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Life trajectories, genetic testing, and risk reduction decisions in 18–39 year old women at risk for hereditary breast and ovarian cancer

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Abstract

This qualitative study identified four life trajectories that influenced the decision in young women to have genetic testing for mutations in *BRCA1/2* and subsequent risk reduction decisions after receiving a positive mutation result. Fifty nine women between the ages of 18–39 years were interviewed in this grounded theory study, 44 of those tested were found to have a mutation in either *BRCA*1 or *BRCA*2. Of those with a mutation, 23 had no history of cancer and 21 had a breast cancer diagnosis. Analysis of the 44 participants tested found that risk reducing decisions were related to the life trajectories that preceded genetic testing. These life trajectories included: 1) Long-standing awareness of breast cancer in the family, 2) Loss of one's mother to breast cancer at a young age, 3) Expression of concern by a health care provider, and 4) Personal diagnosis of breast cancer. Understanding possible influences behind decision making for genetic testing and risk reduction in young women may assist health care providers in offering age appropriate guidance and support.

Keywords

BRCA1/2 mutation testing; young women; decision making; breast cancer; oncology; genetic counseling

INTRODUCTION

Young women (18–39 years) who are at risk for hereditary breast and ovarian cancer (HBOC) and who have a *BRCA1* and/or *BRCA2* mutation face a high risk of developing cancer before age 50 and a 50% chance of transmitting that risk to each offspring. These young women do

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not fit the typical profile of women at risk for or affected with breast cancer which most frequently occurs between the ages of 62 and 79 (SEER: Surveillance, 2005). Subsequent to discovering a personal high risk for hereditary breast and ovarian cancer (HBOC) women 39 years of age or younger deal with a cascade of decisions for which they may have little preparation.

BACKGROUND

Young Adulthood

Young adulthood is defined by Erikson (1963) to be between the ages of 18 and 40 years. Challenges across young adulthood are seeking independence from parents, establishing gender identity, internalizing moral values, and examining career choices. Young adults are typically exploring intimate relationships, while making childbearing, work, and lifestyle decisions (Newman and Newman, 2006).

Several sociological, anthropological and psychological studies (Arnett, 1994, 1997, 1998, 2000; Perry, 1970/1999; Schlegel and Barry III, 1991) suggest that role transitions such as marriage, finishing education, beginning full-time employment and becoming a parent are the important transition points into adulthood. The characteristics that have been consistently reported by young Americans as criteria for transition to adulthood are characteristics of individualism such as: accepting responsibility for oneself, making independent decisions, financial independence and establishing a relationship with parents as an equal adult (Arnett, 1997, 1998, 2000, 2001). This emphasis on individualism matches the American culture where independence and self-sufficiency are highly valued (Arnett, 1998; Triandis, 1995). Young adult women who are at risk for HBOC experience an overlay of genetic risk on these already significant life events.

A particularly useful model to consider when associating individuals' developmental stages with their risk for HBOC is the Family Systems Genetic Illness (FSGI) Model (Rolland and Williams, 2005). This model is an adaptation of Rolland's earlier Family Systems Illness (FSI) Model (Rolland, 1988, 1990, 1994, 2003) and incorporates the growing knowledge of the importance of genetics in disease risk, manifestation, prediction of disease and diagnosis. The typology of this model offers a way to consider the psychosocial demands of different kinds of genetic illnesses. By emphasizing the interaction of both symptomatic and non-symptomatic phases of a genetic illness this model highlights the nature of genetic conditions and the uncertainty often present. The timeline of the FSGI model begins at the time of awareness of a possible genetic risk and moves through the pre-test, post-test and long-term adaptation stages. For our purpose, the incorporation in the typology of timing of clinical onset of the illness is important as it situates the experience within a given span of years and permits the exploration of the consequences of a genetic illness in the young to middle adult ages. Variability may exist for people at risk for HBOC regarding their likelihood of developing the condition, timing of clinical onset, and treatment options. Breast and/or ovarian cancer are serious conditions for which life long surveillance and/or treatment are needed, and they may result in a shortened lifespan. After predictive testing, young women at risk for HBOC are in their young adult years, and also in the post test stage for a serious condition with variable illness patterning in terms of onset, course, outcome and severity (Rolland and Williams, 2005)

One's age may significantly affect decision making about risk reduction strategies. The youngest of these women, aged 18–24, may have little decision making experience to draw upon and may be unsettled by worry about which decision is right (Newman and Newman, 2006). Women who are 25–39 may find themselves facing decisions about risk reduction

options that reflect their attempts to balance and integrate multiple emerging roles in educational/vocational, relationship and social areas of life

Breast and ovarian cancer in young women—While breast and ovarian cancer are generally considered diseases of postmenopausal women, younger women can also develop breast and/or ovarian cancer. Breast cancer incidence rates per 100,000 are 1.3 for women between 20 and 24; 7.7 for women between 25 and 29; 25.6 for women between 30–34; and 58.9 for women between 35 and 39 (Ries et al., 2008). Ovarian cancer incidence rates in young women are lower, ranging from 1.84 (ages 20–24) to 5.54 (ages 35–39) (SEER: Surveillance, 2005). More than 250,000 women under age 40 in the U.S. are currently living with breast cancer, and 11,100 young women will be diagnosed this year. Young women with a *BRCA* mutation face a significantly increased risk for breast cancer.

BRCA mutations

Of the 184,450 new cases of breast cancer expected in the United States in 2008, approximately 5–10% will be associated with a germline mutation in a cancer susceptibility gene (Jemal et al., 2008). *BRCA1* and *BRCA2* account for more than 50% of hereditary breast cancer due to a mutation in one of these highly penetrant susceptibility genes (Miki et al., 1994; Tavtigian and ent., 1996; Wooster et al., 1995).

Cancer risks associated with mutations in *BRCA1* and *BRCA2* include a lifetime risk of female breast cancer approaching 50–85% by the age of 80, with much of that risk occurring before age 50, when traditional screening modalities like mammograms are the least sensitive (Barcenas et al., 2006; Easton et al, 1995; Ford et al., 1998). Mutation carriers also face risks for non-breast cancers most remarkably ovarian cancer, a disease in which screening and early detection remain elusive. Lifetime ovarian cancer risks vary by the gene, approximately 20–40% in *BRCA1* mutations carriers and 10–20% in *BRCA2* (Barcenas et al., 2006; Easton et al., 1995; Ford et al., 1998).

Cancer risk management of *BRCA1* or *BRCA2* mutation carriers is complex and includes options for risk reducing surgery, intensified cancer screening and/or surveillance, chemoprevention and risk avoidance (Berliner and Fay, 2007; Burke et al.,1997; Eisen et al., 2005; Madalinska et al., 2007; Rebbeck et al., 2004). Even in the presence of accumulating evidence regarding the efficacy of each strategy, the management of cancer risk in these women is complicated by life planning issues such as making intimate relationships, childbearing, career, and lifestyle decisions typically faced during emerging and young adulthood developmental stages. For example, while tamoxifen may be used to reduce the risk of development of breast cancer in this population it also can significantly alter a woman's reproductive timeline (Metcalf et al., 2005).

Challenges for health care providers

As primary health care providers become increasingly educated about presymptomatic genetic testing it is possible that more young women will obtain genetic testing and face the difficult decisions that arise after receiving a deleterious mutation result. Little is known regarding young women and their experiences of genetic testing as well as decision making concerning follow-up health care. This age group of HBOC at-risk women is seeking independence at the same time that they need expert guidance. One factor to be considered by health care professionals is the life trajectory women have experienced relative to breast cancer and/or ovarian cancer. Given these considerations, the purpose of the present study was to explore the influences on decision making for this population.

METHODS

Grounded Theory Method

This study used a grounded theory design to describe the decisional processes of young women with increased risk for HBOC. The primary reason grounded theory was chosen was the desire to explore in detail and from their perspective what influences young women who receive a positive *BRCA* mutation test result. Grounded theory is a method that is both systematic and rigorous and allows the participant to be the expert in describing the experience. The participants in this study actively constructed the meaning (MacDonald and Schreiber, 2001) of being *BRCA* positive and in doing so gave light to the processes and consequences of this action.

From a grounded theory standpoint, action is meaningful, and individuals work out the meaning of an experience through action. Within this statement lie both the pragmatist background and theoretical underpinning of grounded theory. Grounded theory is theoretically based in symbolic interactionism (Bryant and Charmaz, 2007; Glaser and Strauss, 1967; Strauss and Corbin, 1998). Symbolic interactionism (SI) is a sociological perspective based on the works of Cooley and colleagues (Crooks, 2001). While the limited space of this article does not permit a full explication of the SI theory, it is important to note that SI is a theory that explores the intersection of interaction, biography and social structure in a given context (Crooks, 2001; Denzin, 1992). A tenet of SI and thus grounded theory is that individuals construct a personal biography through observation of others, life experiences, self reflection and interactions with others and their culture (Blumer, 1969; Crooks, 2001).

A secondary reason for choosing grounded theory is that it is often used to explore topics or phenomena where there is inadequate or no coherent theory to guide research or practice (Bowers, 1989; Caron and Bowers, 2001; Strauss, 1987). Very little has been published on the experience of young women who are *BRCA* positive. Grounded theory as an agile method can respond to the empirical leads generated during data collection and analysis. Grounded theory is designed to explore how people understand their situation, how they experience (define) reality and how those understandings are related to action (Glaser and Strauss, 1967; Strauss and Corbin, 1998). In this study it is the participants' understandings of risk, and of the other important decisions in their lives, that come together, and how this is related to their actions (risk reduction). Their understandings have significant consequences for their lives and decisions. Using grounded theory allows the complexities of genetic testing within the context of emerging and young adulthood developmental stages to be concurrently explored.

Participants

Recruitment—Participants in this study were recruited from two Internet sites specific to young women with *BRCA* mutations and/or breast cancer: FORCE (Facing Our Risk of Cancer Empowered at www.facingourrisk.org) and Young Survival.org. Demographic characteristics such as age, race, and income of the population that uses the Internet increasingly reflects the general population (Hamilton and Bowers, 2006; PEW, 2006, 2007). Inclusion criteria were: female, ages 18–39, history of genetic testing for a *BRCA* mutation and having received test results. Fifty nine individuals responded to the recruitment announcement and were interviewed. This report is only on the women who tested positive (44 of the 59) for a *BRCA* mutation. Women were from 22 states in the United States (41) and from Canada (3). This study was approved by the Institutional Review Board at the University of Pittsburgh. Participants were compensated $20.

Procedures

The geographic diversity required adaptation in interviewing. To maximize participation, women were given the choice of phone or email interviews (Hamilton and Bowers, 2006) (Beck, 2005)(Meho, 2006). Email interviews (n=33) consisted of sending 3–4 questions for 4–5 cycles of emails to the participant. Phone interviews (n=11) typically took up to 90 minutes to complete and were scheduled at the participant's convenience. Phone interviews were transcribed verbatim. All interviews were conducted by the first author an experienced grounded theory researcher.

Consistent with the grounded theory method, open-ended questions were used at the beginning of the interview. If the interviews were conduced by email, the initial responses were analyzed before generating the next set of questions and by the third or fourth set of questions the interview questions had moved toward what influenced decision making relative to risk. In a phone interview, the questions were guided as the interview proceeded to capture what influences and timing were involved in decision making concerning risk management. The initial questions in the phone interviews, as with the email interviews, were broad becoming increasingly focused as the interview progressed. The number of question asked in a phone interview depended on the participant's ability to tell her story; if she needed more prompting more questions were asked. Analysis and evolution of interview questions occurred over time as data was analyzed across interviews as email answers were received and transcribed phone interviews were available. This allowed data analysis to occur across interviews throughout the data collection phase of the study. All participants in this study agreed to be re-contacted for clarification if the need arose.

Data analysis

The data from the interviews were analyzed following procedures described by Strauss and Corbin(1998)and Charmaz (2006). The interviews were entered into the NVivo computer program (Scolari, Inc.) for data management. While Charmaz (2006) and Strauss and Corbin (1998) use slightly different terms for describing coding, the technique is basically the same. The initial questions in the interviews are non-directive, allowing the participants to define their experience in their own words. Analysis begins with open coding which is a way of "naming segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data" (Charmaz, 2006, p.43). This begins the process of analytic interpretation. The transition from open to axial coding occurred when areas of focus were identified, such as role of family history in perception of risk, whether or not the participant was in a committed relationship, and experiences with health care providers relative to her genetic risk. Interview questions were then re-crafted to facilitate in-depth exploration of focus areas. Axial coding techniques (in depth focused coding) were used at this point to link the dimensions to each other and to the context of situations (Clarke, 2005; Schatzman, 1991; Strauss, 1987) A process used throughout the coding and analysis is a constant comparison between data, codes and categories both within an interview and across interviews. This technique is rigorous and advances the conceptualization of the data.

Two other techniques used in grounded theory analysis are theoretical sampling and memo writing (Strauss and Corbin, 1998). Theoretical sampling is a means of data collection that refines and elaborates on developing categories (Charmaz, 2006). Based on what the women identified as the most significant conditions, theoretical sampling was used to explore how each of those conditions influenced their experiences. For example, depending on whether or not a woman had a breast cancer diagnosis the direction of the interview then diverged to capture their specific experiences. Important theoretical sampling decisions also followed the analysis. An example of this was recruiting women with children after the investigator heard statements regarding the significant influence reproductive choices had on risk reduction

choices. Other theoretical sampling related to stability of relationships and career choices. Memo writing is a crucial step in grounded theory data analysis as it forces the researcher to analyze data and the developing codes early in the research process which then can drive the theoretical sampling (Charmaz, 2006). Memoing is part of the disciplined process of coming to see the relationships among developing concepts in the analysis (Piantanida, et al., 2004). This process allows the researcher to bring a conceptual prospective to the participants' individual and situational experience which in turn directs the development of theory from the data (Piantanida et al., 2004).

The concept of trajectory is used in this article. Unlike the generic meaning of a path, the meaning of trajectory as used in a grounded theory study implies a process, not as an ordered series of stages, but rather changes or experiences over time in actions/interactions and in relationship with changes in conditions (Wiener, 2007). So while a health care provider may take a detailed family history of breast cancer/ovarian cancer this action may not capture the life trajectories as defined here. A pedigree denoting family history of cancer is a 2-dimensional iconic representation of risk; a life trajectory is a multi-dimensional description of the processes of knowing one's risk.

Grounded theory method is a theory generating research method. The goal is to build theory in an area, substantive or conceptual. The ultimate goal of grounded theory research is to build mid range theory but this is achieved only after multiple studies that can collectively provide a more general theory. In this study we are in the early stages of theory development, and present here a conceptual rendering of one of the aspects of what will eventually be a more general theory. A previously published nascent theory, Theory of Genetic Vulnerability (Hamilton and Bowers, 2007), describes the conditions and consequences of becoming aware of genetic risk for individuals at risk for HBOC or Huntington disease. Subsequent studies will be built around what is needed to achieve the development of a substantive grounded theory.

Results

Participant Demographics

Of the 44 participants who were found to have a mutation in either *BRCA*1 or *BRCA*2, 23 had no history of cancer and 21 had already received a breast cancer diagnosis. Twenty four had a *BRCA*1 mutation, 14 a *BRCA*2 mutation and one had both a *BRCA1* and *BRCA*2 mutation. Twelve participants were single, one was divorced, one was separated and the remaining 30 were married. All but one was Caucasian. (See Table 1)

Interview Process

Our experience has shown email interviews to be more succinct and reflective. Participants who wrote their answers via email sometimes also offered their own interpretation of their experiences. For example, one participant described how her genetic mutation status had become "normal" but then went on to describe how that had made it easier for her not to watch her diet, exercise etc. Phone interviews on the other hand tended to be much longer (for example, 60 pages double spaced vs. 15 for email interviews) and not as 'on-track'. However, that may have allowed the participants to guide the interview more than the researcher which also has some advantages when trying to gather the experience from the participant's perspective. From the researcher's perspective both formats resulted in detailed and rich data. It appeared the most important point in terms of format type from the participants' view was being given a choice that fit their schedules and life the best.

Life Trajectories

The analysis of the interviews resulted in identification of four life trajectories which influence the choices regarding genetic testing and subsequent risk reduction strategies:

1. Acutely Aware: Women with a long standing awareness of risk, often from family experiences with breast cancer.
2. Loss of Mother: Women whose mother had died at a young age from breast cancer.
3. Health Care Provider Concern: Women became aware of their risk following a medical history and an expression of concern from their health care provider.
4. Diagnosis of Breast Cancer: Women who received a premenopausal breast cancer diagnosis.

While we are presenting four discrete trajectories, the first two trajectories were actually somewhat fluid, that is participants' experiences may have placed them in both and if that were the case the data from their interviews were used in the development of both trajectories. We will present data that explicates each of these trajectories for both the experience of genetic testing and risk reduction decisions (Italicized text in the quotations presented are the interviewer's questions, and statements from phone interviews were abbreviated to remove phrases such as "um" or "you know").

Genetic testing and life trajectories

1) Acutely aware—Women who were acutely aware of their risk for breast cancer were generally receptive to having genetic testing done and often were very aggressive in seeking it.

> After the death of my aunt, I was very aware of our family history of breast cancer and the studies with "large university" that my mom participated in. Sometime at least a year before my eighteenth birthday, I remember my mom informed me that I could be tested with the university to find out if I too had the "breast cancer gene." I didn't know at the time that it was called *BRCA* or that it was also linked with ovarian cancer. I wanted to find out, so the summer after my eighteenth birthday, we arranged to have my blood tested. (19 year old woman)

Being acutely aware of one's family history was an important motivator for having *BRCA* genetic testing for study participants. They saw it as a way of finding out if they were a member of that particular family group or if they had escaped the risk for breast cancer. For the most part little equivocation over genetic testing occurred when this life trajectory was present. Family members sometimes advised the young woman to wait until certain life events had passed (finishing college, getting married), but few took that advice.

2) Loss of mother—Few life events have more lifelong impact than losing one's mother as a child or young woman. Because of the age of participants in this study, those who had lost a mother to breast cancer were generally children or adolescents at the time of her death. In this case the loss is compounded by a possibility of personal risk. In some instances the young woman herself did not want to be tested but felt pressure from family members, especially the father, to be tested at a young age.

> My mom died when I was 10, in fifth grade. She had been very sick for a good year before she died. I don't think that the risk hit me then; I think it hit me more once I had started to go through puberty. I would hear things in the news stressing that you were at higher risk with a family history. I knew that some of her cousins had also been diagnosed once I was a little older as well, so I just figured it was in my blood…. My dad had been pressuring me to have the test done for a couple years. I had always

> assumed that I would get BC eventually, but until I was 18, I wasn't really aware that I could get tested for the gene. At the time he told me about it, I was open to the idea, but didn't feel ready to get tested. I finally gave in to my father's pleading requests over Thanksgiving and made my appointment. (20 year old woman)

These young women have grown through the stage of emerging adulthood without a mother and with the knowledge that due to the cause of her death, they too may carry the same risk. Genetic testing for them was both something to be desired and to be feared. Participants who were a bit older, in their late 20's and 30's were more independent than our youngest participants in their decision to have genetic testing and saw it as a way to take control and not be like their mothers:

> I am the 6th one to my knowledge going back to my grandmother's generation. My mom died of breast cancer when she was 26 she was diagnosed when she was pregnant with me. (*What influenced your decision to have the test?*) Probably my drive to live to be honest… Yeah that's really what did it and that is really why I went through everything I went through and researched all I did and did what I did. (32 year old woman)

Women who are in the young adult stage typically will have experience with decision making outside of the sphere of their parent's influences, but even they cannot move out from under the sphere of their mother's death from breast cancer.

3) Health Care Provider Concern—Some participants were first made aware of their potential risk for HBOC when a health care provider took a family history and identified young and/or multiple family members having been diagnosed with breast cancer and/or ovarian cancer. These participants tended to see the choice of testing as being more pragmatic and less emotional than those in the two previous trajectories. While they recognized that genetic testing was different than other medical tests they were convinced it was simply a way to take control of their health.

> I was interested to know if I had this gene. My husband's father is a general practitioner and was interested in having me go to a breast cancer prevention clinic to visit a doctor he knew there. I went and right away received counseling encouraging me to have the test done. I have always been good about going to the doctor, but my age made a difference. I was only 29 when I had the results of my genetic test. I had never had a mammogram and I would occasionally check my breasts for lumps – but I still did not take my familial risk of cancer very seriously in actuality because of my age… I do feel like I am still lucky. I am so lucky to know that I have this gene. I am the only woman in my family who has had a chance to know what my future potentially holds-what my Achilles' heel is. Knowledge really is power. (35 year old woman)

While participants who lived this trajectory tended to be matter of fact about the actual genetic testing, they found making risk reduction choices difficult.

4) Diagnosis of Breast Cancer—When a young woman is diagnosed with breast cancer, the medical recommendations are for aggressive treatments to start quickly. Some participants in this study were counseled not to wait for genetic testing but to go ahead with bilateral mastectomies without testing and others were counseled to treat the breast with cancer and follow-up with genetic testing and a possible risk reducing surgery of the unaffected breast at a later date. For women living this trajectory, genetic testing was more of an after thought, then a planned intentional event. They were consumed with the need for treating the breast cancer and considered genetic testing a secondary concern.

> The day the surgeon told us it was cancer he also said it was a large tumor and that the pathology report stated that the cells were "angry looking" and likely aggressive. For those reasons, he said I needed an immediate mastectomy with sentinel lymph node removal and scheduled the surgery for the following week…. Mostly I was frustrated by the speed. I needed to make a lot of decisions quickly. My oncologist wanted to do chemotherapy first because of the estimated tumor size and my surgeon wanted to do the surgery first because he was sure he could get "good margins" right then but maybe not later. With very little information I had to go with my instincts and chose to have the surgery first. My oncologist stated that I could not afford any delay in starting chemotherapy beyond healing from the surgery. That meant that I couldn't harvest any of my eggs in case I was put into menopause by chemotherapy. I was really made to feel that any delays in my treatment could cost me my life. (36 year old woman)

While there was variability in whether women with a breast cancer diagnosis waited for a genetic test result before beginning treatment, because they were young, it was in each case recommended that they have the test as part of their treatment program.

Risk reduction choices and life trajectories

1) Acutely aware—Women who were in this life trajectory for the most part leaned toward having risk reducing surgery before they became like the "other" women in their families. This was even true for the youngest participants.

> (23 years old at time of risk reducing mastectomy) I knew I was at high risk due to the knowledge of my family history. After I had tested positive for the *BRCA2* gene in the Summer of 2004 I decided to not take any immediate action. I got a job in New York City and started working full-time. About the beginning of Spring 2005 the news started weighing on me. More and more I would hear about young women in their late 20's and early 30's getting diagnosed with the cancer. I would think about the possibility of me being diagnosed as if it was going to happen that day or the next or in the next week. Finally, in May 2005 I elected to get a risk reducing bilateral mastectomies and reconstruction. (24 year old woman)

Participants who had lived the Acutely Aware life trajectory found it very difficult to trust the increased surveillance protocols and spoke of being too anxious waiting for the "next" time of their breast or ovarian screening. Those who did decide to do screening and/or surveillance for some period of time lived on the edge of deciding for risk reducing surgeries and the slightest change in a mammogram or abdominal pain of any kind pushed them toward risk reducing surgeries.

> (Had a risk reducing mastectomy at 35 years) My mother is definitely the third generation breast cancer in her thirties that we know of… She's 51 now she is the first woman in our family to live past 50 in five generations….. I admire women who can live with surveillance but that wasn't for me. I do worry about breast cancer everyday…. I definitely have worried a lot about what if I get cancer what if I have cancer every time I feel anything I think that is what it is…. knowing that I have the gene now for lack of better term and I don't know if I put it in this term to him (physician) but basically I just expressed I am kind of like a ticking time bomb it could be tomorrow. (35 year old woman)

2) Loss of Mother—As with the decision to have *BRCA* mutation testing, women who lost their mothers to breast cancer were largely motivated to take aggressive action to reduce their risk for cancer but that does not mean it was an easy decision for some of these young women.

> My mother actually beat her breast cancer in 1987/88, but died from ovarian cancer in 1990, just nine months after the initial diagnosis. I was 20 years old. (*Have you had any risk reducing surgery(PM)?*) I did have my ovaries removed two years ago… I am now starting to consider my options in terms of having a risk reducing double mastectomy. It is brutal to think about going through with it since I am only 36, but I cannot imagine not doing it…. I remember feeling (after receiving a positive *BRCA1* result) like I was reading a death sentence. I was so alarmed to think that it was almost an inevitable fate… I am still shaky about the PM, but it looks like I may just try to follow the momentum and get it over and done with this summer. I go back and forth in my mind all day long…. I think that the sad fact is that it is all in my control, and that is why I am going to have to come to this terrible, inevitable conclusion that I am going to have to have this risk reducing mastectomy surgery. (35 year old woman)

Participants who had lived this trajectory were very anxious to avoid their mother's fate and some found the choice of risk reducing mastectomy and/or risk reducing oopherectomy less troubling and the most likely way they would not follow their mother's experience.

> So with regards to PM, I think it is mostly that I am becoming less and less content with the idea of catching breast cancer at an early, treatable stage; and more and more interested in actually avoiding getting breast cancer in the first place. I am now several months older than my mother was at diagnosis so I'm sure that plays into it on some level -- like, I've already been luckier than mom was, how far do I really want to push my luck? (35 year old woman)

The influence of living the Loss of Mother life trajectory was apparent with all ages interviewed.

3) Health Care Provider Concern—When a participant decided to have testing because of a health care provider's concern thet tended to express less emotion. These women were more matter-of-fact about the need to have risk reducing surgeries though some still struggled with the timing of such events. They also tended to be more positive about knowing they had the mutation and saw such knowledge as a means to an end, that being reducing their risk for breast cancer/ovarian cancer.

> I think I have handled this information well. I truly am grateful to know. I feel empowered by this information and know that I can save my life…. Well knowing that I have the mutation I want to do everything I can to protect myself from ever getting cancer. So, I have been extremely proactive in taking the most extreme measures available to me – My path has been to rid my body of what can cause cancer (ovaries and breast tissue) that I have control over. (36 year old woman)

The young adult participants in this study who were largely informed of their risk for HBOC through conversations with health care providers tended to be proactive in terms of risk reduction choices and more inclined to regard the mutation as useful information instead of a "death sentence".

4) Diagnosis of Breast Cancer—Participants who had already been diagnosed with breast cancer at the time of the interview had either already had bilateral mastectomies (one side risk reducing) or had made the decision to remove the cancerous breast and were considering having a risk reducing mastectomy on the remaining breast. One of the youngest participants had a diagnosis of ductal carcinoma insitu (DCIS) and responded aggressively based largely it seems on her family history and extremely young age:

> I was diagnosed with DCIS at 23 and have a strong family history of breast cancer including my mother, maternal grandmother and two maternal great aunts. My physician recommended the genetic testing as he had no other way to explain my breast cancer at such an early age…. I had already decided to have a double mastectomy before my genetic test results were in, as I was convinced I had the gene before I really knew. (24 year old woman)

Participants who were in their late twenties or early thirties were equally shocked at a breast cancer diagnosis. Because a breast cancer diagnosis in a young woman is generally considered an aggressive cancer, choice of treatment options sometimes was difficult. If a woman chose to have radiation and conserve breast tissue but then subsequently discovered she carried a *BRCA* mutation, she would have undergone a therapy with significant co-morbidities and still faced the choice of bilateral mastectomies based on her genetic risk. Sequencing of treatment issues and the sense of urgency that accompanies a breast cancer diagnosis in young women complicated things for some participants; for others having waited for a genetic test result made the surgical decision easier.

> I tested positive for *BRCA2*, without any family history whatsoever. …I would never have considered bilateral mastectomy if I had tested negative for *BRCA*. But the chance of second breast cancer after being diagnosed at 28 is so high for me, bilateral became the most sound option. (29 year old woman)

Young women with breast cancer and a *BRCA* mutation face a very difficult time. They must endure the treatments for cancer which almost always include surgery, chemotherapy and/or radiation and must also consider future risks based on their genetic test results. The participants in this study, regardless of their age, generally opted for the most aggressive treatment in an attempt to decrease their risk for another cancer diagnosis in the future.

Discussion

Young women who are at risk for HBOC face difficult choices (Hamilton, 2003). The choices they make whether about genetic testing or risk reduction after a mutation is identified are influenced by the life trajectories that have preceded their knowledge of risk. We have identified four such trajectories and suggested some consequences of living those trajectories. While no argument is put forth that these are the only life trajectories that may be influential in decision making in the overall population of women at risk for HBOC, they do represent a summary of what was found in this geographically diverse sample of 44 women ages 18–39 years. Life trajectories among young adult women may be important criteria for health care providers to understand when interacting with this particular population. Many of these young women reflected on their family history, and specific events in the lives of their female biologic relatives. They also noted the importance of making difficult decisions, which for some included satisfactory, and for others, not so satisfactory options. Some described their decisions as personal events, while others noted the important influence of family and health care providers. For all however, the main condition was the awareness of risk.

Beery and Williams (2007) in a systematic review of 55 research reports on risk reduction and health promotion behaviors after genetic testing for adult-onset disorders found little evidence reported for situational variables that may influence behavior outcomes. Our data on life trajectories begin to address that deficit. While no other studies specifically address the age group we have targeted, the issues of family experience and risk perception have been reported. A comparison of findings from some of these research reports with our data will be summarized.

d'Agincourt-Canning (2005) examined the impact of experiential knowledge on the construction of risk perception for HBOC and described how family patterns of inheritance,

personal experience and the experience of caring for others with cancer shape an individual's perception of risk and knowledge of breast cancer/ovarian cancer. In a second study (d'Agincourt-Canning, 2006) described how the majority of women at risk for HBOC found having genetic information enabling, while the younger participants (in their late twenties) expressed greater anxiety after a positive *BRCA* mutation test, reporting little faith in screening measures. She reported that these younger women saw little opportunity to fight what they perceived to be the inevitable disease, leading them to feel vulnerable and troubled. Other researchers have noted the influence that family history of breast cancer/ovarian cancer can have on perceived risk (Decruyenaere et al. 2000; Hallowell et al., 2004; Hallowell, et al., 2004; Kenen, et al., 2003; Skirton and Eiser, 2003; Metcalfe et al., 2008; Werner-Lin, 2007) which is certainly supported by our data. This study however extends that knowledge by focusing specifically on young women and begins to suggest how age and family history may interact in terms of deciding to have the genetic test, and to the type of follow-up treatments women choose. Our analysis suggests that when young women are very aware of their family history of breast cancer/ovarian cancer, they describe themselves as being proactive and in the position to control their risk in comparison to older family members. Unlike the d'Agincourt-Canning study (2006), our youngest participants expressed a determination to control their risk and the older participants (late 20's and 30's) were more likely to express that fate was controlling their lives to some extent.

Interest in genetic testing has been found to correlate with family history of breast cancer, age and education (Bottorff et al., 2002). The present study found that women between 20 and 40 years of age without breast cancer but with a family history of breast cancer were most interested in genetic testing. Uptake of risk reducing surgeries has also been shown to be influenced by family history (Metcalfe et al., 2008). Specifically women with a sister who had a breast cancer diagnosis were more likely to have risk reducing mastectomy than women whose sister(s) did not have breast cancer. Likewise having a mother or sister with ovarian cancer significantly predicted uptake of a risk reducing oopherectomy in a *BRCA* mutation carrier (Metcalfe et al., 2008). Findings from the current study carry this a step further by reporting the life trajectories behind decisions to have genetic testing and how those experiences influence follow-up treatments.

There are not many parallel examples of young people being at risk for detrimental health outcomes that do not involve risky choices. Considerable research exists on the risky choices young people may make that can be detrimental to their health but with HBOC, the young person does not choose a risky behavior, but rather s/he is at risk simply because of inheritance. One population that may offer comparisons is that of young women with breast cancer who *do not* have knowledge of their genetic risk. Quality of life (Bloom et al., 2004), concerns and experiences (Dunn and Steginga, 2000), and psychosocial problems (Avis, et al., 2003) of young breast cancer survivors have been reported. Most women who remained cancer free after five years reported a good quality of life, while simultaneously reporting sexual problems, being embarrassed about their bodies, feeling stressed and anxious and worried for the future (Bloom et al., 2004). Major concerns of young women with breast cancer were reported as: 1) Worry about not seeing children grow up, 2) Thinking they were too young to get breast cancer, 3) Feeling different from peers, and 4) Loss of choice about having children (Dunn and Steginga, 2000). The highest rated psychosocial problems reported in a study of 204 women with breast cancer at age 50 or younger were premature menopause and pregnancy related issues (Avis et al., 2003).

There are similarities in the concerns reported with those who have a *BRCA* mutation whether or not they have a breast cancer diagnosis. All four of the major concerns reported by Dunn et al (2000) were reported by the participants in the present study. Likewise young women in our study who had or were considering a risk reducing oopherectomy expressed significant

concerns about the instant onset of menopause and the potential secondary detrimental health affects. All of the participants in our study who were single or wanted more children expressed concerns about the impact of a pregnancy and the possibility of passing on the mutation to offspring.

However, unlike the participants in the Bloom et al (2004) study, the young women in our study, whether they had been diagnosed with breast cancer or "just" had a *BRCA* mutation did not regard five years as a point of reassurance because of their understanding that the risk is ongoing because it is genetic. In the Bloom et.al. study (2004), the age range was 22–51 years with 12% (23) of the sample between the ages of 22–39 years, while the age range for the Dunn et.al. study (2000) was 31–47 years, and the age range in the Avis et.al. study (2003) was 25–50 years (mean = 42 years). Our sample is younger and more geographically diverse and provides insights on being at risk for breast cancer/ovarian cancer as well as having a breast cancer diagnosis resulting from a known genetic mutation.

Other researchers have looked at the variability in choices after genetic testing (Meiser, 2005) as well as variables that seem to affect inherited cancer risk (Mellon et al., 2008). In a review article (Meiser, 2005) the uptake of risk reducing mastectomy ranged from 0% to 54% and risk reducing oopherectomy from 13% to 53% in unaffected *BRCA* mutation carriers. The various authors suggest that uptake of risk reducing surgery may reflect differences in physician recommendations; attitudes toward bodily integrity, femininity and risk reducing surgery and health care funding systems. Variables that have been reported (Mellon, et al., 2006) to affect inherited cancer risk perception included income, race, family history of cancer, and cancer worries. Mellon et al.'s (2006) study did not include data on whether or not participants knew their *BRCA* mutation status. Older women had less perception of risk than younger women. Our analysis extends these findings by assessing factors that influence risk awareness and how the individual's life trajectory influences choices for both genetic testing and follow-up treatments.

Implications

The life trajectories presented here may be useful for genetic counselors and clinicians providing specialty and primary care to young women with a *BRCA1/2* mutation. Understanding a young woman's life trajectory could guide the provider in anticipating the types of reactions to testing that may occur and the kinds of additional education and support that are needed. For example if a client is 19 years old, and lost her mother to breast cancer, it can be anticipated that her needs for support in thinking through her options are going to be significant. The data suggest a real sense of urgency in these emerging adults with this life trajectory, and provide insights into factors to consider when young women make risk reducing surgery decisions.

Particularly important for the discussion of the trajectories influencing young women's decisions is the timing of clinical onset and treatment that can alter the onset or progression of the disease. Our participants were all young adults and did have options for delaying the onset of breast cancer and ovarian cancer (risk reducing mastectomy and risk reducing oopherectomy) as well as non-surgical treatment options prior to diagnosis (increased screening) and after the diagnosis of breast cancer (surgery, chemotherapy and radiation and long-term increased surveillance). According to the FSGI model (Rolland and Williams, 2005), our participants were in the Crisis II: Test/Post-testing phase of a genomic disorder in that all had received their *BRCA* mutation test result at the time of their interview. Persons in this phase seek to incorporate this new knowledge and evaluate how it may affect the individual's and family's life. The family must also create a new sense of meaning with this information and a degree of flexibility as a family to deal with an uncertain future (Rolland and Williams, 2005).

What was most striking in the data from this study is the personalized nature of responses, with relatively little reflection on the meaning of the risk information and decisions for the young women's' biologic or hoped for new nuclear families. Although genetic conditions are of concern to the entire family, for young adult women, implications of genetic risk and the family may not be foremost in their minds. These young women referred to their family members' concerns for them, but spoke more so on their own decision making process, that may or may not take into account the opinions of certain family members. Ultimately they spoke about their personal approaches to these decisions. The findings may provide useful guidance in genetic counseling encounters, both during risk assessment and evaluation of family history data, and the discussions regarding decisions facing young women. Specifically, genetic counseling involves helping an individual adapt to the medical, psychological, and familial implications of genetic risk (NSGCDTF et al., 2006). Assessment of these trajectories may be used to help guide the direction of the education and counseling session. In addition, this information can assist the provider in planning for the impact of the test results. Understanding an individual's life trajectory can provide information to help guide post test counseling by identifying issues the individual, herself, may not be considering in her decision-making, even though such decisions have life long consequences.

Much remains to be learned regarding how women who are young adults move through these crises and the impact of decision making on the family unit. Most participants in this study in the Acutely Aware and Loss of Mother life trajectories already had a sense of themselves as being a "breast cancer family", so dealing with an identity of a person at higher risk for HBOC may not have been novel for these individuals. However, having an actual genetic test result as opposed to just a strong family history did create this need to come to terms with the permanence of the risk for themselves. Several participants in this study and the earlier study (Hamilton, 2003) made a distinction that the results of their own test meant that now "everyone" (siblings, cousins, children, grandchildren, etc.) was at risk. The meaning of this information for family members was not collected in this study. Others (Oostrom et al., 2006; Oostrom et al., 2007) reported that family systems characteristics, such as family cohesion and adaptability impact the psychological adjustment to knowledge of genetic risk for cancer in a family. The FSGI model also suggests families must create new meaning based on the awareness of their risk for a genetic illness (Rolland and Williams, 2005). For families with young adult women, this includes accommodating and coping with life planning issues women face as young adults.

Uncertainty for the participants in the first three life trajectories consisted of not knowing if and/or when they might develop cancer. They entered the arena of increased surveillance or opted for risk reducing surgeries as a way to catch the disease early or minimize their risk for developing any disease. Participants in the Diagnosis of Breast Cancer life trajectory had already passed the point of uncertainty about getting breast cancer but now faced the uncertainty of reoccurrence in the "healthy" breast and/or ovaries. Uncertainty remained for all the participants in this study though those who had had both a risk reducing mastectomy and risk reducing oopherectomy described feeling less uncertain about the future than other participants.

Regarding research implications, it is unknown if these life trajectories are associated with satisfaction with decisions about genetic testing and follow up. It is also unclear if the extent of distress during decision making is related to the life trajectory. Both areas of research could provide important information for this population to those involved in genetic counseling and follow-up.

Limitations of the Study

While the sample size (44) and the variability of experiences was sufficient for a grounded theory study (Starks and Trinidad, 2007), there was potential bias in that recruitment was done on the Internet at two sites specifically addressing the needs of young women at risk for HBOC. The women who visit such sites may be more proactive than women with a *BRCA* mutation who do not use such information/support sites. Also except for a few participants all interviews were retrospective and participants were recalling how they felt after genetic testing and how they made decisions for treatment.

Conclusion

This study of 44 young women with *BRCA* mutations describes how they came to have the genetic testing and the decisions they made. Genetic counselors who interact with young women seeking BRCA mutation testing may find these trajectories a useful way to frame their interactions with clients. They could use the information on life trajectories to anticipate what information patients may find useful and how they may react to testing and follow-up recommendations. These trajectories may also provide a concise heuristic for other health care providers such as genetic nurses, geneticists and physicians who interact with this population. Findings from this study suggest that a “one-size-fits-all” model for counseling and/or follow-up guidance is unlikely to benefit the younger women who opt for genetic testing and that awareness of life trajectories may be useful for clinicians.

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Table I

Participant Characteristics (*n*=44)

Variable	***n***
Age in Years	
18–28	14
29–40	30
BRCA mutation [one participant had both]	
*BRCA*1	30
*BRCA*2	15
Breast Cancer	
Yes	21
No	23
Marital status	
Married	31
Single/Divorced	13
Ethnicity	
White European	43
African American	1
Risk Reducing Mastectomy	
Yes	23
No	21
Risk Reducing Oophorectomy	
Yes	16
No	28