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Distinctive psychological and social experiences of women choosing prophylactic oophorectomy for cancer prevention

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Abstract

Women known to have significantly elevated ovarian cancer risk due to genetic mutations or family history can reduce this risk by surgically removing both ovaries and fallopian tubes (RRBSO, risk-reducing bilateral salpingo-oophorectomy). We used interpretive phenomenological analysis (IPA) to explore the psychosocial experiences of women who chose RRBSO for cancer prevention. We extended the traditional use of IPA to compare the experiences of women who chose RRBSO for cancer prevention to those of women who underwent similar gynecologic surgery for benign indications. The analysis resulted in three superordinate themes describing women's psychosocial experiences related to RRBSO: (1) psychological facets of cancer risk (2) social support and (3) shared medical decision making. Findings illustrate that women choosing RRBSO for cancer prevention experience heightened psychosocial challenges before and after surgery compared to women undergoing surgery for benign indication. Furthermore, they may need distinct types of information and support from healthcare providers.

Ovarian cancer is the fifth leading cause of cancer death in U.S. women (Siegel, Miller, & Jemal, 2016). Genetic testing for *BRCA1* and *BRCA2* mutations has produced a growing population of cancer-free women who have been identified as being at high risk for ovarian cancer. The average cumulative lifetime risk for ovarian cancer among mutation carriers is 45% for those with a *BRCA1* mutation and 12% for those with a *BRCA2* mutation (Graeser et al., 2009). Clinical options for reducing these elevated risks include ovarian cancer surveillance and risk-reducing surgery. Current surveillance methods include the CA-125 blood test and transvaginal ultrasounds, but concurrent use of these two surveillance methods on a yearly basis results in a mortality rate reduction of only 15% (Jacobs et al., 2016).

Risk-reducing surgery refers to bilateral salpingo-oophorectomy (RRBSO), which is the prophylactic removal of both ovaries and fallopian tubes. Among mutation carriers, RRBSO

results in an 80% reduction in ovarian cancer incidence and 77% reduction in overall mortality (Finch et al., 2014). The United States, England, and European Union have all published clinical guidelines recommending RRBSO for cancer risk-reduction for women with *BRCA* mutations (National Comprehensive Cancer Network [NCCN], 2016; National Institute for Health and Care Excellence [NICE], 2013; Paluch-Shimon et al., 2016). Guidelines recommend that *BRCA*-positive women undergo RRBSO between the ages of 35 and 40 (upon completion of childbearing), based on the evidence that an equivalent reduction in cancer risk cannot currently be achieved through other methods. International uptake of RRBSO in high risk women is estimated to be 49% among women for whom it is recommended (Metcalf et al., 2008); this issue thus affects a large number of women worldwide.

Clinical guidelines also direct health care practitioners to address psychosocial and quality of life implications of RRBSO (NCCN, 2016; NICE 2013; Paluch-Shimon et al., 2016), which are mainly driven by the effects of surgically-induced menopause. However, neither the psychosocial factors that shape decision making nor the psychosocial effects of RRBSO have been well studied. Women themselves report lacking desired information about the effects of RRBSO prior to surgery (Bonadies, Moyer, & Matloff, 2011). Therefore, there is a critical need to study the psychosocial aspects of RRBSO so that (1) women can be fully informed about the possible psychosocial effects and options for coping with them before their surgical decisions and (2) those who provide care for high-risk women can be better equipped to educate and support them through the range of psychosocial experiences related to RRBSO.

In the context of health-related decision making for *BRCA*-positive women, the clinical goal should be to facilitate a patient-empowered, collaborative, and well supported choice regarding RRBSO, but current clinical interactions often fall short of this objective (Joseph-Williams, Elwyn, & Edwards 2014). Such a model would require shared decision making (SDM) between high risk women and their healthcare providers, to facilitate both health-protective decisions and psychosocial health. SDM is a collaborative decision-making approach that involves clinicians sharing evidence and supporting patients to achieve informed decisions that incorporate their personal values and preferences (Elwyn et al., 2012). Among *BRCA1/2* mutation carriers, SDM has beneficial long-term effects including fewer intrusive thoughts about cancer, better self-reported general health, and fewer depressive symptoms (van Roosmalen et al., 2004). High quality decision making and support for high-risk women can occur in interactions with primary care providers or specialists, may also involve decision aids (Giles, 2015) or other sources of care, such as genetic counselors, psychologists, social workers, support groups, or complementary and alternative medicine practitioners.

Existing research on the psychosocial and quality of life (QOL) aspects of undergoing RRBSO offers a range of helpful insights based on both quantitative and qualitative data, but falls short of providing the evidence base for the patient-empowered model of SDM described above. Quantitative researchers have focused mainly on two issues: the physical effects of RRBSO and women's satisfaction with undergoing RRBSO. Researchers have discovered the physical effects of inducing menopause through RRBSO, finding that

women's post-surgical experiences commonly include estrogen deprivation symptoms, such as hot flashes, vaginal discomfort, sexual pain and dysfunction, and poorer physical functioning (Johansen et al., 2016; Moldovan, Keating, & Clancy, 2015; Finch & Narod, 2011). Although women who undergo RRBSO before natural menopause experience these symptoms more acutely, post-menopausal women who undergo RRBSO also experience hormone deprivation symptoms (Wierman et al., 2010). The use of hormone replacement therapy among women who have undergone RRBSO (which is controversial and often avoided in the context of hereditary cancer risk) decreases some but not all of these symptoms (Finch & Narod, 2011; Johansen et al., 2016).

Fewer researchers have explored psychosocial effects of RRBSO. Cancer-specific worry is associated with both poorer general QOL and menopause-specific QOL (Moldovan et al., 2015). RRBSO significantly reduces cancer-specific worry, so that women who undergo RRBSO report similar QOL scores to the general population (Finch & Narod, 2011). However, emotional and social functioning are lower following RRBSO, and some women continue to worry about developing ovarian cancer after surgery (Finch & Narod, 2011; Moldovan et al., 2015). In general, women report high levels of satisfaction with their decision to have RRBSO (Moldovan et al., 2015). A small number of researchers have moved beyond measuring psychosocial effects of hereditary cancer risk to investigating the mediators of these effects. Den Heijer and colleagues demonstrated that social resources, such as open communication about hereditary cancer and perceived support from family and friends, are associated with less general and cancer-specific distress (Den Heijer et al., 2012). More studies of this kind will be needed to fully equip clinicians and other healthcare providers with the information they need to provide individually tailored information and care for high-risk women.

Qualitative studies have offered more in-depth perspectives on women's experiences of RRBSO. Women describe high levels of cancer worry that motivate their decision to undergo RRBSO; describe their ovaries as "ticking time bombs"; and feel that RRBSO gives them the opportunity to take control of their health by reducing their level of cancer worry (Hallowell et al., 2012, Howard, Balneaves, Bottorff, & Rodney, 2011). Women also express a sense of "family obligation" to reduce their cancer risk (Maeland, Eriksen, & Synnes, 2014). Although women are generally satisfied with their surgery decisions, they often feel unsatisfied with the levels of support or information provided by healthcare practitioners, regarding issues such as the negative impact of menopausal symptoms and use hormone replacement therapy (Bonadies et al., 2011; Hallowell et al., 2012;). Active support from a partner after RRBSO has also been shown to alleviate negative effects (Maeland et al., 2014). These studies offer a useful beginning, but much work remains to be done in understanding the psychological aspects of the RRBSO experience, and the mechanisms by which these psychosocial dynamics occur.

The present study addresses some of these knowledge gaps using a qualitative and phenomenological approach. By documenting women's stories in their own words, we seek to illuminate women's RRBSO experiences more fully than has been done previously, and to set the stage for further investigations that may help build better clinical and alternative health management methods for women at high risk of ovarian cancer. We have two central

objectives for this study. First, we aim to describe and interpret the psychosocial experience of women choosing RRBSO as a cancer prevention option. Second, we aim to compare the experiences of women undergoing RRBSO to those of women who have undergone a similar gynecologic surgery for benign (non-cancer-related) medical indications, to see if the specific context of cancer risk shapes the psychosocial challenges posed by RRBSO.

Methods

Design

We applied interpretive phenomenological analysis (IPA) to in-depth qualitative interviews with 12 women who have made the decision to undergo gynecologic surgery (Smith, Flowers, & Larkin, 2009). IPA is an idiographic approach that allows researchers to closely examine individual cases to describe in detail the perceptions and understandings of a particular group, rather than prematurely make more general claims. IPA follows a two-stage interpretation process, or double hermeneutic. That is, 'The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world' (Smith and Osborn, 2015). In general, phenomenological modes of inquiry seek to understand human experiences within the context of the lifeworld in which they are lived (Giorgi, 1997). Researchers focus on capturing the qualitative meaning of experiential phenomena, which requires understanding the personal and social context in which individuals make sense of their own experiences. IPA specifically involves a bottom-up form of analysis, during which the researcher moves from data to theoretical ideas instead of testing a pre-determined theory, and back and forth between the participants' words and the researchers' own interpretation of those words (Larkin, Watts, & Clifton, 2006). IPA is distinct from other qualitative methods in its focus on describing and interpreting the meanings of human experiences, rather than on explicitly causal analysis. In this study, we are concerned with not only understanding common experiences of women choosing RRBSO as a cancer prevention option, but also how the context of cancer prevention affects the experience of surgical decision-making. Since IPA is commonly used to describe the nature of gaps that exist between a situation and an individual's perception, we regard IPA as an appropriate approach to be adapted for this study.

Participants

Our study is a secondary analysis using a subsample of participants from a larger parent study. In the parent study, we explored decision-making processes and effects on women's health and well-being related to cancer prevention choices among women at elevated risk of breast and ovarian cancer. We recruited a purposive sample of 50 women who met the following inclusion criteria: (1) at least 18 years of age (2) never been diagnosed with cancer (3) at elevated risk for breast and ovarian cancer as a result of a positive *BRCA1/2* test or family history (Hampel, Sweet, Westman, Offit, & Eng, 2004). Participants were recruited between April 2015 and March 2016 through two methods: (1) in-person recruitment of patients at the High Risk Breast Cancer and Genetic Counseling clinics at the Ohio State University James Comprehensive Cancer Center (2) online recruitment of users of two research databases: ResearchMatch and StudySearch. Recruitment continued until theoretical saturation was reached in all the key content areas of the semi-structured

interview protocol. Participants consented in writing, and received a \$25 Amazon gift card incentive after completing the interview.

For the present study, we used interview data from a sub-sample of 12 parent study women who have made a decision to undergo gynecologic surgery (i.e. RRBSO or hysterectomy). We extended the traditional use of IPA by categorizing these women into two distinct groups. The primary group (referred to below as the “RRBSO Group”) consists of 8 women who chose to undergo RRBSO as a method of ovarian cancer prevention, including five who have already undergone RRBSO and three who have made the decision but not yet had the surgery. The secondary group (the “Gynecologic Surgery Group”) is a comparison set of 4 women who underwent gynecologic surgery, motivated by a benign (non-cancerous) gynecologic indication instead of by a purposeful attempt to prevent cancer. These women had partial or full hysterectomies with (2 women) or without (2 women) ovarian removal. Because the primary aim of IPA is the interpretive exploration of meaning and sense-making within detailed accounts, the recommendation for sample size is between 4 and 10 participants depending on various features of the study (Smith et al., 2009); both our groups are within this recommended range. Categorizing women into two groups allowed us to (1) explore how women in each group make sense of their cancer risk and surgical experience and (2) examine similarities and differences between groups. Women in both groups were at elevated risk of breast and ovarian cancer, but were distinct in their reasons for undergoing surgery. Descriptive characteristics are shown in Table I.

Data Collection and Procedure

Ethical approval for this study was obtained from the Institutional Review Board at The Ohio State University. Semi-structured interviews were designed to elicit detailed prevention-related stories and to encourage women to speak in their own words. The interviewer asked women to describe their awareness of breast cancer risk and their own perceived risk status, the sources and content of risk information they have obtained, their understanding and deliberations about potential prevention actions, their use of financial, time, and other resources in relation to managing breast cancer risk, and their psychosocial well-being. Initially, the interviewer interrupted only to encourage women to continue talking or raise new topics when the story trailed off; later, the interviewer asked follow-up questions to fill in gaps in the initial story. Interviews ranged from 22 to 120 minutes, averaging 57 minutes. Interviews were digitally recorded and professionally transcribed. Participants are identified below by pseudonym and age, to maintain their confidentiality. Women’s words are quoted verbatim, except for the trimming of stuttering and repetitive verbalizations such as “you know” or “um”.

Analyses

Since the interview data from the larger parent study encompassed multiple research questions, we first reduced the data using structural codes. Structural codes were generated inductively by three separate coders; the final list of structural codes was chosen by consensus, and included as many codes as needed to capture all possible aspects of the topics described. Two coders coded each transcript using NVivo 11, checking each other’s coding and discussing any points of disagreement until a consistently-applicable coding

principle was agreed upon. This structural coding method consolidated large segments of textual data from the parent project into chunks that would be relevant for subsequent analyses (Guest & MacQueen, 2008).

Our interpretive phenomenological approach analyzed all structural codes relevant to RRBSO or gynecologic surgery: perceptions of cancer risk, personal exposure to cancer, preventive oophorectomy, psychological impact, interactions with healthcare practitioners, identity, body, and sexuality, support structures, and relationship impact. Structural codes not relevant to RRBSO or gynecologic surgery but pertaining *only* to other types of interventions (such as prophylactic mastectomy or chemoprevention) were excluded. Our analytic process reflected the six steps of IPA described by Smith et al.: (1) reading and rereading the transcript, (2) taking initial notes, (3) developing initial themes, (4) searching for connections among emergent themes, (5) moving to the next case, and (6) looking for patterns across cases. After close, repeated reading of the content in all appropriate structural nodes from each transcript, we pursued the steps separately for the primary RRBSO group and the comparison gynecologic surgery group. We took initial notes and identified themes within each participant's interview, then made connections among participants within each group. Comparisons and interpretation of experiences across the two groups were made after patterns within groups were identified. The first author was responsible for the primary analyses and met regularly with the second author to confirm emerging themes and patterns across participants. We made deliberate efforts to ensure that our parsing of themes, finding connections and patterns across cases, and interpretation of experiences preserved the authentic experience of each informant, as she expressed it during the interview.

Results

The psychosocial experiences of women in this study cohere around three central domains, which emerged as superordinate themes in our analysis (see Table 2): (1) psychological facets of cancer risk (2) social support and (3) shared medical decision making. The first domain encompasses relationships between participants' thoughts and feelings about cancer risk and their perspectives on cancer prevention, altering their bodies, and the future. The second domain describes participants' experiences of negative and positive social support, and the impacts of these experiences. The third domain illustrates the degree to which women achieve shared decision making with their doctors and the psychological effects of those relationships.

Psychological Facets of Cancer Risk

Intense Cancer Worry Motivates Active Prevention

RRBSO group: All eight women who chose RRBSO experienced intense worry about the risk of getting cancer, and were motivated to undergo RRBSO in order to mitigate both cancer risk and cancer worry. Women described their worry and fear in terms of "running from cancer" or feeling like a "ticking time bomb".

For six of these women, a high level of cancer worry arose from traumatic cancer experiences within their families. These experiences were directly tied to women's strong

emotional reactions when asked to describe their own cancer risk, and to their thoughts about prevention. Three women – Lucy, Lainie and Kathryn – witnessed their mothers' struggles with the breast or ovarian cancers that ultimately killed them. Kathryn described how this experience impacted her own decision-making process:

I was told that I had an 87% [higher] chance of getting breast cancer in my lifetime than the average woman, and a 60% [higher] chance of ovarian cancer than the average woman. And you know, you watch it happen to your mom and you see many relatives die of cancer, and I was really scared. (Kathryn, 42)

For Kaitlyn and Marsha, familial experiences of cancer were more abstract. Although both knew about specific cases of cancer in their families, neither had been closely involved with those relatives' experiences of cancer. Nevertheless, both women were “anxious and worried” about getting breast and ovarian cancer. Kaitlyn explained, “My aunt was diagnosed ten years ago... [and] my mom was diagnosed [with breast cancer] when I was in my late 20's.” After her mother's positive genetic test result Kaitlyn was also tested and found out that she carries a *BRCA2* mutation. Her reaction reflected both substantial cancer worry and a resulting desire to take proactive steps:

I was kind of in a place of sadness at first...I know I have up to an 80 percent chance of getting it...And then I thought, ‘Well, at least I know...I'd rather have had a negative result, but now that I know, I can do what I need to do.’ (Kaitlyn, 36)

Consistent with their motivation to reduce worry by choosing RRBSO, all four of the women who have already undergone the surgery felt protected from ovarian cancer afterward. Megan described the transition in her mental state as follows:

It feels like you're caught in a whirlwind...when you're healthy...you just feel like you're a ticking time bomb... I know that percentage, the 86%, is there. I know I had [RRBSO] only because I had the *BRCA* test done, and I have two small children. And I knew it reduced my rate... you do everything you can just to get the number down. (Megan, 41)

These women use phrases like “reduc[ing] my rate” and “mitigating the risk” to indicate their understanding that RRBSO cannot completely eliminate ovarian cancer risk, but still experience considerable post-surgical relief:

I was told, ‘Now, there always is that remote chance that you could have one rogue cell floating around in there [that] could all of a sudden start going crazy’...but, I felt like I was protected more...I did everything I could do to hopefully prevent this. (Lainie, 59)

While worries about *ovarian* cancer were largely alleviated by RRBSO, three of these four women still experienced breast-specific or generalized cancer worry after having their ovaries removed. Acutely aware that every woman in her family has had breast or ovarian cancer, Megan continued to worry that she will face cancer someday:

Every time [I] go to the doctor, every time [I] go have a mammogram, every time I feel like I'm waiting longer than everybody else because they found [something], [I] live in paranoia.

Gynecologic Surgery Group: For women who had gynecologic surgery for benign health reasons, cancer worry appeared not as a motivation for surgery, but as a more general phenomenon permeating their lives. The worries of these women differed from those of the first group in two ways. First, while women considering RRBSO for cancer prevention expressed very specific worries about ovarian cancer, women who had been through gynecologic surgery for another reason worried about cancer in general. Two of these four women had already had their ovaries removed and therefore (like the women who had undergone RRBSO) had little reason to worry about ovarian cancer specifically. In addition, many different kinds of cancers ran in these women's families, resulting in a more general sense of cancer worry like that described by Sue:

I have friends of my age and older than me that their parents are still living. I don't have any parents left. People in my family don't live as old as other people, so I think about [cancer] more because of that. (Sue, 56)

Second, women who had gynecologic surgery for reasons unrelated to cancer prevention told stories of other health issues they experienced as higher priority than cancer risk, including diabetes, COPD, and heart disease. Trish remarked, for instance:

For me, it's for my heart, I don't think of the other diseases...I'm more concerned with my heart than I am with the cancer. (Trish, 58)

For these women, serious health problems were not just a future worry, but also a contemporary reality. They had each already encountered at least one illness substantial enough to require abdominal surgery, and they each struggled with other health challenges as well.

In this context, women also expressed strong motivation to prevent disease, but it was not organized around RRBSO. Active prevention in this case tended to involve positive lifestyle behaviors, as Sue describes:

My dad died...I was 18 when he was first diagnosed... and it was not a good death... So that rocked my world – if there's things I can do to take care of myself... I've tried to live a pretty healthy life for the most part – like going in for the annual mammogram, trying to eat all fruits and vegetables I can, trying not to drink too much. (Sue, 56)

Feeling Attached To One's Ovaries

RRBSO Group: All eight women in this group chose RRBSO because it is currently the most effective ovarian cancer prevention option, but some arrived at this decision more easily than others. A clear distinction arose between women who felt a strong sense of emotional attachment to their ovaries, and those who did not. Perhaps contrary to what might be expected, more than half of these women (5 of 8) articulated *not* feeling any particular attachment to their ovaries. Lainie's point of view illustrated this perspective:

I don't link my ovaries or my breasts to my femininity or my person, so you know – that's like saying someone that has an arm amputated, they're less of a person because they have an artificial arm, you know? (Lainie, 59)

Lainie felt depressed by the idea of having a body part that might kill her, and was willing to sacrifice those pieces of her physical self. For women like Lainie, this lack of attachment to specific body parts made it easier to choose RRBSO for cancer prevention. Kaitlyn was similarly pragmatic:

I knew I was done having kids, so I was prepared to do the oophorectomy... I decided that I'd rather take the opportunity to get it done and stop worrying about getting cancer...why do I want to sit around and wait to see if I have cancer if I can do something about it now? (Kaitlyn, age 36)

For the other three women in our RRBSO group, strong feelings of attachment to their ovaries not only made it harder choose to have them removed, but also made psychological coping after RRBSO more difficult. Marsha described why it was so hard to think about undergoing the preventive surgery:

Basically to have everything surgically taken out that makes you female [was] messing with my head, and I never would have expected it to...it's the intimacy, the vanity, the pieces of yourself gone that make you female. (Marsha, 41)

Despite these deep reservations, Marsha ultimately chose RRBSO – largely because there is no effective screening option for ovarian cancer:

Ovarian cancer is really scary...we don't have good surveillance...I talked to a woman the other day who was like, 'Every time I get a transvaginal ultrasound, every 6 months, my doctor tells me, 'We're probably still not going to catch it.' (Marsha, 41).

For women whose strong feelings of attachment to their ovaries made the RRBSO decision difficult, the negative psychological impact could be quite lasting. Kathryn reflected on the effects of risk-reducing surgery on her life:

It is very scary, as a woman, to make such a major decision to change who you are – because it does change who you are. It absolutely does. And so, I don't think, unless you've gone through it, that you can possibly understand... I've given up my uterus and my ovaries...It's changed me. (Kathryn, 42)

Gynecologic Surgery Group: Unlike some of the women removing healthy ovaries in order to prevent cancer, women in the comparison group expressed no feelings of attachment to specific body parts that could stand in the way of their surgical choice. These women all suffered from a specific gynecological problem (see footnotes to Table 1) for which surgery was the recommended solution. Their situation was very different from that of women in the RRBSO group, who faced a need to take action to reduce the risk of a potentially-deadly health problem that may or may not occur in the future. Sue's experience exemplified the simplicity of the choice of surgery for women in the comparison group:

I was having a lot of heavy bleeding every month. It was not fun. And I tried other things, and that didn't work, and so, I [had the hysterectomy]. (Sue, 56)

In addition, the women in this group report no psychological difficulty coping with either the surgical decision or the effects of their surgery. In the context of chronic suffering caused by

a specific gynecological problem, surgery was a comparatively more straightforward choice for both women and their doctors. The need to weigh the potential costs and benefits of life without ovaries (or uterus), and the psychological challenges of giving up body parts were all much less relevant for women choosing gynecologic surgery for reasons other than cancer prevention.

Perspectives on Longevity

RRBSO Group: Women's talk about cancer risk and RRBSO decision making frequently included reflections on longevity. Thinking about one's future lifespan emerged as an important theme in these interviews, and women generally articulated one of two perspectives: a focus on family duty, or a *carpe diem* approach to life with cancer risk. For the women (5 of 8) who articulated a sense of family obligation, RRBSO offered an opportunity to take proactive cancer prevention steps for the sake of their loved ones. Kathryn expressed a deep motivation to be a part of her children's lives for as long as possible, and an intense desire to protect them from having to watch their mother suffer and die:

I want to share in their lives. I want to watch them graduate, I want to see them get married. But I also just don't want them to go through the trauma that I went through as a kid, which is - it's not right. (Kathryn, 42)

Lucy, too, lost her mother to ovarian cancer. After testing positive for a *BRCA2* mutation, she struggled for years to come to the decision to have her ovaries removed. Her emotions were right at the surface as she described how she might feel one day if she did not undergo RRBSO: "It would be a guilty and gut-wrenching experience...knowing that [my daughter] would have to go through that pain of watching her mom get that sick (Lucy, 45)."

Other women (3 of 8) focused not on how to extend their lives for the sake of their families, but on the "here and now". These women live with a *carpe diem* attitude, because cancer risk means that they do not know what will happen in the future, or how long they have to live. As Marina explained, "When you have this increased risk you just need to live your life and enjoy...cause you're not guaranteed that you're gonna have a future (Marina, 59)." These women pursued active cancer prevention steps, but did not see them as guaranteeing their future. As Lainie described, prevention represents hope but not security:

I'm going to do everything I can to reduce my risk for the obvious things, and change my attitude and lifestyle to live my life like I can be diagnosed tomorrow. (Lainie, 59)

Gynecologic Surgery Group: These same two perspectives on longevity were present here as in the RRBSO group. Some experienced a strong sense of obligation to make choices that would extend their own lives, for the sake of their families. Teresa explained:

I have two new grandkids. And I want to be around for them...I want to make steps on purpose to do better for myself, and then do what I can to increase the time that I'm here. (Teresa, 48)

Consistent with the fact that these women worried not so much about ovarian cancer but about a range of current and potential future health problems, however, they tended to focus on living a healthy lifestyle (instead of undertaking RRBSO) as the best chance to live longer. Along these lines, Teresa talked about her efforts to control her diabetes, “I cook, we don’t do a lot of fast food, I don’t do a lot of already prepared stuff,” and thinks about her other lifestyle behaviors, “I’ve been smoking cigarettes for a really long time...I’m trying to quit (Teresa, 48).” For other comparison group women, familial cancer risk produced a *carpe diem* view: life is finite, and these women focused on living it to the fullest for whatever time remains:

I better go live life while I’m here...Am I doing what I want to be doing? I better figure out what that is. (Sue, 56)

Social Support

As the 12 women in this study navigated cancer risk and decision making, they experienced varying levels of social support from family and friends. Some women received social support from family members and friends who could understand their reasoning for taking active cancer prevention steps. This social support had a substantial positive impact on women’s psychological well-being when it was present and a substantial negative impact when it was not. With the exception of differences in the specific health topics about which women sought support, those in both RRBSO and gynecologic surgery groups described similar experiences.

Negative Social Support

RRBSO Group: For some women, it was the lack of needed social support and its negative effects on well-being that came through most clearly. Lainie explained her frustration that neither her coworkers nor her son express any sympathy for her struggle with surgical- and other risk-related decisions. At work, “Everybody seems to think, ‘Oh, what’s the big deal?’”. At home, she found herself asking her son, “Do you not realize the impact of this? I feel like you don’t understand the impact that this is having, or will have, on me.” She described her longing for the people around her to understand at least a bit about how profoundly her cancer risk affects her life: “I just wanted [my son] to realize the stoic mom isn’t always stoic and can’t do it all, all the time... (Lainie, 59).” Kathryn expressed similar frustration at her husband’s lack of support, which negatively affected her psychological well-being both before and after surgery:

I’m frustrated with him because he has not shown the compassion that I need...It’s hard for women to go through this and then also face what they face with their children and their spouse...I don’t know how he’s felt through all this because I’m so angry at him...I don’t want to ask him because he hasn’t given me the support I need. (Kathryn, 42)

Gynecologic Surgery Group: Women in the comparison group similarly described the harms of lacking social support as they grapple with health issues. Reflecting on her journey through a range of health problems including diabetes, arthritis, and neuropathy, Teresa described the loss of support from friends and family who have been witness to her long

struggle, “People are disinterested, you stop getting invites to things, etc. Everybody is living their own lives (Teresa, 48).” Despite the pain it caused, however, these women tended to accept the lack of social support they experienced as normal.

Positive Social Support

RRBSO Group: For other women, it is their positive experiences of social support that came through as critical, fostering better psychological well-being through the RRBSO experience. Kaitlyn shared her experiences with a local support group:

Originally, every time I would talk, I would just start crying, but now I feel like I kind of know them, and the meetings are a little more intimate... We just go around and talk about our stories... So the last time...I got to tell everyone I have my [RRBSO] date scheduled... I’ve been going every month. I can ask questions about people who are going through the same thing. (Kaitlyn, 36)

Kaitlyn also reflected further on the support she was receiving in Facebook groups from other women facing RRBSO: “I feel like it’s preparing me for the surgery because the women who are on there have all had it, or are planning to have it, and they give a lot of tips. It’s really helpful actually.”

Support groups were only one potential source of positive social support. For some women (3 of 8), it came from individuals who had seen a family member suffer through ovarian cancer and therefore understood the physical and emotional toll it can take. Lucy’s story about her father demonstrated how empathy can produce social support, or even active help:

My mom got diagnosed when I was 13... And she was sick pretty much from the time I was 13 to 19... He went through my mom’s illness day-in and day-out... When he found out about the [*BRCA*] gene, every time I talked with him, he was like, ‘Did you get tested? Did you call the doctor? You really can’t drop the ball on this.’ So he was pushing. When it came back positive, then he was like, ‘Okay, what are you going to do? When are you going to have surgery?’ He was pretty intense. He wasn’t going to rest until I dealt with the problem. (Lucy, 45)

For other women (3 of 8), positive social support emerged when a family member or friend was educated about cancer risk and risk-reducing interventions. This education could be informal or formal, as in the case of Marsha’s extremely unsupportive husband, who completely reversed his perspective after attending a genetic counseling session and was afterward able to support her decision to take preventive action. Initially focused on his desire for more children, his first reaction to Marsha’s positive *BRCA* test was, “I hope you’re not going to hack off a healthy organ just because of a test.” After an extended period of his blocking her attempts to think about preventive surgery she finally realized he needed to hear it from somebody else:

[The genetic counselor] laid everything out statistically for him, and that’s what my husband needed... I asked him all the questions...and he said ‘at the end of the day...the truth of it is, you’re not going to find the ovarian cancer until it’s late stage...you’ve got to have the oophorectomy.’ And I think that was what my husband needed to hear... [Afterward] it was a different ballgame. (Marsha, 41)

Gynecologic Surgery Group: Like women in the RRBSO group, comparison group women described the positive impacts of social support around their own health issues. Trish has dealt not only with a substantial risk of familial cancer but also with two heart attacks, and nevertheless continues to experience the positive support of her family. Her cousin keeps her motivated to protect her heart by managing her weight and exercising, and they bike together three times a week to keep each other accountable to these goals. The experiences of women in this group also reflected the role of education in producing the understanding that leads to social support. Trish regularly received both informational and emotional support from her sister – who has been in the medical field for 30 years – and her daughter – who is in nursing school.

Shared Decision-Making (SDM)

The issue of how surgical decision making is (or is not) shared with doctors emerged without prompting from many women's stories about navigating cancer risk and prevention. Specifically, women discussed the degree to which they perceived themselves as having been able to actively contribute to decision making about their preventive surgery; the degrees and types of information, support, and advice they received from doctors; the advantages some perceived specialists to offer over generalists; and how their surgical decisions were ultimately made. This information allowed us to identify two types of outcomes in each woman's RRBSO decision-making story: (1) the level of SDM achieved in their RRBSO decision process (categorized as positive SDM experiences, difficult SDM experiences, or complete lack of SDM) and (2) the psychological impact of their level of SDM on their overall experience of RRBSO.

RRBSO Group – Positive SDM—Positive SDM experiences were identified as those manifesting a balance of a doctor's guidance and a patient's preferences, leading the two parties to reach a joint, mutual decision. Both Kathryn and Megan were identified as at high risk for ovarian cancer by their OB/GYNs and presented with the option of RRBSO. Initially, they both expressed desire to undergo RRBSO, but both OB/GYNs asked them to consider waiting until they were completely sure they were done childbearing. Both were happy to have had this advice, and ended up having another child before moving ahead with the surgery. Megan's positive SDM experience was extended through the involvement of a surgical specialist, with whom she was extremely satisfied:

I think it was the right decision because Doctor Martin's an expert, and he knows my family history, did my mom's surgery, and I feel comfortable talking to him. My OB is a great baby doctor, but I felt more comfortable having an oncologist, a specialist, doing [my RRBSO]. (Megan, 41)

Marina's case illustrated a somewhat more complex situation in which a positive SDM experience was nonetheless achieved. When Marina suggested that she was an appropriate candidate for RRBSO, her OB/GYN objected: "Well usually we don't do that...if the organ's not diseased, why take it out? (Marina, 59)." She subsequently explained the logic of her high cancer risk, the limited hormonal effect RRBSO would have since she was already in menopause, and her strong preference to have her ovaries removed; they subsequently reached agreement to do the surgery. Despite the positive SDM outcome here, Marina's case

reveals a major potential barrier to both RRBSO and SDM: lack of clinician education about RRBSO. SDM was achieved here because the patient initiated a conversation, gathered all the relevant information herself, and presented it to an open-minded clinician, but had Marina been less proactive or her physician been less amenable to learning from a patient, the surgery that alleviated both Marina's objective risk and her cancer worry would not have been considered.

RRBSO Group – Difficult SDM—For other women, SDM was more difficult to achieve. In some cases, the challenge was in gathering enough information from their doctors to feel like they could make an informed decision about choosing RRBSO. Marsha described trying to get the information she needed:

[After I found out I was *BRCA* positive] I was so desperate to get [information] because it seemed like there was no real information. I called my gynecologist to set up an appointment, to go in and I was expecting a consultation with him...and he's like, "Well, yeah, you should have an oophorectomy." ...I remember walking out of there just going, now what? I feel like there's more... like I should be getting more information. I should have somebody else to ask about this stuff. (Marsha, 41)

In Lucy's case, difficulty achieving SDM was caused by the combination of her need for detailed information and her regular OB/GYN's unwillingness to engage with her ambivalence. Soon after she discovered she carried a *BRCA* mutation, Lucy realized that her regular OB/GYN was not equipped to answer detailed questions about RRBSO and its potential effects. A highly educated woman with other complicating health issues, Lucy obtained a referral from her genetic counselor to see a specialist OB/GYN more experienced with high-risk patients:

I was in his office for an hour...Which as you know, these days, never happens. And he explained everything to me, and answered all my questions, and did an incredibly thorough examination...And so at the end of his visit, I had decided I was going to have my ovaries and fallopian tubes removed. (Lucy, 45)

Unfortunately, her story did not end there. A breast cancer scare delayed action on her RRBSO decision, and by the time that situation was resolved, Lucy had begun to wonder whether she should (for both personal and professional reasons) delay her RRBSO. When she returned to her regular OB/GYN for routine care, Lucy first found herself having to apologize for having offended her by seeking out a specialist who could address her concerns about RRBSO, and later found herself dismissed because she was not ready to undergo RRBSO immediately. Lucy recalls the confrontational tone of the conversation in which her OB/GYN remarked:

I'm not really sure how to follow you up, because you're *BRCA2* positive, you're high-risk, but you won't have the surgery, and you basically won't do what we tell you to do.

Ultimately, Lucy returned to the specialist OB/GYN, who addressed her concerns at regular appointments every six months for several years until she was ready to have the surgery. She reflects on the positive impact of this transition: "With him it was less black-and-white, and

he was much more willing to work with me. And so he's the one I've been seeing ever since".

Lainie too experienced difficulty talking about RRBSO with her OB/GYN, who actively disagreed and dismissed her arguments, even though she was technically a candidate for the surgery. An active advocate for herself, Lainie switched to a female OB/GYN who was more willing to work with her. Reflecting on this decision after her surgery, she remarked, "It's the best thing, now looking back at it, that I ever did (Lainie, 59)." Both Lainie and Lucy ultimately achieved a SDM experience that allowed them to make a confident prevention choice, but in both cases this required finding a new clinician who was able to fill in the gaps left by the initial, difficult, provider-patient relationship.

RRBSO Group – Complete Lack of SDM—A third situation arose when women experienced a complete and final lack of SDM with their physician. Barberette (age 58) tried to advocate for her educated preferences but was not successful. She begged her OB/GYN to remove her ovaries on multiple occasions, but he refused, in spite of her family history of ovarian cancer, because "they were still healthy". When she was forced to undergo a hysterectomy for other health reasons, Barberette argued that she was already mostly through menopause and should have her ovaries removed at the same time, but her surgeon still refused. Ultimately, this failure of SDM resulted in Barberette being unable to undergo RRBSO, and she continues to struggle with fears of ovarian cancer today.

Gynecologic Surgery Group—In the case of the SDM superordinate theme, the results of our analysis were much simpler for women in the gynecologic surgery group than for those in the RRBSO group. The 8 women who chose RRBSO were healthy women making a decision about risk-reducing surgery, whereas the 4 comparison group women experienced urgent or painful health problems that gynecological surgery could rectify. In gynecologic surgery cases like that of Sue, who had heavy bleeding every month for a long period of time, or Trish, who suffered from fibroid tumors, these women did not struggle with SDM. Instead, their doctors diagnosed specific problems and recommended surgery to correct them, and women agreed to the treatment offered in order to be relieved of their illness. SDM experiences among RRBSO group women were far more complex and differentiated.

Discussion

The results of this study confirm findings from the pre-existing research on women who choose risk-reducing surgery to prevent ovarian cancer, offer new insights about three aspects of their psychosocial experiences, and suggest novel support interventions that could be valuable additions to the clinical care of these women. Consistent with previous studies, our results demonstrate that the decision to undergo RRBSO is driven by a high level of ovarian cancer worry, and that RRBSO generally alleviates that worry (Hallowell et al., 2012; Moldovan et al., 2015). These data also confirm that a subset of women who undergo RRBSO continue to experience ovarian cancer-related distress (Finch & Narod, 2011). Women considering RRBSO may find it helpful for clinicians to validate not only their desire to mitigate the ovarian cancer risk, but also their desire to find relief from the intense experience of cancer worry. Follow-up care also offers an opportunity for healthcare

providers to assess women's psychological states after RRBSO, identify the subset of women who continue to feel substantial cancer worry, and overtly address the need for other interventions to help them cope with these concerns.

Second, we articulate women's thoughts about longevity, and confirm two perspectives present in the literature (Hallowell et al., 2001; Jeffers et al., 2014). Some women feel obligated to undergo RRBSO to stay alive longer for their children and save them from the potentially traumatic experience of seeing their mother suffer through ovarian cancer. Although prior research has shown that a sense of family obligation motivates genetic testing (Etchegary et al., 2009), our study is only the second to document that it also extends to prophylactic surgery (Hallowell et al., 2001). We also identified a conscious priority on living for today (*carpe diem*). Previous work has shown that women at elevated risk find a greater appreciation for life (Jeffers et al., 2014), and we expand on this by showing that a newfound sense of *carpe diem* motivates behavior change. Because thinking about longevity is a significant part of the decision making process for cancer prevention, women may benefit from psychological support to help them identify and execute specific actions consistent with their life priorities.

Third, this study also identified a rarely studied dynamic that seems to have substantial impact on the experiences of some women considering RRBSO: strong feelings of attachment to one's ovaries. A previous study also showed that women attribute special meaning to their ovaries, as part of their identities regarding youth and womanhood (Howard et al., 2011). We found supporting evidence that women who link their ovaries to their sense of femininity struggle psychologically with losing this part of their physical selves, and might benefit from help in the form of short-term psychotherapy or support groups.

Our findings build on prior research demonstrating the importance of social support to the psychological health of women engaging in RRBSO decision making (Den Heijer et al., 2012; Moldovan et al., 2015;). Based on this study, we suggest that social support results from the ability of significant others to empathize with one's situation. When this understanding is not already present, deliberate educational efforts can produce it, thereby generating social support. Careful monitoring of women's social resources could identify significant others who could be offered educational interventions that may facilitate their ability to provide necessary support.

This study also offers a new perspective on shared decision making from stories about patient experiences. We confirm previous findings that SDM is often not achieved in provider-patient medical encounters due to a range of barriers (Joseph-Williams et al., 2014). We found that highly self-motivated women may be more likely to start and complete the decision-making process that can lead to RRBSO for cancer prevention. Many high-risk women eligible for RRBSO likely lack a physician who initiates conversation about the procedure or the education, as well as the resources or psychological orientation to discover the RRBSO option and initiate discussion of it themselves. To achieve the greatest impact on lowering ovarian cancer incidence in this high-risk population, health care providers must be educated about and comfortable discussing RRBSO, as well as able to initiate a positive

shared decision making process through which women may select and undergo the procedure.

Finally, our findings suggest that the experiences of women undergoing RRBSO are more psychologically challenging than those of women undergoing similar gynecologic surgeries to treat current, non-cancerous health problems. The psychosocial experiences of these two groups are different both in terms of the decision-making process that leads to surgery, and post-surgical coping and well-being. Given the similarity of the surgical interventions, the generalist OB/GYNs and gynecologic surgeons who have the closest contact with high-risk women may not think of the two groups as particularly distinct. From women's perspectives, however, these experiences are dramatically different. Women choosing RRBSO as a cancer prevention method may need more, or different, information or support from their healthcare providers, and may benefit from the involvement of a broader range of practitioners in their care.

The rigorous, in-depth understanding of women's experiences facilitated by IPA allows us to generate trustworthy insights about the psychosocial experiences of high-risk women considering RRBSO. In addition, our extended use of IPA to compare the experiences of the two groups of high-risk women sheds light on the heightened psychosocial challenges associated with a surgery that is explicitly motivated by a desire to prevent ovarian cancer. However, our sample was restricted to participants from the parent study, and therefore lacked diversity. The RRBSO group included mostly highly educated white women, compared to a majority Black gynecologic surgery group. Transferability to other contexts is limited; therefore our results may not be consistent with studies performed in other racial or ethnic populations of women undergoing RRBSO. A larger sample size including a greater variation in socioeconomic status and racial/ethnic background would allow for confirmation of the observed patterns.

Conclusions

This interpretative phenomenological analyses of women's experiences surrounding the RRBSO decision illuminates the unique challenges women face in the domains of psychological coping, social support, and shared decision making. Within the context of broader research on the predictors and effects of RRBSO among high-risk women, these psychosocial dynamics deserve ongoing attention. Prospective, mixed methods research with women considering and undergoing RRBSO would be the most powerful way to help build interventions that can support the high-risk women for whom RRBSO is recommended. These interventions might include some that will influence clinical interactions, such as educating healthcare providers about the full range of psychosocial experiences associated with RRBSO and use of decision aids to support SDM. Effective interventions should also take place in a broader range of settings, to provide women with expanded medical and social resources to help mitigate the challenges they face during the decision-making process and any negative psychosocial effects they encounter afterward. Continued efforts along these lines will ultimately make it possible for healthcare providers to successfully fulfill the national directives to address the psychosocial and quality-of-life implications of RRBSO.

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Table 1

Descriptive Characteristics (n=12)

Participant	Group	Age	Race	Marital status	Education	Severity of risk	BRCA tested? (result)
Lainie	1	59	White	Divorced	Some college	Severe	Yes (+)
Kathryn	1	42	White	Married	College graduate	Severe	Yes (+)
Megan	1	41	White	Married	Some college	Severe	Yes (+)
Marina	1	59	White	Married	Graduate degree	High	No
Barberette	1	58	White	Married	Some college	High	Yes (-)
Marsha	1	41	White	Married	Graduate degree	Severe	Yes (+)
Kaitlyn	1	36	White	Married	College graduate	Severe	Yes (+)
Lucy	1	45	White	Divorced	Graduate degree	Severe	Yes (+)
Teresa	2	48	Black	Widowed	High school graduate	High	No
Sue	2	56	White	Married	College graduate	High	No
Tamara	2	37	Black	Widowed	Some college	High	No
Trish	2	58	Black	Divorced	Some college	High	No

Note. Group 1 included women who have undergone RRBSO (Lainie, Kathryn, Megan, Marina) and women who have decided to undergo RRBSO but have not yet done so (Barberette, Lucy, Kaitlyn, Marsha). Group 2 is the comparison group, and included women who have undergone gynecologic surgery for a benign indication (heavy bleeding, uterine prolapse, fibroids, or infection). Barberette is classified in Group 1 because she chose to undergo RRBSO (our primary category of interest), but she is unlikely to be able to execute this decision because her other gynecologic surgery has already been completed (see text).

Table 2

Overview of themes

Superordinate Themes	Subordinate themes
Psychological facets of cancer risk	Intense cancer worry motivates active prevention
	Feeling attached to one's ovaries
	Perspectives on longevity
Social support	Negative social support
	Positive social support
Shared medical decision making (SDM)	Positive SDM
	Difficult SDM
	Complete lack of SDM