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Seeking Balance: Decision Support Needs of Women Without Cancer and a Deleterious *BRCA1* or *BRCA2* Mutation

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Abstract

Recommendations for women with a deleterious *BRCA1* or *BRCA2* gene mutation include complex medical approaches related to cancer risk reduction and detection. Current science has not yet fully elucidated decision support needs that women face when living with medical consequences associated with known hereditary cancer risk. The purpose of this study was to describe health communication and decision support needs in healthy women with *BRCA1/2* gene mutations. The original researchers completed an interpretive secondary qualitative data analysis of 23 phenomenological narratives collected between 2008 and 2010. The Ottawa Decision Support and Patient Centered Communication frameworks guided the study design and analysis. Women described a pattern wherein breast and ovarian cancer risk, health related recommendations and decisions, and personal values were prioritized over time based on life contexts. Knowing versus acting on cancer risk was not a static process but an ongoing balancing act of considering current and future personal and medical values, further compounded by the complexity of recommendations. Women shared stories of anticipatory, physical and psychosocial consequences of the decision making experience. The findings have potential to generate future research questions and guide intervention development. Importantly, findings indicate a need for ongoing, long-term, support from genetics professionals and decision support interventions, which challenges the current practice paradigm.

Keywords

Decision support; Hereditary breast and ovarian cancer syndrome; Patient centered care

Introduction

A woman with a deleterious gene mutation predisposing her to cancer, such as in *BRCA1* or *BRCA2*, and who does not have a personal diagnosis of cancer, has a 60–85 % risk of breast

cancer in her lifetime compared to a woman of average breast cancer risk who has approximately a 12 % lifetime risk. Additionally, while 1.4 % of American women will have an ovarian cancer diagnosis in their lifetime, 15–40 % of women with a deleterious *BRCA1* or *BRCA2* gene mutation will receive an ovarian cancer diagnosis (National Comprehensive Cancer Network (NCCN) 2013). Therefore, women living with hereditary breast and ovarian cancer syndrome (HBOC) live with cancer predisposition that is greater than the general population and subsequently live with increased cancer-related medical engagement.

Current national guidelines endorsed by both the National Society of Genetic Counselors (Berliner et al. 2013) and the NCCN (2013) recommend a multimodal approach to breast and ovarian cancer risk reduction and early detection that begins at a younger age, occurs more frequently, and utilizes increased modalities when compared to guidelines for woman at average cancer risk. These guidelines include surveillance, chemoprevention, surgery, and lifestyle changes that often occur concurrently (NCCN 2013). Importantly, findings indicate that following cancer prevention guidelines, specifically with ovarian cancer prevention can have survival benefits (Domcheck et al. 2006).

Moreover, this means that having risk information and acting on health recommendations in any capacity will lead to increased interaction and engagement with the health community over the course of a woman's life. As part of genetic counseling and medical follow-up, a health care provider will inform a woman of the multiple complex care options and will encourage the woman to make a decision about which action she will or will not take regarding her cancer risk (Riley et al. 2012). Table 1 summarizes these guidelines, the identified benefits of these guidelines, and subsequent decisions women face when considering HBOC health decisions.

Decision support interventions related to complex medical decision making aimed at managing risk associated with HBOC is perceived as positively related to decision quality outcomes (Crotser and Dickerson 2010a, b; Howard et al. 2009; Underhill and Dickerson 2011; Underhill et al. 2012). From both clinical experience and research findings, it is clear that women with HBOC can benefit from decision support, however, literature within this domain remains heavily focused on decision making intended for genetic testing. The cycle of complex decisions increases after a positive genetic testing result, even in the absence of a cancer diagnosis (NCCN 2013). Our knowledge must expand to meet these care needs after receipt of results indicating higher risk. The magnitude of patient impact related to HBOC is augmented further as genetic testing becomes an increasingly common component of standard breast and gynecological care, both in oncology and in generalist settings for high risk women. This paper will add to and expand on current literature regarding decision support and informational/communication needs of healthy women at high risk for HBOC.

Purpose

The purpose of this exploratory qualitative secondary analysis was to describe health communication and decision support needs in healthy women with deleterious *BRCA1* or *BRCA2* gene mutations. The specific aims of the analysis were to: 1) Describe the interaction between personal context and cancer risk decision supportive, informational, and

communication needs, 2) Understand experiences of women making health decisions related to HBOC risk, and 3) Identify practical support strategies to guide health related decisions described as important by women with HBOC syndrome. The long term objective of this research is to improve the experience of women living with hereditary cancer risk and to promote positive psychosocial and physical outcomes.

Approach

Study Rigor

We report findings from a secondary analysis of qualitative data collected within a hermeneutic, phenomenological framework. Four parent studies provided the data for this secondary analysis; the primary data analysis has been reported elsewhere (Crotser and Dickerson 2010a, b; Underhill and Dickerson 2011; Underhill et al. 2012). The overall aims of the initial studies were to describe the meaning and experience of living with HBOC risk. Each study had a specific focus which was, a) the experience with communicating genetics results and hereditary risk within a family (Crotser and Dickerson 2010a, b) the experience of managing HBOC risk through surveillance (Underhill and Dickerson 2011), and c) experiences living with HBOC risk and forming self-identity, determining self-care strategies, and receiving care through a high risk cancer program (Underhill et al. 2012). The initial interviews were open ended and unstructured, and asked the participant to share their story. In-depth, rich, descriptive interviews were completed and, due to the openness of the discussion, additional data was provided related to decisions and decision support needs which were outside of the scope of the initial studies.

For the current study, data quality was evaluated as recommended by Hinds et al. (1997) and our data demonstrated high quality suitability for secondary analysis. The investigators led both the original and the current analysis, and therefore defined data collection process and sampling techniques, provided full access to complete and accurate data, and displayed sensitivity to the context in which the original data was collected to maximize rigor in the present study.

Theoretical Framework

The Ottawa Decision Support Framework (Légaré et al. 2006; O'Connor et al. 1998; Stacey et al. 2011) and the Patient Centered Communication Framework (Epstein and Street 2007) guided the study design and aims. The original data analyses and results suggested further secondary analysis in order to understand decision support needs and how communication and information provision between a woman and her care providers influenced perceived decision needs. Key theoretical concepts that were not initially explored in the primary analyses, such as (a) the type of decision, (b) support and resource needs or utilization, (c) personal characteristics, values, and qualities, and (d) patient-provider communication needs and experiences, were identified and interpreted within the current analysis.

Within decision science literature the Ottawa Decision Support Framework (Légaré et al. 2006; O'Connor et al. 1998; Stacey et al. 2011) commonly guides research focused on the relationship between decision needs, preferences, intervention, and quality decision making. We focused on the decisional needs component of this framework to describe how to best

move forward with future research. Additionally, the Patient Centered Communication framework (Epstein and Street 2007) further augments what we know from decision support literature, highlighting the importance of patient-provider communication as part of the context in which decision support occurs. Patient centered communication is important to improve patient experiences with medical consultation and subsequently, patient reported health outcomes associated with decisions and health behaviors.

Participants

Recruitment methods and procedures have been previously reported (Crotser and Dickerson 2010a, b; Underhill and Dickerson 2011; Underhill et al. 2012). It is important to note that for this study recruitment occurred within two metropolitan areas of upstate New York with access to at-risk women (based on NCCN 2011 criteria) who either attended support groups, sought cancer genetic counseling services, or responded to recruitment from the community. Additionally, recruitment occurred through Facing Our Risk of Cancer Empowered (FORCE), a national organization to support families with HBOC, both online and in person at the annual conference. This secondary analysis included only participants without a personal history of cancer who had an identified deleterious *BRCA 1* or *BRCA2* gene mutation.

Procedures

All parent studies obtained Institutional Review Board (IRB) approval for data collection. Original consent documents included consent for secondary data analysis of de-identified data. Both investigators consulted their current IRB for approval prior to analysis and studies were exempt from further IRB review. Primary data was collected from May of 2008 through August of 2010 and the interview guides and methods for all studies are cited in previous publications (Crotser and Dickerson 2010a, b; Underhill and Dickerson 2011; Underhill et al. 2012).

Analysis

This analysis followed a directed content analysis approach (Hsieh and Shannon 2005), allowing for an iterative and exploratory process to uncover the meaning and lived experience within the data, focused on communication and decision support needs. Concepts from the Ottawa Decision Support framework and Patient Centered Communication framework were central to the analytical focus, however the authors remained open to new interpretations outside of these frameworks to allow for an in-depth understanding of the meaning and contextual influence on women's health communication, information, and decision-making needs. Once common themes were identified, the data was entered into NVIVO 9 qualitative data analysis software for the summary, collection of themes, and identification of exemplar quotations. Analysis included 23 transcribed interviews from 22 unique participants (Crotser and Dickerson 2010a, b; Underhill and Dickerson 2011; Underhill et al. 2012) and was completed by both authors both independently and as a team.

Results

Overview

Results depicted three distinct themes and one pattern that were present in each, in which cancer risk, health related recommendations and decisions, and personal values are incorporated into the process of living with HBOC risk over time. Decision support needs were not static, but women report continually seeking balance when considering current and future personal and medical decisions or needs. Table 2 connects the two theories that guided the study aims to the resulting themes and practical information that emerged within analysis.

Description of Participants

Sample demographics are summarized in Table 3, stratified by risk reduction or early detection decisions that were made. All participants were Caucasian and ages ranged from 19 to 65 years old, with a mean of 37.5 (9.8). Participants that met the inclusion criteria for this analysis were recruited from local community services ($n=3$), local cancer centers ($n=6$), and FORCE ($n=13$).

Theme 1: Planning for Risk Reduction and Detection

Incorporating Values: Weighing Personal and Medical Options—Personal and familial values and priorities were an important component of how medical information and options were interpreted. Women who do not want to have children or have already completed childbearing found risk reducing salpingo-oophorectomy (RRSO) an easier choice to make. Not having children or not yet reaching a place in life to start a family made the choice for RRSO more challenging because of the finality of risk-reducing surgery and the impact on future family planning. Participants sought balance between managing cancer risk and still having the ability to bear children.

[I was informed to].... just wait and have kids and then worry about it but it was highly recommended that I do it by the age of 40. So no pressures (laughing), in the next 7 years, make sure you have kids and get it all done in 7 years. (*Partnered woman with no children, early 30's, recently made decision for risk reducing mastectomy (RRM)*)

These women were seeking balance between desires for a family with desires to reduce cancer risk. Priorities for surgery versus surveillance changed over time based on this family planning and led to women wanting varying levels of support over time from health care providers that was based on a personal understanding of the woman's present values and goals.

Women considered personal concerns about side effects from surgery such as body image and sexuality changes or menopausal symptoms when considering surgical prevention. One woman contemplating RRSO shared her concerns:

I am just nervous that my body is going to completely change going through surgical menopause and if I am going to get fat (laugh) and I will lose sexual

interest. I am nervous so I will put that off until I have to do it... (*Married woman with children, late 30's*)

Body image perceptions also influenced RRM decision making. The same woman as above was contemplating RRSO and has already undergone RRM. She described her thought process when she was making this decision.

First of all, I hated my breasts. They were too big and I hated them. Even if I didn't have breast cancer, I might have gotten a reduction at some point. I didn't have a loving relationship with my breasts, but like I said, I have three young children and I did not want to go through what my mother went through. I didn't want to have chemo... Even though getting the double mastectomy was very difficult, the decision to have it done was easy.

Family experiences were important to how women processed the decisions to undergo risk reduction or early detection, as elaborated on in the original publications (Crotser and Dickerson 2010a, b; Underhill and Dickerson 2011; Underhill et al. 2012). We see this experience was not only important in defining the meaning of cancer risk for these women, but also how they approached and made decisions about how to manage cancer risk.

Knowing Versus Acting—How a woman confronts, values, interprets, and adapts to HBOC risk information changes over time, and reflects an evolution in life situation (marriage, childbearing status, employment). For example, a woman may undergo genetic testing and then not apply the knowledge gained until a later time, after genetic counseling and genetics follow up has ended, when it was perceived as more relevant or important.

I was very torn, torn between what I knew I needed to do what I didn't really want to do and what they were telling me...I was so ambivalent about how to handle it. Knowing what I needed to do and actually doing it are two different things... (*Married woman with children, late 40's, completed RRM*)

Knowing risk status is a different phenomenon than acting on risk status through behavior change. One 19-year-old single woman with no children described cancer risk information and genetic counseling as important for future health planning as her aunt had died of cancer months prior to her genetic testing. It was important to this young woman that she had knowledge now about future risk management options; however, she was not currently acting on this knowledge through surveillance or surgery. Instead, she was waiting until an older age when she felt the information would be pertinent and anticipating having to undergo cancer prevention behaviors.

...it will be helpful in the future but as of right now, there is not really that much I can do since I am only 19. It is not like I am going to go and have surgery within the next five or maybe even 10 years, it will be longer than that. It is helpful to know what to prepare myself for....

Personal factors that influenced this experience included both patient and provider factors, such as their family experience with cancer, experiences with screening and surveillance, trust in the provider's recommendations, and developmental changes. Certain participants described delaying genetic testing until after learning about their potential risk and sought

genetic testing when they were ready to start making decisions for surgical risk reduction. Though not all women acted immediately after learning of cancer risk, they did describe beginning to think about decision making and what choices they would make right after learning of cancer risk. Women who had young children had the additional need to balance where and when to have preventative surgery based not only on surgical outcome, but how it could best be fit into their life responsibilities. Having time to consider options, access to resources and other life priorities were influential when a woman was choosing the right place and time to seek surgical prevention.

Taking Time to Make Decisions—When asked to reflect on what advice the participant would give to another woman in a similar situation, a common response was that a woman should take time to make her decisions. Asking “what will I do with this information” is an important component of undergoing and interpreting genetic counseling and testing information. Women reflected upon the importance of waiting to act until you knew how you would live with genetic testing outcomes. Women who sought further opinions, often those who had been recruited through the FORCE organization, described taking up to 18 months to seek several opinions before finalizing their risk reduction decisions.

Making one cancer related health decision at a time was a recommendation from the women who participated. Though many women in this sample received risk reducing surgery and early detection simultaneously, focusing on one surgical decision at a time helped women to face recommendations and make informed health choices. Surveillance was discussed as a way to manage risk while making surgical decisions or waiting to be ready for surgery. This was not true for one of our oldest participants, who had undergone oophorectomy but felt comfortable with continuing breast surveillance.

Even when taking the time to understand the meaning of risk within each unique context, being faced with multiple health decisions remained a challenge. It was not only a challenge to understand personal cancer risk, but to be placed in a situation where it was important to truly understand oneself, your own needs and values, and make decisions that were not only currently important but had future impact. These decisions were dynamic and changed over time.

I mean now it has been a little over a year and I am getting really close to wanting to do breast surgery actually. I have not done a total 180 but I'm definitely going to do that surgery as well and probably before I do the ovarian surgery... I'm clearly in a completely, completely different place than I was in the beginning and I don't know, somebody just today, a friend of mine was asking me how I got to this place, like this is so different, how did you get here and I don't know, I mean I think one of the main things is just time... I think time and being, getting better informed, hearing other people's stories and seeing the results of some of the surgeries and getting more clear about the fact that you know like wow, why did I get the testing done in the first place, and that the whole point of getting the testing was to be able to if I have the gene was to be able to avoid getting cancer and this is the way I can avoid getting cancer then, that is it. (*Single woman with no children, late 30's, decided on RRM first, not scheduled yet.*)

In summary, planning for risk reduction and early detection is a process that develops over time. It is not a decision that is influenced only by a woman and her risk or health needs. The individual's family, children, and life stage influence what information about risk she needs and how priorities are established when planning to take action related to risk.

Theme 2: Interpreting Complex Information and Making Decisions

Complexity of Health Recommendations and Decisions—Making a decision to undergo surveillance or surgery cascaded into a process of subsequent complex decision making. For example, when undergoing RRM the procedure was described as “more than just getting your breast removed.” Women then had to take into account medical choices about reconstruction, including type of reconstruction, as well as logistical choices about geographic location of the surgeon, and how to fit recovery into their already busy lives. They described having to independently access and interpret resources and information associated with this decision. Describing the process of RRSO was perceived as easier than the RRM decision. Though it was a challenge for women, those who reported being ready to choose RRSO described that the decision was not difficult. RRM was described as a bigger and more complex decision.

It [RRM] is something I have to consider I think. I mean, I have to either be okay with surveillance or be okay with surgery. There is no third option and both of those options suck so I have to decide which one sucks less, which one I can live with and I haven't really decided yet. *(Single woman with no children, early 40's, completed hysterectomy and RRSO, in the process of decision making for RRM)*

Many opinions were voiced about types of mastectomy or reconstruction. One woman reported “I knew that I wanted nipple conservation” when discussing reconstruction and surgical planning. Another stated “I am just not clear, I don't want implants...”. Other women were not clear what procedure was best for them as an individual. As one participant stated,

We like this one better [health professional] and I was like, ‘tell me why you like it better like between the implant and the TRAM, tell me why medically that it wouldn't work for me’ or what in the recovery is or what the downside is, logically, not your opinion ... *(Married woman with children, late 20's, RRM scheduled)*

There were many different options for the best choice based on the perceptions of each woman, expanding on the theme that this is a complex and dynamic decision.

Similarly, with breast surveillance or ovarian surveillance, women described not only having to choose to undergo surveillance but then choose how to maintain the follow-up appointments and scheduling. One woman in her late 30's, who was married with children, described the frequency of health visits that have resulted from learning of her *BRCA2* gene mutation:

... the first one is CBE (clinical breast exam), 3 months later a mammogram, 3 months later a CBE, 3 months later an MRI (magnetic resonance imaging) and that would be my year, every year...*(made decision for hysterectomy with RRSO)*

Another participant, 49 years old and married with children, did not have knowledge of hereditary cancer risk prior to her sister being diagnosed with cancer, and discussed the magnitude of learning about her *BRCA2* gene mutation and the impact on her present and future life. She had been undergoing surveillance but at the time of the interview discussed her plans for RRM.

I could have the MRI's and that every 3 months but for the rest of my life and there is still no guarantee that they would catch it in time. When I heard that, I thought, I don't want to go through that for the rest of my life. I don't, I don't want to be waiting for test results all the time.

Support Resources and Access—Decision-making experience varied based on the resources women had access to in their local and virtual communities. For those women who only had one provider to consult, one clinic and had fewer options to consider, decision making was perceived as less complicated. This occurred in women being seen with a local community provider. Some of these women were satisfied with the initial information and counseling they received and sought little external advice for care. When the women received all of her hereditary cancer care at the same center she typically described satisfaction with her experience, denoting comprehensive risk information and understanding risk management options. These women were referred within their health system and had sought minimal external advice for care.

The women who were recruited from FORCE felt that the website was helpful for informational support, though some felt that the amount of information could be overwhelming at times. Women who were recruited from local health centers or within the community did not always have access to or know of support resources, such as FORCE. Though these women may have received support pamphlets or handouts, they did not necessarily access the resources provided. Some women who had multiple resources and communicated with many people about risk options described an overwhelming exposure to a large amount of information. One 38 year old woman who was recruited from the community and had not known about FORCE described the internet as a “horrible place to go” for information that “can provide a lot of information that you don't want to have”. She did not want to “search the internet” and found it overwhelming. She only accessed the Myriad genetics website for information, which was given to her when she had genetic testing. Two women who were not recruited from FORCE mentioned FORCE in their interviews. Both did not access the resource. One felt it was too much information and overwhelming and the other had not had time to access the website. One woman who was recruited from the community did not mention knowing about FORCE, though she was actively seeking resources.

There is still, I have gone on line a couple times and I just don't find much out there. I think there, I wish there were places more like groups or something about the *BRCA1/2* gene that you could talk to other people about it. Because I haven't been able to find anyone else who has had the surgery you know without having the cancer. *(50 year old woman married with children, has decided on RRM)*

Participants, regardless of where they were recruited from to participate in the study, wanted HBOC experts to provide information directly so that the woman could interpret the information based on her own personal values, but described this as a challenging process to navigate.

I mean that whole it is a personal decision thing. That is the thing that is most not helpful to me. It seems like an excuse to back off and not give information, that whole prophylactic mastectomy is a personal choice, well, okay fine, tell me what I need to know to make the choice... I think doctors think they are being helpful by not encouraging a woman to make a decision she might regret later. But it is not helpful; it is not helpful at all. It's that whole, you know let her be and she can make her own personal decision is not helpful, I really... whichever decision I make, I felt like I needed more help than I got. I am tired of being my own primary care physician. It's really stressful. And it is still not helpful when I read that statement that it is a personal choice. Well to me that seems like a write off. It sounds like a brush off, like we are not going to think about it... let her figure it out. *(Single woman with no children, early 40's; completed RRSO)*

Women wanted to make their own decision and sought direct and in-depth guidance about each decision that needed to be made. This was especially true for women who had access to information but not access to health resources within their community. They knew what support was needed to assist them in decision making by hearing the stories of others through FORCE or other support resources, but did not have access to the health care experts that they perceived as necessary to meet those needs. They also did not have access to peer support from others in a similar situation. They knew about cancer risk and what decisions they felt were important to make, whether that was risk reduction or detection, but a practical way to operationalize these decisions was not clear within their local resources.

Theme 3: Experiencing Consequences of Risk Related Health Decisions

Anticipatory Consequences—Decision making regarding HBOC risk led to emotional responses related to anxiety, worry, guilt, and regret. Women considered the multifactorial costs of decisions and what actions they would subsequently choose to take to reduce cancer risk. Factors important to this consideration include what risk meant to the individual woman, her family, or her future family. Several women felt that there was no easy answer and that the decision to act was not a choice, but a mandate to come either now or in the future.

There were costs associated with making decisions. These costs included financial costs, not only based on insurance coverage for procedures, but also taking time off of work and family obligations. Time costs were also evidenced. Surveillance required frequent time commitment at multiple intervals throughout the year. Surgery required time to consider options, have the procedure and then recover.

Just knowing that I was having surgery... It made me nervous. It was scary worrying about whether the anesthesia would be a problem for me, even though the chances are very low. The reason I did it was to be with my kids, but that worried me. Also, just knowing that I was going to wake up and [my breasts] were going to

be gone and what I was going to have to deal with for the following year. (*Married woman with children, late 30's, completed RRSO, now planning RRM*)

Some participants also felt positive about having preventive surgery. Two of the women not only hoped to reduce cancer risk, but looked forward to cessation of their menstrual cycle and eliminating premenstrual syndrome. If a woman was not satisfied with her breasts, having breast surgery and reconstruction was also viewed as a positive outcome of having surgical prevention. Yet some women read about the possible side effects of removal of the ovaries and that influenced their timing and order of surgical risk reduction.

I started thinking about a surgical menopause and freak out about that so I would do things like Google, I would Google surgical menopause and bad idea, don't do that. I would Google surgical menopause and the FORCE website came up and I clicked on it and immediately this page came up that was it was so awful, it was like a list of all the awful things that can happen, you know like memory loss, loss of libido, dryness you know just like all this awful, awful list, I said, Okay, that is enough of that...(Single woman without children, late 30's, planning RRM; originally thought she would have RRSO but has changed mind.)

Physical and Psychosocial Consequences—Side effects were evident with both surveillance and surgery. For the women who had undergone prophylactic surgery, most stated that the side effects were tolerable within the context of perceived cancer risk and worry. For women who had made the decision to undergo surgery but had not yet acted, it was expected that these side effects would occur but they were perceived as minimal compared to potential cancer risks. However, surgery did lead to physical side effects of pain, changes in body image, menopausal symptoms, as well as the effects of surgical recovery. Women would preface their discussion with statements about how they “had no choice” but to undergo surgery, but then would talk about how they hadn't anticipated the severity of the physical side effects. One woman even reflected that if she had known ahead of time that her surgical menopause symptoms would be so severe she may have considered other options or at least discussed it more with her provider. She did not feel empowered to care for herself or able to reduce her symptoms and was waiting for her next scheduled doctor's appointment to seek help.

Sometimes, I am not [satisfied], because it is so bad, I think, why did I even do this, but at the same time, it was something I had to, I just didn't know how bad it was going to be. People are like, your scars are healing; but you're not healing. You don't have the estrogen in you like you are supposed to and that accounts for a lot of it...Mood swings and the physical changes (*Single woman with children, early 40's, completed RRSO, not planning to have RRM*).

Surveillance also had side effects associated with multiple interactions with health care providers and time spent at health appointments. Women weighed the experiences of having fear of cancer versus the surgical or surveillance experience.

It's very stressful, extremely stressful. I can't even explain it. Every time I go into the cancer center for a mammogram or a sonogram I'm stressed out the week before I go. Then when I do get in there it's never easy because my breasts are

very, very dense, they're very, very lumpy. They can never get a good reading, so it's never an easy appointment (*Married woman with children, late 30's*).

Pattern- Seeking Balance: Weighing Cancer Risk Decisions with Personal Values Over Time

Throughout each theme we found that these decisions occurred over time and were a dynamic process of balancing personal and medical factors. Women are faced with complex decisions that are interpreted as important within the present life context and in anticipation of future need. Women seek information that varies based on what she needs at that specific time and what phase of the decision making process she is in at present. The time in which women perceived needing support did not always coincide with the time of genetic counseling or testing. Support needs depend on where the woman is within the decision making process, from contemplating what to do with genetic information, planning an action, or experiencing the consequence of a decision.

Discussion

Communication Needs

Participants in this study described a need for follow-up interactions and decision support over time or over the long term. Having data to support both how women approached planning for making health decisions and how they reflect back on the process of making health decisions allowed us to get a rich description of decision needs from multiple perspectives. Study participants were faced with uncertainty about their risk management and, similar to other study results, learning the results of BRCA testing can be emotionally charged. This uncertainty demands that HCP's remain sensitive to individual developmental concerns, such as forming life-long relationships and understanding how the individual's life path has unfolded (Hamilton and Hurley 2010), and information needs for applying genetic testing results. Several participants desired interactions with knowledgeable health professionals which utilized principles of shared decision making that extended well beyond the genetic testing period. This is significant for genetic counselors as in current practice most engage in limited follow-up with patients after the genetic testing period, though patients still require genetics expertise to guide their care. It is critical that health professionals establish rapport and a trusting relationship with the patient and the patient's support person(s) for quality decision-making to occur (Epstein and Street 2007). Establishing trust takes time and requires the provider to possess technical knowledge, knowledge of the latest recommendations for BRCA risk management, and quality relationship skills. While this is essential and known within all aspects of healthcare, it is clear that these women do not perceive that their needs are met.

Decision needs are complex and are influenced by individual factors such as (a) personality traits, (b) individual and family experiences in health care, (c) interpersonal factors such as interactions with health professionals and (d) the impact of health decisions on the family (Hoskins et al. 2012). In previous qualitative studies, women described a perceived need for health care professional support and that this support empowers women by giving them

knowledge to make informed choices and ultimately to provide hope for a future without cancer (Dagan and Goldblatt 2009; McAllister et al. 2010; McQuirter et al. 2010).

Support Needs

Understanding the patient's perspective, the patient's life context and the patient's desired involvement in decision-making is essential. Although making a decision for risk reducing surgery is a personal decision, women require varying levels of support in making this decision and health professionals did not always accurately determine the patient's desired support needs.

Moreau et al. (2012) also noted that knowledge transfer for health decision-making is interactive and includes the expertise of the provider and the patient's lay "expertise". This mutually shared expertise includes knowledge of the patient's body and who they are as a person. Other researchers have noted that the desires of patients are often different than what is perceived by health professionals. In a quantitative study of 181 women, Ozanne et al. (2010) also speak to the importance of the physician or HCP being intentional about asking preferences of patients when the patient is making health decisions. Flexibility in communication between the health care professional and patient is essential, based on the patient's preference for their role in the decision making process, therefore decision aids should include the patient's preference for involvement in the decision-making process.

As noted in the themes emerging from this analysis, experiences making health decisions for individuals with HBOC are complex and dynamic. Values, family experiences, and the current context of a woman's life all contribute to the complexity of decision making for surveillance, surgery, or medications to reduce risk. Additionally, the choices in medical procedures add to the complexity, such as reconstruction choices (the type of breast implant, nipple preservation, or no reconstruction), and choices for ovarian cancer risk reduction (hysterectomy versus salpingo-oophorectomy versus medication, etc.). This is congruent with the findings of other qualitative researchers (McQuirter et al. 2010). Health professionals supporting women with HBOC can help individuals understand their own values in order to support health decision making.

Health coaching, or assistance with approaching decisions and seeking information, might improve follow up care for women with HBOC. Important components of health coaching include provision of information on options, risks and benefits of options with the addition of values clarification, and reviewing progress in decision making. A recent systematic review of 10 RCT's (Stacey et al. 2011) concluded that individuals who received a coaching intervention were more satisfied with their decisions, exhibited improved knowledge and increased participation in decision-making. Interventions that help with processing this personal information could improve experiences living with HBOC risk.

Women in this study felt that their peers did not understand their decisions and were not always supportive, similar to findings from Hamilton and Hurley (2010). Young women are faced with decisions that others their age do not face and often feel rushed to complete marriage and childbearing plans. Some women in this study desired support groups, however many were not able to find a support group specifically for women with HBOC and

no diagnosis of cancer. Several mediums for supportive interventions within oncology have been developed through telephone (Graves et al. 2010), computer (Schwartz et al. 2009), and internet (Culver et al. 2011). Graves et al. (2010) noted that women who received a telephone support intervention had decreased depression and anxiety 6 months after receipt of positive genetic test results compared to women randomized to usual care. Although this was a small study, it demonstrates the importance of continued decisional support for women with deleterious BRCA mutations as they make complex decisions to manage their risk and navigate the healthcare system. Additionally, Kurian et al. (2012) developed a model to help guide decisions, acting as informational support through an interactive web-based modality.

Practical Advice

Study participants recommended taking time to make health decisions and making one decision at a time. These decisions evolve over time as women fit their risk management health behavior into their life as it unfolds. This finding is also supported by a study of women with BRCA mutations (Howard et al. 2010). Decision-making in women with HBOC risk and no diagnosis of cancer is usually not urgent. Women can be encouraged to take time to process the information and complex choices they face and make decisions based on their individual needs and context (Landsbergen et al. 2010). Though clinically the urgency of decisions is clear, our findings support that the personal feeling of urgency to make decisions is reflective of contextual factors (family, work, life phase) outside of genetic information.

Theoretical Connection

Results from this study further highlight the impact of understanding decisional needs and the individual's values within the framework of quality decision making, which are key components of the Ottawa Decision Support Framework. Importantly, it was evident that these needs and values must be assessed, clarified, and managed at more than one point in time. Women in this study did not and could not express their needs at the initial time of genetic counseling. Their needs changed and developed over time within their personal, family, and social context. Additionally, information access and interpretation developed over time. Though it was understood that risk reduction or detection personally affected their lives, they did not always want to make the decision "personally". They sought shared decision making and an expert partner to guide them with the medical information they faced.

The key functions of communication with health professionals expressed by women in this study were managing uncertainty, exchanging information and making decisions. Women sought expert care to help interpret information and guide their decision making process. Women desired to know the benefits and limitations of each option for surveillance or risk reduction and then time to process and integrate this information into their personal beliefs, values and experiences to make a personal risk management choice. Women's desired level of participation in decision making varied supporting the need for clarifying the patient's needs once a trusting relationship is established.

Limitations

All participants in this sample were Caucasian and these findings cannot be directly generalized to other races or ethnicities. Additionally, data is from two geographic locations within one state and with volunteers who participate in FORCE, therefore results may vary within other sites. The results may be limited by including participants from FORCE as they are actively seeking online resources, however we have also included women who do not utilize the FORCE resource within our analysis and have represented their stories within the findings. Results from this study are also limited to HBOC syndrome and cannot be applied to other hereditary cancer syndrome experiences. Due to the nature of the secondary data analysis study design, member checking and validation of findings was not possible. The scope of results was limited based on what participants reported in the initial study and further probing of themes was not possible.

Future Research & Practice Implications

Research Recommendations

Personalized medicine within the realm of cancer predisposition is constantly changing and being developed, therefore, health professionals must assure that clinical interventions are structured in a way to incorporate these changes effectively. From the decision making literature, we know that decision support interventions can improve decision making quality and knowledge for persons who are trying to choose between multiple health options (Légaré et al. 2006; O'Connor et al. 1998; Stacey et al. 2011). Decision making aides have been developed to help support women at high risk for hereditary breast and ovarian cancer (Culver et al. 2011; Hooker et al. 2011; Kurian et al. 2012; Metcalfe et al. 2007; Schwartz et al. 2009; Van Roosmalen et al. 2004), making genetic testing decisions or for those with cancer making surgical decisions. Our study adds to this literature by exposing the context in which decision making occurs. Women in our study demonstrate that the time of genetic counseling or testing may not be the most useful time to aide in the decision making process. This process changes over time, and therefore it may be some time before healthy women not currently living with a cancer diagnosis need to access, utilize, and apply information from a decision aid. van Dijk et al. (2008) discuss how women, a majority with a history of cancer, make decisions about RRM. In this study it was found that women often knew their RRM preferences up front. Our study reveals that this is not the experience of all women and offers more detailed information from women who do not have a cancer diagnosis about how their values and needs may change over time.

This study emphasized the ever changing, temporal nature of decision support needs experienced by these women. Therefore, interventions created to aid persons with HBOC risk should also be dynamic, customizable and iterative to allow for continued improvement, updates, and specifications as both patient preferences and the scientific body of evidence change. Currently, there are minimal resources that have been tested and substantiated as effective that meet the aforementioned criteria.

Practice Considerations

The results from this group of participants indicate that health professionals have a continued role in decision support of women with HBOC long after receipt of genetic testing results. This challenges the current paradigm of genetic counseling which typically occurs at one time point. Instead of providing all of the complex medical information required of a typical genetic counseling session in one sitting, participants in this study sought more long term comprehensive care that evolved as their specific needs and experiences evolved. Though this sample all had deleterious BRCA1 or BRCA2 gene mutations, this may true also be true for those women who do not have genetic testing but have known familial risk.

Health professionals can improve interactions with women at high risk for HBOC by discerning what the patient knows about their risk, what decisions are important to them in the moment and how the woman wants to be involved in the decision making process. Values clarification is an important component of the decision making process for women who are uncertain about what action to take to manage risk. Questions such as what their breasts mean to them, how important it is to maintain childbearing ability, and what surveillance means to them are a starting place to determine values.

It is important for clinicians to understand that these values and decisions are not static; therefore, health care follow up and support should provide long term interaction. McCullum et al. (2007) demonstrated through case studies the diverse and complex nature of making decisions about RRM and concluded that decision support is needed over time. The data for our current study was collected in 2008 and the women still reported this need, and our data provides further evidence to support a need for a changing practice structure that lends itself to long term care for women with deleterious BRCA mutations.

While the current model of genetic counseling does include providing support and referring patients to available resources at the time of counseling and testing as an essential component (Berliner et al. 2013), a greater emphasis needs to be placed on confirming that patients have access to the follow up support that they need at the time they need guidance. This research provides further emphasis that follow-up, long-term care is needed to fully support women living with risk. Through interdisciplinary collaboration, the standard of care can be improved to not only provide patients with information at the point of care, but also long after, when they are seeking decision making guidance.

Discussions at this phase of risk management also need to provide information about the risks and benefits of all surgical options as women may be able to name procedures but don't understand the intricacies of the procedure. Even after surgical risk reduction, continued support is needed to manage side effects. Health professionals must be intentional about assessing a woman's experience because women sometimes feel there is nothing that can be done to manage side effects due to their high risk status. Some women were not aware of support available for women with HBOC. Although women might receive this information when they get their genetic testing results, this information is often tucked away and forgotten.

Without reinforcement and follow-up, women may not access all of the support resources available to them or may not fully understand where to seek those resources. Previous research has described the needs of women post RRSPO, related to sexual health (Brotto et al. 2012) and informational needs (Bonadies et al. 2011). However, our study adds to this literature and reinforces that informational support is not enough; women also seek experts to follow-up with and support them over time to guide the application and usage of cancer prevention and early detection recommendations.

Conclusion

Women in this study identified multiple decisions to be made when living with and acting upon hereditary breast and ovarian cancer risk. These decisions were more than just having surgery or surveillance and included complex factors related to the person, family, procedure, and health care system. Emotional and physical consequences of these decisions, both actual and potential, were important to the decision making process and require ongoing, long-term support and assessment by health care professionals.

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Table 1Summary of HBOC health recommendations^a

	Clinical decisions (NCCN 2013)	Evidence	Additional patient considerations
Risk reduction surgery	RRM	Up to 90 % reduction in breast cancer risk	• Reconstruction considerations
	RRSO	Up to 50 % reduction in breast cancer risk & 85 % risk reduction in ovarian cancer	• Family planning • Hormone replacement therapy for side effects
Chemoprevention	Tamoxifen	Potential for up to a 62 % breast cancer risk reduction, mainly with <i>BRCA2</i> mutation	• Family planning • Side effects
	Oral contraceptives	Potential for up to a 50 % risk reduction for ovarian cancer	• Family planning
Surveillance	<ul style="list-style-type: none"> • Breast awareness • Clinical breast exam • Mammogram & MRI annually • Trans-vaginal ultrasound • CA-125 	Early breast cancer detection and treatment Limited evidence	<ul style="list-style-type: none"> • Potential for false positive or false negative results • Consideration of weight of the evidence

^aBased on NCCN 2013 and Berliner et al. 2013

Table 2

Connection of theory to themes

Theory	Key constructs from theory	Connecting theme from data	Needs & preferences from data
Patient centered communication framework for cancer care	<ul style="list-style-type: none"> • Exchanging information • Making decisions • Enabling patient self-management • Managing uncertainty • Responding to emotions • Fostering healing relationships 	<ul style="list-style-type: none"> • Interpreting complex information and making decisions (Theme 2) • Experiencing consequences of risk related health decisions (Theme 3) 	<ul style="list-style-type: none"> • Support for obtaining, interpreting, and applying medical information • Clarification of options and risk • Support while living with anticipated and actual consequences • Support over time
Ottawa decision support framework	<ul style="list-style-type: none"> • Decisional needs • Decision support • Decision quality 	<ul style="list-style-type: none"> • Planning risk reduction and detection over time (Theme 1) • Experiencing Consequences of risk related health decisions (Theme 3) 	<ul style="list-style-type: none"> • Recognizing personal values and evaluating over time • Accessing support • Choosing type of medical decision based on personal factors • Seeking information and choosing when to act • Living with impact or consequences

(Epstein and Street 2007; O'Connor et al. 1998)

Table 3

Participant demographics stratified by risk reduction or early detection decisions

<i>a</i> Total N=22	RRM n=4	RRSO n=9	Breast surv. n=18	Ovarian surv. n=12	RR decisions in process n=9	Total n (%)
Age						
< or = 25	0	0	2	2	0	2 (9.1)
26–35	0	2	6	4	2	6 (27.3)
36–45	3	6	8	5	5	11 (50.0)
> or = 46	1	1	2	1	2	3 (13.6)
Marital status						
Married/Partnered	4	7	12	8	7	16 (72.7)
Single	0	2	6	4	2	6 (27.3)
Has children						
Yes	3	5	11	8	7	14 (63.6)
No	1	4	7	4	2	8 (36.4)
Highest level of education						
< than High school	0	0	1	1	0	1 (4.5)
High school	0	0	3	3	2	3 (13.6)
Some college	2	3	4	3	2	6 (27.3)
College graduate	1	0	2	2	1	3 (13.6)
Graduate school	1	6	8	3	4	9 (40.9)

a Surv. surveillance; RR risk reducing; RRM risk reducing mastectomy; RRSO risk reducing salpingo-oophorectomy; 2 participants had completed both RRM and RRSO; 11 participants were undergoing both breast and ovarian surveillance