease often takes place following the death of a public personality or someone close to them (e.g., Angelina Jolie), women noted that the walk and other public events were significant in helping the public to connect with survivors and to be reminded that ovarian cancer could be survived.

Limitations and Future Directions

It is important for me to acknowledge some of the limitations of this study in order to highlight the parameters of what can be known about ovarian cancer through this research. First, the study population is homogeneous, comprising mainly of married, Caucasian, Christian, and heterosexual survivors. Thus, women’s views might not be representative of all ovarian cancer survivors. Future research should seek to get participants of diverse backgrounds to help understand how they construct their lived experiences of the disease. Further, the wide gap in

years of survivorship provided variations in women's views. However, this was necessary in providing different perspectives about the disease. Additionally, low interest in focus groups made it difficult to pair survivors based on specific criteria such as age and recurrence status; women's availability was the criterion for group formations. Future research could be more deliberate about including women in focus groups where, for instance, long-term survivors would be grouped together for a discussion to better understand how long-term survivorship impacts women's lived experiences. Or, women living with recurrent disease could be joined together to understand the nuances of the disease following a recurrence; this is because meanings people construct of illnesses and how they communicate about their experiences change with time (Charmaz, 1991). Moreover, this research constituted the experiences of survivors only. It would be helpful to understand the disease from the perspectives of caregivers, loved ones, and support providers because the cancer experience is a shared one (Faulkner, 2016; Goldsmith, 2009). Future research could also explore how healthcare workers construct, communicate about/with, and act on women's complaints about disease symptoms and how this can be brought in sync with women's own constructions of the disease to enhance early diagnosis and consequently, chances of survival. Lastly, it would be crucial to understand how the health system in the United States, including what medical tests physicians can order on women and who determines when these tests can be ordered, may be contributing to the persistent late diagnosis of ovarian cancer. Future research could explore this issue further.

These limitations notwithstanding, this dissertation is significant in bringing a communication and feminist perspectives to the lived experience of ovarian cancer. It also helped add survivors' voices to the constructions of the disease, helping demystify "what it means to have ovarian cancer" (Holmes, 2006). The findings are useful for practitioners,

researchers, and loved ones; understanding women's experiences makes it easier to provide medical and social support. For practitioners, the findings highlight that social support and other initiatives directed at survivors should be individualized and congruent to the specific stage of the disease survivors are at. Further, findings of this research suggest areas for further research including the notion of survivor's guilt and how survivors manage their uncertainties. For loved ones, the findings indicate that survivors' lives are permanently changed by ovarian cancer and they will need to be supported, as deemed appropriate by survivors, to transition to becoming survivors. This project was an attempt to bring ovarian cancer to the public radar and increase awareness about the disease.

REFERENCES

- Abbott-Anderson, K. & Kwekkeboom, K. L. (2012). A systematic review of sexual concerns reported by gynecological cancer survivors. *Gynecologic Oncology*, 124, 477–489.
- Alvarez, R. D., Karlan, B. Y., & Strauss, J. F. (2016). Ovarian cancers: Evolving paradigms in research and care: Report from the Institute of Medicine. *Gynecologic oncology*.
- American Cancer Society (2014). *Cancer facts and figures 2014*. Retrieved from <http://www.cancer.org/acs/groups/content/@research/documents/webcontent/acspc-042151.pdf>
- Anderson, M. S. & Johnson, J. (1994). Restoration of body image and self-esteem for women after cancer treatment: A rehabilitation strategy. *Cancer Practice*, 2(5). 345-349.
- Andersen, B. L. (2009). In sickness and in health: Maintaining intimacy after breast cancer recurrence. *The Cancer Journal*, 15(1), 70–73.
- Anzaldúa, G. (1992). The new mestiza nation: A multicultural movement. In C. R. McCann & S. Kim (Eds.), *Feminist Theory Reader: Local and Global Perspectives* (277-284). New York, NY: Routledge.
- Arden-Close, E., Gidron, Y. & Moss-Morris, R. (2008). Psychological distress and its correlates in ovarian cancer: A systematic review. *Psycho-Oncology*, 17, 1061-1072.
- Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., Palmer, N., Ream,

- E., Young, A., Richardson, A. (2009). Patients' supportive care needs beyond the end of cancer treatment: A prospective, longitudinal survey. *Journal of Clinical Oncology*, 27(36), 6172-6179. doi: 10.1200/JCO.2009.22.5151
- Arnold, E. M. (1999). The cessation of cancer treatment as a crisis. *Social Work in Health Care*, 29, 21–38.
- Arriba, L. N., Fader, A. N., Frasure, H. E., von Gruenigen, V. E. (2010). A review of issues surrounding quality of life among women with ovarian cancer. *Gynecologic Oncology*, 119, 390–396.
- Atkins, L. (2016). Half the battle: Social support among women with cancer. *Qualitative Inquiry*, 22(4) 253–262. doi: 10.1177/1077800415574911.
- Avis, N. E., Crawford, S. & Manuel, J. (2004). Psychosocial problems among younger women with breast cancer. *Psycho-Oncology*, 13, 295–308.
- Babrow, A. S., Hines, S. C. & Kasch, C. R. (2000). Managing uncertainty in illness explanation: An application of problematic integration theory. In B. B. Whaley (Ed.) *Explaining illness: Research, theory, and strategies* (41-67). Wahwah, NJ: Lawrence Erlbaum Associates.
- Babrow, A. S., Kasch, C. R. & Ford, L. A. (1998). The many meaning of uncertainty in illness: Toward a systematic accounting. *Health Communication* 10(1),1-23.
- Badr, H., & Taylor, C. L. C. (2006). Social constraints and spousal communication in lung

cancer. *Psycho-Oncology*, 15, 673-683.

Bankhead, C. R., Collins, C., Stokes-Lampard, H., Rose, P., Wilson, S., Clements, A., Mant, D.,

Kehoe, S. T. & Austoker, J. (2008). Identifying symptoms of ovarian cancer: a qualitative and quantitative study. *British Journal of Obstetrics Gynecology*, 115, 1008–1014. doi: 10.1111/j.1471-0528.2008.01772.x

Blythe, S., Wükes, L., Jackson, D., & Halcomb, E. (2013). The challenges of being an insider in storytelling research. *Nurse Researcher* 21(1), 8-13.

Bodurka, D. C. & Sun, C. C. (2006). Sexual function after gynecologic cancer. *Obstetrics and Gynecology Clinics of North America*, 33, 621-630.

Bowes, D. E., Tamlyn, D. & Butler, L. J. (2002). Women living with ovarian cancer: Dealing with early death. *Health Care for Women International*, 23, 135–148.

Bradway, K. E. & Beard, R. L. (2015). “Don’t be trying to box folks in”: Older women’s sexuality. *Affilia: Journal of Women and Social Work*, 30(4) 504-518. doi: 10.1177/0886109914560741.

Brain, K. E., Smits, S., Simon, A. E., Forbes, L. J., Roberts, C., Robbé, I. J., Steward, J., White, C., Neal, R. D. & Hanson, J. (2014). Ovarian cancer symptom awareness and anticipated delayed presentation in a population sample. *BioMed Central Cancer*, 14(171), 1-10.

- Brashers, D. E. (2001). Communication and uncertainty management. *Journal of Communication, 51*(3), 477-497.
- Brashers, D. E., Neidig, J. L., Haas, S. M., Dobbs, L. K., Cardillo, L. W. & Russell, J. A. (2000). Communication in the management of uncertainty: The case of persons living with HIV or AIDS. *Communication Monographs, 67*(1), 63-84.
- Brashers, D. E., Goldsmith, D. J., & Hsieh, E. (2002). Information seeking and avoiding in health contexts. *Human Communication Research, 28*, 258–271.
- Brashers, D. E., Neidig, J. L. & Goldsmith, D. J. (2003). Social support and the management of uncertainty for people living with HIV or AIDS. *Health Communication, 16*(3), 305-331.
- Brashers, D. E. (2000). A theory of communication and uncertainty management. In B. B. Whaley & W. Samter (Eds.) *Explaining communication: Contemporary theories and exemplars* (201-218). Wahwah, NJ: Lawrence Erlbaum Associates.
- Burleson, B. R. (2010). Explaining Recipient Responses to Supportive Messages: Development and Tests of a Dual-Process Theory. In S. W. Smith & S. R. Wilson (Eds.), *New directions in interpersonal communication*, (179-199). Thousand Oaks, CA: Sage.
- Butler, L., Banfield, V., Sveinson, T. & Allen, K. (1998). Conceptualizing sexual health in cancer care. *Western Journal of Nursing Research, 20*(6), 683-705.
- Butler, S., & Rosenblum, B. (2001). *Cancer in two voices*. Duluth, MN: Spinsters Ink.
- Callaghan, P. & Morrissey, J. (1993). Social support and health: A review. *Journal of*

- Advanced Nursing* 18, 203-210.
- Carey, M. A. & Smith, M. W. (1994). Capturing the Group Effect in Focus Groups: A Special Concern in Analysis. *Qualitative Health Research*, 4(1), 123-127. DOI: 10.1177/104973239400400108.
- Carlson, J. A. (2010). Avoiding traps in member checking. *The Qualitative Report*, 15(5), 1102-1113.
- Charmaz, K. (1990). Discovering chronic illness: Using grounded theory. *Social Science Medicine*, 30(11), 1161-1172.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (2014). *Constructing grounded theory* (2nd Ed.). Thousand Oaks, CA: Sage.
- Chiseri-Strater, E. (1996). Turning in upon ourselves: Positionality, subjectivity, and reflexivity in case study and ethnographic research. In P. Mortensen & G. E. Kirsch (Eds.), *Ethics and representation in qualitative studies of literacy* (pp. 115-133), Urbana, IL: National Council of Teachers of English (NCTE).
- Cho, S., Crenshaw, K. W. & McCall, L. (2013). Toward a field of intersectionality studies: Theory, applications, and praxis. *Signs: Journal of Women in Culture and Society*, 38(4), 785-810.
- Centers for Disease Control and Prevention (2010). Top 10 cancer sites: 2010, female, United States—All races. Retrieved from <http://apps.nccd.cdc.gov/uscs/toptencancers.aspx#All>

- Cesario, S. K., Nelson, L. S., Broxson, A. & Cesario, A. L. (2010). Sword of Damocles cutting through the life stages of women with ovarian cancer. *Oncology Nursing Forum*, 37(5), 609-617.
- Cleary, V. & Hegarty, J. (2011). Understanding sexuality in women with gynecological cancer. *European Journal of Oncology Nursing*, 15, 38-45.
- Cohen, S. & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98(2), 310-357.
- Collins, P. H. (1990). Defining Black Feminist thought. In C. R. McCann & S. Kim (Eds.), *Feminist Theory Reader: Local and Global Perspectives* (379-394). New York: Routledge.
- Collins, P. H. (1986). Learning from the outsider within: The sociological significance of Black feminist thought. In A. M. Jaggar (2014, Ed.), *Just Methods: An interdisciplinary feminist reader* (pp. 308-320). Boulder, CO: Paradigm Publishers.
- Costa-Requena, G., Rodríguez, A., Fernández, R., Palomera, E. & Gil, F. L. (2011). Cognitive processing variables in breast cancer: Worry and distress at the end of treatment. *Journal of Cancer Education*, 26(2), 375-379
- Coward, D. D. & Kahn, D. L. (2005). Transcending breast cancer: Making meaning from diagnosis and treatment. *Journal of Holistic Nursing*, 23(3), 264-283. doi: 10.1177/0898010105277649

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, 43(6), 1241-1299.

Crossen, H. S. (1942). The menace of “silent” ovarian carcinoma. *Journal of American Medical Association*, 119(18), 1485-1489.

DeShazer, M. K. (2003). Fractured borders: Women's cancer and feminist theatre.

NWSA Journal, 15(2), 1-26.

Donovan-Kicken, E., Tollison, A. C. & Goins, E. S. (2011). Grounded theory of control over communication among individuals with cancer. *Journal of Applied Communication Research*, 39(3), 310-330. doi: 10.1080/00909882.2011.585398

Donovan-Kicken, E., Tollison, A. C. & Goins, E. S. (2012). The nature of communication work during cancer: Advancing the theory of illness trajectories. *Health Communication*, 27, 641–652. doi: 10.1080/10410236.2011.629405

Dubois, S. & Loisell, C. G. (2009). Cancer informational support and health care service use among individuals newly diagnosed : A mixed method approach. *Journal of Evaluation in Clinical Practice*, 15, 346-359.

Duffey-Lind E. C., O'Holleran, E., Healey, M., Vettese, M., Diller, L. & Park, E. R. (2006). Transitioning to survivorship: A pilot study. *Journal of Pediatric Oncology Nursing*, 23(6), 335-343.

Edwards, W. M. & Coleman, E. (2004). Defining sexual health: A descriptive overview.

Archives of Sexual Behavior, 33(3), 189–195.

Ekman, I., Bergbom, I., Ekman, T., Berthold, H. & Mahsneh, S. M. (2004). Maintaining normality and support are central issues when receiving chemotherapy for ovarian cancer. *Cancer Nursing*, 27(3), 177-183.

Ellingson, L. L. (2004). Women cancer survivors: Making meaning of chronic illness, disability, and complementary medicine. In P. M. Buzzanell, H. Sterk & L. H. Turner (Eds), *Gender in applied communication contexts* (pp. 79-98). Thousand Oaks, CA: Sage.

Faulkner, S. L. (2016). Cancer triptych. *Health Communication*, 1-4. doi: 10.1080/10410236.2015.1020262

Ferrell, B., Smith, S. L., Cullinane, C. A. & Melancon, C. (2003). Psychological well-being and quality of life in ovarian cancer survivors. *Cancer*, 98(5), 1061-1071. doi:10.1002/cncr.11291

Fife, B. L. (1994). The conceptualization of meaning. *Social Science Medicine*, 38(2), 309-316.

Fitch, D., Deane, K., Howell, D. & Gray, R. E. (2002). Women's experiences with ovarian cancer: Reflections on being diagnosed. *Canadian Oncology Nursing Journal* 12(3), 152-168.

Fitch, M. I., Gray, R. E. & Franssen, E. (2001). Perspectives on living with ovarian cancer: Older women's views. *Oncology nursing forum*, 28(9), 1433-1442.

Fleming, Jean S., Beaugié, Clare R., Haviv, I., Chenevix-Trench, G., and Tan, O. L. (2006).

Incessant ovulation, inflammation and epithelial ovarian carcinogenesis: Revisiting old hypotheses.” *Molecular and Cellular Endocrinology*, 247.

Gallelli, A. (2014). *Ovarian cancer: My walk with it*. Author.

Garofalo, J. P., Choppala, S., Hamann, H. A. & Gjerde, J. (2009). Uncertainty during the transition from cancer patient to survivor. *Cancer Nursing*, 32(4): E8–E14.
doi:10.1097/NCC.0b013e31819f1aab.

Gilbert, E., Ussher, J. M. & Perz, J. (2010a). Sexuality after breast cancer: A review. *Maturitas*, 66, 397-407.

Gilbert, E., Ussher, J. M., & Perz, J. (2010b). Renegotiating sexuality and intimacy in the context of cancer: The experiences of carers. *Archives of Sexual Behavior*, 39, 998–1009. doi: 10.1007/s10508-008-9416-z

Gilbert, E., Ussher, J. M., & Perz, J. (2011). Sexuality after gynecological cancer: A review of the material, intrapsychic, and discursive aspects of treatment on women’s sexual wellbeing. *Maturitas*, 70 42– 57

Glaser, B. G. (2004). Remodeling grounded theory. Forum: *Qualitative Social Research*, 5(2), Art 4.

Glaser, B. G. & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York, NY: Aldine.

Goldsmith, D. J. (2009). Uncertainty and communication in couple coping with serious illness.

- In T. Afifi & W. Afifi (Eds.), *Uncertainty, information management, and disclosure decisions: Theories and application* (203-225). New York, NY: Routledge.
- Gorelick, S. (1991). Contradictions of feminist methodology. *Gender and Society*, 5, 459-477.
- Greenberg, M. & Smith, R. A. (2016). Support seeking or familial obligation: An investigation of motives for disclosing genetic test results. *Health Communication*, 31(6), 668-678. doi: 10.1080/10410236.2014.989384
- Gubar, S. (2012). *Memoir of a debulked woman*. New York, NY: W.W. Norton & Company.
- Hamilton, A. B. (1999). Psychological aspects of ovarian cancer. *Cancer Investigation*, 17(5), 335-341.
- Hankivsky, O., & Cormier, R. (2009). *Intersectionality: Moving Women's Health Research and Policy Forward*. Vancouver: Women's Health Research Network.
- Hawkins, Y., Ussher, J., Gilbert, E., Perz, J., Sandoval, M. & Sundquist, K. (2009). Changes in sexuality and intimacy after the diagnosis and treatment of cancer: The experience of partners in a sexual relationship with a person with cancer. *Cancer Nursing*, 32(4), 271-280.
- Hensley, M. L., Robson, M. E., Kauff, N. D., Korytowsky, B., Castiel, M., Ostroff, J., Hurley,

- K., Hann, L. E., Colon, J. & Spriggs, D. (2003). Pre- and postmenopausal high-risk women undergoing screening for ovarian cancer: anxiety, risk perceptions, and quality of life. *Gynecologic Oncology*, *89*, 440–446.
- Hesse-Biber, S. (2014). A re-invitation to feminist research. In S. N. Hesse-Biber (Ed.) *Feminist Research Practice* (pp. 1-13). Thousand Oaks, CA: Sage.
- Hipkins, J., Whitworth, M., Tarrier, N. & Jayson, G. (2004). Social support, anxiety and depression after chemotherapy for ovarian cancer: A prospective study. *British Journal of Health Psychology*, *9*, 569–581
- Hewitt, M., Greenfield, S. & Stovall, E. (2006). *From cancer patient to cancer survivor: Lost in transition*. Washington, D.C: The National Academies Press.
- Holmes, M. S. (2006). Pink ribbons and public private parts: On not imagining ovarian cancer. *Literature and Medicine*, *25*(2), 475-501. doi: 10.1353/lm.2007.0005
- Hoskins, C. N. & Haber, J. (2000). Adjusting to breast cancer. *The American Journal of Nursing*, *100*(4), 26-33.
- Howell, D., Fitch, M. I. & Deane, K. A. (2003). Impact of ovarian cancer perceived by women. *Cancer Nursing*, *26*(1), 1- 9.
- Jaggar, A. M. (2013). Introduction: The project of feminist methodology. In A. M. Jaggar (2014, Ed.), *Just Methods: An interdisciplinary feminist reader* (pp. vii-xiii). Boulder, CO: Paradigm Publishers.

Jasen, P. (2009). From the “silent killer” to the “whispering disease”: Ovarian cancer and the uses of metaphor. *Medical History*, 53, 489-512.

Juraskova, I., Butow, P., Robertson, R., Sharpe, L., McLeod, C. & Hacker, N. (2003). Post-treatment sexual adjustment following cervical and endometrial cancer: A qualitative insight. *Psychooncology*, 12, 267-279.

Kauff, N. D., Satagopan, J. M., Robson, M. E., Scheuer, L., Hensley, M., Hudis, C. A., Ellis, N. A., Boyd, J., Borgen, P. I., Barakat, R. R., Norton, L., & Offit, K. (2002). Risk-reducing salpingo-oophorectomy in women with a BRCA1 or BRCA2 mutation. *The New England Journal of Medicine*, 21(346), 1609-1615.

Kernan, W. D. & Lepore, S. J. (2009). Searching for and making meaning after breast cancer: Prevalence, patterns, and negative affect. *Social Science Medicine* 68, 1176–1182.

Kitzinger, J. (1995). Introducing focus groups. *British Medical Journal*, 311, 299-302.

Knobf, M. T. (2007). Psychosocial responses in breast cancer survivors. *Seminars in Oncology Nursing*, 23(1), 71–83.

Kreps, G. L. (2003). The impact of communication on cancer risk, incidence, morbidity, mortality, and quality of life. *Health Communication*, 15(2), 161-169.

Krychman, M. & Millheiser, L. S. (2013). Sexual Health Issues in Women with Cancer. *The Journal of Sexual Medicine*, 10(S1), 5-15.

Lalwani, N., Shanbhogue, A. K. P., Vikram, R., Nagar, A., Jagirdar, J. & Prasad, S. R. (2010).

Current update on borderline ovarian neoplasms. *American Journal of Roentgenology*,
194

Lancastle, D., Brain, K. & Phelps, C. (2011). Illness representations and distress in women

undergoing screening for familial ovarian cancer. *Psychology and Health*, 26(12), 659–
1677.

Lee, V., Cohen, S. R., Edgar, L., Laizner, A. M. & Gagnon, A. J. (2006). Meaning-making and

psychological adjustment to cancer: Development of an intervention and pilot results.
Oncology Nursing Forum, 33(2), 291-302.

Lee, V., Cohen, S. R., Edgar, L., Laizner, A. M. & Gagnon, A. J. (2004). Clarifying “meaning”

in the context of cancer research: A systematic literature review. *Palliative and
Supportive Care*, 2, 291–303.

Lethborg, C. E., Kissane, D., Burns, W. I. & Snyder, R. (2000). “Cast adrift”: The experience of

completing treatment among women with early stage breast cancer. *Journal of
Psychosocial Oncology*, 18(4), 73-90.

Linden, W., Vodermaier, A., MacKenzie, R. & Greig, D. (2009). Anxiety and depression after

cancer diagnosis: Prevalence rates by cancer type, gender, and age. *Journal of Affective Disorders*, 141, 343–351

Lockwood-Rayermann, S. (2006). Survivorship issues in ovarian cancer: A review. *Oncology Nursing Forum*, 33(3), 553-562.

Lorde, A. (1997). *The cancer journals (Special Edition)*. San Francisco, CA: Aunt Lute Books.

Matei, D., Brown, J. & Frazier, L. (2013). Updates in the Management of Ovarian Germ Cell Tumors. *American Society of Clinical Oncology Educational Book*.

Markman, M. & Malviya, V. (2008). An example of ovarian cancer as a ‘chronic disease process’ –11-year survival with multiple treatments for recurrent and progressive disease. *Case reports in oncology*, 1(1), 1-4.

Martin, E. (2001). *The women in the body: A cultural analysis of reproduction*. Boston, MA: Beacon Press.

McCallum, M., Jolicoeur, L., Lefebvre, M., Babchishin, L. K., Robert-Chauret, S., Le, T. & Lebel, S. (2014). Supportive care needs after gynecologic cancer: Where does sexual health fit in? *Oncology Nursing Forum*, 41(3), 297-306.

McCallum, M., Lefebvre, M., Jolicoeur, L., Maheu, C., & Lebel, S. (2012). Sexual health and gynecological cancer: Conceptualizing patient needs and overcoming barriers to seeking and accessing services. *Journal of Psychosomatic Obstetrics & Gynecology*, 33(3), 135–142. doi: 10.3109/0167482X.2012.709291

McDonough, P. & Walters, V. (2001). Gender and health: Reassessing patterns and explanations.

Social Science and Medicine, 52, 547-559.

McKenzie, H. & Crouch, M. (2004). Discordant feelings in the life-world of cancer survivors.

Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 8(2), 139-157.

McKinley, E. D. (2000). On being a patient: Under toad days: Surviving the uncertainty of cancer recurrence. *Annals of Internal Medicine*, 133(6), 479-480.

Miller, L. E. (2014). Uncertainty management and information seeking in cancer survivorship.

Health Communication, 29, 233–243. doi: 10.1080/10410236.2012.739949

Mirabeau-Beale, K. L., Kornblith, A. B., Penson, R. T., Lee, H., Goodman, A., Campos, S. M., Duska, L., Pereira, L., Bryan, J., Matulonis, U. A. (2009). Comparison of the quality of life of early and advanced stage ovarian cancer survivors. *Gynecologic Oncology*, 114, 353–359.

Mishel, M. H. & Braden, C. J. (1987). Uncertainty: A mediator between support and adjustment.

Western Journal of Nursing Research, 9(1), 43-57.

Mishel, M. H. (1988). Uncertainty in illness. *Image: Journal of Nursing Scholarship*, 20(4), 225-231.

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: Journal of Nursing Scholarship*, 22(4), 256-262.

Mishel, M. H. (1999). Uncertainty in chronic illness. *Annual Review of Nursing Research*, 17(1), 269-294.

Morgan, D. L. (1995). Focus Groups. *Annual Review of Sociology*, 22, 129-152.

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research.

International Journal of Qualitative Methods, 1(2), Article 2, 1-19.

National Coalition for Cancer Survivorship (n.d.). *Our mission*. Retrieved from

<http://www.canceradvocacy.org/about-us/our-mission/>

National Cancer Institute (2012). SEER stat fact sheets: Ovary cancer. Retrieved

from <http://seer.cancer.gov/statfacts/html/ovary.html>

National Cancer Institute, National Institutes of Health, and U.S. Department of Health and

Human Services (2012). Gynecologic cancers portfolio. Retrieved from

https://www.icrpartnership.org/Publications/ICRP_GYN_analysis.pdf

National Ovarian Cancer Coalition (n.d.). *Ovarian Cancer Frequently Misdiagnosed*.

Retrieved from http://www.ovarian.org/view_pr.php?id=28

Ng, J. S., Low, J. J. H. and Arunachalam, I. (2012). Epithelial Ovarian Cancer. *Best Practice &*

Research Clinical Obstetrics and Gynaecology, 26(3).

Neville, K. L. (2003). Uncertainty in illness: An integrative review. *Orthopaedic Nursing*, 22(3),

206-214.

O'Connor, A. P., Wicker, C. A. & Germino, B. B. (1990). Understanding the cancer patient's search for meaning. *Cancer Nursing*, 13(3), 167-175.

Office of Women's Health (2002). A century of women's health: 1900-2000. Retrieved from

<http://www.womenshealth.gov/archive/owh/pub/century/century.pdf>

Ozga, M., Aghajanian, C., Myers-Virtue, S., McDonnell, G., Jhanwar, S., Hichenberg, S. &

Sulimanoff, I. (2015). A systematic review if ovarian cancer and fear of recurrence.

Palliative and Supportive Care, 13, 1771-1780. doi:10.1017/S1478951515000127

Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning

making and its effects on adjustment to stressful life events. *Psychological Bulletin*,

136(2), 257–301.

Parton, C. M., Ussher, J. M. & Perz, P. (2015). Women's construction of embodiment and the

abject sexual body after cancer. *Qualitative Health Research*, 1-14. doi:

10.1177/1049732315570130

Price, B. (1990). A model for body-image care. *Journal of Advanced Nursing*, 15, 585-593

Price, B. (1995). Assessing altered body image. *Journal of Psychiatric and Mental Health*

Nursing, 2, 169-175.

Price, B. (1998). Cancer: Altered body image. *Nursing Standard*, 12(21), 49-55.

- Reb, A. M. (2007). Transforming the death sentence: Elements of hope in women with advanced ovarian cancer. *Oncology Nursing Forum*, 34(6), E70-E81.
- Reis, N., Beji, N. K. & Coskun, A. (2010). Quality of life and sexual functioning in gynecological cancer patients: Results from quantitative and qualitative data. *European Journal of Oncology Nursing*, 14, 137–146.
- Rubin, L. R., Margolies, L. & Kaschak, E. (2014). Women and Cancer. *Women & Therapy*, 37(3-4), 198-204. doi: 10.1080/02703149.2014.897545
- Rubin, L. R. & Tanenbaum, M. (2011). “Does that make me a woman?”: Breast cancer, mastectomy, and breast reconstruction decisions among sexual minority women. *Psychology of Women Quarterly*, 35(3), 401-414. doi: 10.1177/0361684310395606
- Rubin, L. R., Nemeroff, C. J. & Russo, N. F. (2004). Exploring feminist women’s body consciousness. *Psychology of Women Quarterly*, 28, 27-37.
- Salander, P. (2001). Bad news from the patient’s perspective: An analysis of the written narratives of newly diagnosed cancer patients. *Social Science & Medicine*, 55, 721–732.
- Schilder, P. (1950). *The image and appearance of the human body: Studies in the constructive energies of the psyche*. New York, NY: International Universities Press.
- Schink, J. C. (1999). Current initial therapy of stage III and IV ovarian cancer: Challenges for managed care. *Seminars in Oncology*, 26(1), 2-7.
- Schneider, S. J., Kerwin, J., Frechtling, J., & Vivari, B. A. (2002). Characteristics of the

- discussion in online and face-to-face focus groups. *Social Science Computer Review*, 20(1), 31-42.
- Schulman-Green, D., Ercolano, E., Dowd, M., Schwartz, P., Mccorkle, R. (2008). Quality of life among women after surgery for ovarian cancer. *Palliative and Supportive Care*, 6, 239–247. doi:10.1017/S1478951508000497.
- Schultz, W. C. M. & van de Wiel, H. B. M. (2003). Sexuality, intimacy, and gynecologic cancer. *Journal of Sex and Marital Therapy*, 29(S), 121-128.
- Sekse, R. J. T., Gjengedal, E. & Råhem, M. (2013). Living in a changed female body after gynecological cancer. *Health Care for Women International*, 34,14–33. doi: 10.1080/07399332.2011.645965
- Simon, R. W. (1992). Parental Role Strains, Salience of Parental Identity and Gender Differences in Psychological Distress. *Journal of Health and Social Behavior*, 33(1), 25-35.
- Skaggs, B. G. & Barron, C. R. (2006). Searching for meaning in negative events: Concept analysis. *Journal of Advanced Nursing*, 53(5), 559-570
- Sotirin, P. (2004). Consuming breasts: Our breasts, our selves. In P. M. Buzzanell, H. Sterk & L. H. Turner (Eds), *Gender in applied communication contexts* (pp. 123-145). Thousand Oaks, CA: Sage.
- Stacey, J. (1997). *Teratologies: A cultural Study of cancer*. New York, NY: Routledge.

Staller, K. M. & Buch, E. D. (2014). What is feminist ethnography? In S. N. Hesse-Biber (Ed.)

Feminist Research Practice (pp. 107-144). Thousand Oaks, CA: Sage.

Stead, M. L., Fallowfield, L., Selby, P. & Brown, J. M. (2006). Psychosexual function

and impact of gynecological cancer. *Best Practice & Research Clinical Obstetrics and Gynaecology*, 21(2), 309-320. doi:10.1016/j.bpobgyn.2006.11.008

Stead, M. L., Fallowfield, L., Brown, J. M. & Selby, P. (2001). Communication about sexual

problems and sexual concerns in ovarian cancer: Qualitative study. *British Medical Journal*, 323, 836-837.

Stewart, D. E., Wong, F., Duff, A., Melancon, C. H. & Cheung, A. M. (2001). “What

doesn't kill you makes you stronger”: An ovarian cancer Survivor Survey. *Gynecologic Oncology*, 83, 537–542. doi:10.1006/gyno.2001.6437.

Strauss, A. & Corbin J. (1990). *Basics of qualitative research: Grounded theory procedures and*

techniques. Newbury Park, CA: Sage.

Sulik, G. (2011). *Pink ribbon blues: How breast cancer culture undermines women's*

health. New York, NY: Oxford University Press.

Sulik, G. & Zierkiewicz, E. (2014). Gender, power, and feminisms in breast cancer advocacy:

Lessons from the United States and Poland. *Journal of Gender and Power*, 1(1), 111-145.

Taylor, C. L. C., Basen-Engquist, K., Shinn, E. H. & Bodurka, D. C. (2004). Predictors of sexual

functioning in ovarian cancer patients. *Journal of Clinical Oncology*, 22(5), 881-889.

- Thompson, S. C. & Pitts, J. (1993). Factors relating to a person's ability for find meaning after a diagnosis with cancer. *Journal of Psychosocial Oncology*, 11(3), 1-21. doi: 10.1300/J077V11N03_01.
- Uchino, B. V. (2004). *Social support and physical health: Understanding the health consequences of relationships*. Nashville, TN, Yale University Press.
- Ussher, J. M., Kirsten, L. Butow, P. & Sandoval, M. (2008). A qualitative analysis of reasons for leaving, or not attending, a cancer support group. *Social Work in Health Care*, 47(1), 14-29. doi: 10.1080/00981380801970673
- Ussher, J. M., Perz, J. & Gilbert, E. (2014). Women's sexuality after cancer: A qualitative analysis of sexual changes and renegotiation. *Women & Therapy*, 37, 205–221. doi: 10.1080/02703149.2014.897547
- Ussher, J. M., Perz, J. & Gilbert, E. (2012). Changes to sexual well-being and intimacy after breast cancer. *Cancer Nursing*, 35(6), 456-465.
- Ussher, J. M. (1989). *The psychology of the female body*. New York, NY: Routledge
- Vaz, A. F., Pinto-Neto, A. M., Conde, D. M., Costa-Paiva, L., Morais, S. S., & Esteves, S. B. (2007). Quality of life of women with gynecologic cancer: Associated factors. *Archives of Gynecology and Obstetrics*, 276(6), 583-589
- White, C. A. (2000). Body image dimensions and cancer: A heuristic cognitive behavioral model. *Psycho-Oncology*, 9, 183-192.

Wilmoth, M. C. & Spinelli, A. (2000). Sexual implications of gynecologic cancer treatments.

Journal of obstetric, Gynecologic, and Neonatal Nursing, 29(4), 413-421.

Wilmoth, M. C. (2007). Sexuality: A critical component of quality of life in chronic disease.

Nursing Clinics of North America, 42, 507-514.

Woods, N. F. (1987). Toward a holistic perspective of human sexuality: Alterations in

health and nursing diagnoses. *Holistic Nursing Practice, 1(4), 1-1.*

Informed Consent for Interviews for **Stories of Teal: Women's Experiences of Ovarian Cancer**

Introduction: My name is Dinah Tetteh, a graduate student in the School of Media and Communication at Bowling Green State University (BGSU). My advisor is Dr. Sandra Faulkner, associate professor of Communication and Director of Women's, Gender, and Sexuality Studies, BGSU. For my dissertation project, I want to learn more about ovarian cancer and social support. You were identified as a possible volunteer in the study because you have been affected by ovarian cancer and/or belong to (ovarian) cancer support group(s).

Purpose: I want to know more about women's experiences with ovarian cancer and social support: what it means to be ovarian cancer patient or survivor, the role social support plays in women's experience of ovarian cancer, and how society's understanding of ovarian cancer and the identities women hold (in terms of age, religion, sexuality, and race) contribute to the experience of ovarian cancer. You will receive a \$20 grocery card for participating. You must be 18 years of age to participate.

Procedure: This study involves conversational interviews. Interviews can be conducted in-person or via the telephone, Skype, email, Google Hangout, or chat services. The interviews will not last more than 60-90 minutes. In preparation, I will ask you to select a photo, an image, or any object that describes your experience with ovarian cancer, to help guide our conversation.

1. During the interview, I will be asking you what it means to be ovarian cancer patient and/or survivor and how social support available to you helps you cope with the illness. I will also be asking you about how your religion, race, age, and sexuality influence your experience of ovarian cancer. This interview is open in that whatever you feel important to say about your experience, I encourage you to share. I will record the interviews with two audio-recording devices that will only be listened to by me and will remain locked in my residence to maintain your confidentiality. After I transcribe the recordings and complete the analysis, they will be erased to further ensure confidentiality.
2. You will also be asked to participate in focus group discussions with other ovarian cancer patients and/or survivors. The point of this is to gain a better understanding of women's experiences with ovarian cancer and social support. If you do not want to take part in this part of the study, you are free to only participate in the interview.

Voluntary nature: Your participation is completely voluntary. You are free to opt out at any time. You may decide to skip questions or discontinue participation at any time without penalty or loss of benefits to which you are entitled. Your decision to participate or not participate in the study will not affect your relationship with Bowling Green State University, the Ovarian Cancer Connection, or the Cancer Connection of Northwest Ohio in any way.

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Confidentiality protection: I will use a pseudonym when referring to you in the research write-up. I will quote you in the write-up but will not provide any information that reveals your identity. All audio-recordings, transcriptions of those recordings, fieldnotes, and transcriptions of the fieldnotes will be stored in a password-protected file on my personal computer. All hard copies of interview notes and physical tapes of interviews will be stored in a locked cabinet at my residence. I am the only person who will have access to these documents. The information will be deleted 5 years after the completion of the study.

Risks: There may be some risks associated with participating in this study. I will be asking for your views about issues that may feel very personal to you. These may include questions about your experience with ovarian cancer and the identities you hold. Discussing these topics may upset you. If at any time you feel uncomfortable with a question you may choose not to answer. As stated earlier, your participation is entirely voluntary and you may leave the study at any time. Should you want to speak with a counselor, can you call the Victory Center in Toledo at 419-531-7600 and request to do so.

Contact information: If you have any questions about the research or your participation in the research, please feel free to contact: Dinah Tetteh at dtetteh@bgsu.edu, 423-946-4487 or Sandra Faulkner (faculty advisor) by phone at 419-372-1998 or email at sandraf@bgsu.edu. You may also contact the Chair, Human Subjects Review Board at 419-372-7716 or hsrb@bgsu.edu, if you have any questions about your rights as a participant in this research. **Thank you** for your time!

I have been informed of the purposes, procedures, risks and benefits of this study. I have had the opportunity to have all my questions answered and I have been informed that my participation is completely voluntary. I agree to participate in this research.

Name of Participant (Please print)

Signature of Participant

Date

Informed Consent for Focus Groups for **Stories of Teal: Women's Experiences of Ovarian Cancer**

Introduction: My name is Dinah Tetteh, a graduate student in the School of Media and Communication at Bowling Green State University (BGSU). My advisor is Dr. Sandra Faulkner, associate professor of Communication and Director of Women's, Gender, and Sexuality Studies, BGSU. For my dissertation project, I want to learn more about ovarian cancer and social support. You were identified as a possible volunteer in the study because you have been affected by ovarian cancer and/or belong to (ovarian) cancer support group(s).

Purpose: I want to know more about women's experiences with ovarian cancer and social support: what it means to be ovarian cancer patient or survivor, the role social support plays in women's experience of ovarian cancer, and how society's understanding of ovarian cancer and the identities women hold (in terms of age, religion, sexuality, and race) contribute to the experience of ovarian cancer. You must be 18 years of age to participate. Snacks and beverages will be provided.

Procedure: This study involves focus group discussions. The discussions will take place in-person with other ovarian cancer patients and/or survivors. The discussions will not last more than 60-90 minutes.

1. You will be informed about the purpose of the study and how your participation will contribute to it. The procedures and activities will be explained to you before any actions are taken.
2. You will be asked to take part in a focus group discussion that looks at women's experiences with ovarian cancer and social support. You will be asked to talk with about 4-8 other ovarian cancer patients and/or survivors about what it means to be ovarian cancer patient or survivor, the role social support plays in women's experience of ovarian cancer, and how society's understanding of ovarian cancer and the identities women hold (in terms of age, religion, sexuality, and race) contribute to the experience of ovarian cancer.
3. Focus groups discussions will be recorded using audio-recording device that will only be listened to by me to protect your confidentiality. After the recording has been transcribed and analyzed, it will be destroyed to ensure further confidentiality.

Voluntary nature: Your participation is completely voluntary. You are free to opt out at any time. You may decide to skip questions or discontinue participation at any time without penalty or loss of benefits to which you are entitled. Your decision to participate or not participate in the study will not affect your relationship with Bowling Green State University, the Ovarian Cancer Connection, or the Cancer Connection of Northwest Ohio in any way.

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Confidentiality protection: What you say in here cannot be guaranteed as completely confidential because this is a group interview. However, I ask that you don't discuss anything other group members say outside of this meeting. I will use a pseudonym when referring to you in the research write-up. I will quote you in the write-up but will not provide any information that reveals your identity. All audio-recordings, transcriptions of those recordings, fieldnotes, and transcriptions of the fieldnotes will be stored in a password-protected file on my personal computer. All hard copies of interview notes and physical tapes of interviews will be stored in a locked cabinet at my residence. I am the only person who will have access to these documents. The information will be deleted 5 years after the completion of the study.

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