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To cite this article: Marleah Dean & Carla L. Fisher (2019): Uncertainty and previvors' cancer risk management: understanding the decision-making process, Journal of Applied Communication Research, DOI: [10.1080/00909882.2019.1657236](https://doi.org/10.1080/00909882.2019.1657236)

To link to this article: <https://doi.org/10.1080/00909882.2019.1657236>



Published online: 25 Aug 2019.



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Uncertainty and previvors' cancer risk management: understanding the decision-making process

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ABSTRACT

Women who test positive for a BRCA genetic mutation, but who have not been diagnosed, or 'previvors,' experience intense, chronological risk-related uncertainty. Women's risk management medical decisions can be a way to manage their uncertainty, but little is known about how uncertainty informs their decision or how uncertainty is impacted by these medical decisions. Using an uncertainty management theoretical lens, we interviewed 46 previvors about their decision-making process. A thematic analysis revealed two uncertainty management (i.e., risk-reducing) decision-making pathways (preventive surgery and increased surveillance) with each pathway encompassing a three-part process of 1) uncertainty appraisal, 2) medical decision (i.e., uncertainty management strategy), and 3) outcomes. The findings advance theoretical thinking about uncertainty and risk management as an ongoing, distressful chronic experience, and highlight the importance of life-span phenomena in women's decision-making process. Based on the findings, we constructed a translational tool to aid genetic counselors and previvors facing these medical decisions.

ARTICLE HISTORY

Received 21 August 2017
Accepted 10 January 2019

KEYWORDS

Uncertainty; decision-making; risk management; hereditary breast and ovarian cancer; BRCA

Women at risk for breast cancer face complex risk-related uncertainty for themselves and their family. At-risk women like daughters of breast cancer patients report worrying about their mothers' and personal disease risk – experiencing a psychological 'chronic risk' or ongoing worry and uncertainty (Dean, 2016; Fisher, 2014; Kenen, Ardern-Jones, & Eeles, 2003). 'Worried well' daughters with more awareness of their increased risk report negative health implications, including distress and increased stress hormones like cortisol (Brashers, 2001; Cohen et al., 2002). Even talking about risk is challenging and distressful for mothers and daughters (Bylund et al., 2012; Tercyak et al., 2013) and can contribute to increased cortisol for daughters (Berlin, Andreotti, Yull, Grau, & Compas, 2013). Some argue that this extended distress and impaired immunological functioning may in part heighten women's disease risk (Cohen et al., 2002).

This chronic uncertainty about risk is more intense for women with hereditary breast or ovarian cancer (HBOC), particularly women who test positive for a BRCA genetic

mutation. Their sense of risk is not necessarily ‘if I get cancer’ but ‘when’ (Dean, 2016). When these women are unable to cope with their uncertainty, they report heightened distress, which can become long term (O’Neill et al., 2006). The medical decisions they make to manage disease risk is critical to both health and uncertainty management, therefore having significant implications for their physical and psychological well-being.

Although some research has explored the genetic testing experiences of women with BRCA mutations who have not yet developed HBOC (e.g. Dean, 2016; Hamilton, Lobel, & Moyer, 2009; Hesse-Biber, 2014; Prouix et al., 2009; Vadaparampil, Scherr, Cragun, Malo, & Pal, 2015), little is known about their subsequent risk management decision-making. Moreover, while risk management options reduce cancer incidences and enhance women’s survival, they are still underused by women with a higher risk of cancer (Padamsee, Wills, Yee, & Paskett, 2017). To date, mostly quantitative, retrospective studies have been conducted that show higher risk women’s decisions are influenced by perceived risk, family history, psychological distress, and age (see Padamsee et al., 2017, for a review). However, studies have not explored the decision-making process from the women’s point of view, and researchers have advocated for more understanding about what informs their decisions (Beattie, Crawford, Lin, Vittinghoff, & Ziegler, 2009; Padamsee et al., 2017).

A recent review advocated for inductive studies on the decision-making process to illuminate influential factors (like uncertainty) and how they function in women’s medical decisions, including how the decisions impact women’s well-being (Padamsee et al., 2017). They note that this knowledge can be used to develop decision tools that help women process their uncertainty, build skills central to uncertainty and risk management, and allow them to compare their risk-reducing (and uncertainty management) choices. Such resources could have a notable impact on at-risk women’s present and long-term health, providing needed psychosocial support – support that is linked with risk reduction (Epplein et al., 2011; Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006). This study seeks to attain that knowledge by capturing how uncertainty informs women’s medical decision-making (and, thus, uncertainty management) after testing positive for a BRCA mutation.

Receiving positive results: uncertainty and risk management

Individuals who test positive for a BRCA genetic mutation are at a significantly increased risk of developing HBOC during their lifetime. Women with a *BRCA1* genetic mutation have a cumulative breast cancer risk of 72% and a cumulative ovarian cancer risk of 44% by 80 years old. Women with a *BRCA2* mutation have a cumulative breast cancer risk of 69% and a cumulative ovarian cancer risk of 17% by age 80 (Kuchenbaecker et al., 2017). Given their high risk, even though these women have not been diagnosed with cancer they are often referred to as ‘previvors’ (www.facingourrisk.org).

While women may have been initially motivated to do genetic testing to reduce their uncertainty about their cancer risk (Bylund et al., 2012), receiving positive BRCA genetic testing results still creates uncertainty coupled with negative emotions that may never dissipate (Dean, 2016; Hoskins & Greene, 2012; Hoskins, Roy, Peters, Loud, & Greene, 2008; Westin et al., 2011). For example, previvors experience shock, worry, anxiety, fear, and depression related to their risk uncertainty (Dagan & Gil, 2005; Dean

& Davidson, 2018; Leonarczyk & Mawn, 2015). Further, previvors have higher levels of psychological distress than BRCA mutation carriers with breast cancer, non-mutation carriers with breast cancer, and non-mutation carriers without breast cancer (Dagan & Gil, 2005).

Their emotional and psychological distress is inevitably tied to their ongoing risk-related uncertainty. Previvors have noted ‘the only potential termination to the uncertainty would be that they develop breast or ovarian cancer’ (DiMillo et al., 2013, p. 128). Samson et al. (2014) reported that previvors had three tasks to adjust to living with a BRCA genetic mutation: (1) limit the impact of the genetic test results, (2) find social support resources, and (3) cope with uncertainty. Recently, research with previvors revealed two main sources of uncertainty – medical and familial (Dean, 2016). Medical uncertainty included being anxious about a future HBOC diagnosis, feeling fearful during screening appointments, and waiting for diagnostic test results when HBOC is suspected. Familial uncertainty included distress when reflecting on family cancer memories and worrying about how a HBOC diagnosis could affect their children.

These studies indicate uncertainty is inherent for previvors (Dagan & Gil, 2005; Dean, 2016; DiMillo et al., 2013; Samson et al., 2014). If left unmanaged, uncertainty can contribute to poor decision-making (Mishel, 1999; Politi & Street, 2011; Wong & Bramwell, 1992) and negative health outcomes (Arora, 2003). Moreover, women who struggle with risk-related uncertainty are not only more distressed, but they are at risk of long-term distress (O’Neill et al., 2006). In short, their subsequent medical decisions are critical to their ability to cope with distressing uncertainty and reduce long-term risk.

Managing uncertainty and risk: medical decision-making

Previvors have unique psychosocial and healthcare needs (Donnelly et al., 2013). To manage those needs, previvors can engage in cancer risk management – decision-making in which individuals weigh the benefits and costs of medical options while considering personal, familial, and social factors (Leonarczyk & Mawn, 2015). According to the National Comprehensive Cancer Network (NCCN), previvors have three options for cancer risk management: (1) increased surveillance, (2) chemoprevention, and (3) preventive surgeries. Increased surveillance encompasses actively monitoring one’s body for cancer through clinical breast screening (i.e. mammograms and MRIs), transvaginal ultrasounds, and CA-125 blood tests (Burke et al., 1997; Evans et al., 2009). Chemoprevention involves administering medication to delay the development of cancer and reduce HBOC risk. Preventive surgery includes undergoing one and/or both a prophylactic bilateral mastectomy (PBM, surgical removal of breast tissue to reduce breast cancer risk) and a bilateral salpingo-oophorectomy (BSO, surgical removal of ovaries and fallopian tubes to reduce ovarian cancer risk) (Pruthi, Gostout, & Lindor, 2010).

Although these medical decisions affect previvors’ disease risk and uncertainty, they continue to be under-utilized, and little is known about that decision-making process. Given that uncertainty informs these decisions (Padamsee et al., 2017), theoretical frameworks of uncertainty could aid in capturing knowledge central to both understanding the decision-making process and developing interventions for BRCA-positive patients (Bailey & Stewart, 2006; Clayton, Dean, & Mishel, 2018).

Theoretical advances on the critical role of uncertainty in health and illness

A number of theories have demonstrated the critical role uncertainty plays in stressful experiences, such as uncertainty reduction theory (Berger & Calabrese, 1975; Berger 1986); stress, appraisal, and coping theory (Lazarus & Folkman, 1984); and problem integration theory (Babrow, 1992). Mishel's (1988, 1990) re-conceptualized uncertainty in illness theory (RUIT) and Brashers (2001) uncertainty management theory (UMT), which extends RUIT, are especially useful in examining previvors' uncertainty and cancer risk management experiences.

Research advancing UMT and RUIT illustrates how illness, disability, and stressful experiences are fraught with complex uncertainty that can extend for short and long periods of time and not always be resolved (Brashers, 2007; Mishel, 1988, 1990, 1999; Mishel & Clayton, 2008). Uncertainty can become chronic, meaning an individual must constantly manage inconsistency, ambiguity, and unpredictability about health and illness over a long period of time (Brashers, 2001). Patients' responses to that uncertainty impact their health. Several overlapping theoretical features of UMT and RUIT are pertinent to understanding how uncertainty informs previvors' cancer risk management: (1) the nature of uncertainty (e.g. sources and antecedents), (2) appraisals or assessments (and emotional responses) of the uncertainty, and (3) strategies or coping approaches to manage uncertainty.

As previously indicated, research has captured the nature of uncertainty previvors experience (Dagan & Gil, 2005; Dean, 2016; DiMillo et al., 2013; Samson et al., 2014). It is chronic and tied to medical and personal sources/antecedents (Dean, 2016). Yet, less is known about how they appraise their uncertainty, and how those appraisals in turn impact their strategic approaches to coping with uncertainty and risk.

Appraisal of uncertainty

UMT and RUIT recognize that patients make assessments of their uncertainty which involves emotional responses (Brashers, 2007; Lazarus & Folkman, 1984; Mishel, 1990). A number of factors inform the appraisal including knowledge, experience, personality, and contextual cues as well as beliefs (e.g. having a positive outlook) (Mishel, 1990). Patients' emotions are also involved as uncertainty can be perceived as either positive or negative (Brashers, 2007; Lazarus, 1991). Emotional responses can range (and be mixed) or even neutral (Brashers, 2007). Patients typically appraise illness-related uncertainty either as a *danger* (i.e. a negative emotional response) or an *opportunity* (e.g. a positive emotional response) (Mishel, 1990; Mishel & Clayton, 2008). These appraisals inform their decision-making (or, for previvors, appraisals inform which medical option they choose to manage risk and uncertainty).

Coping with (or managing) uncertainty

Patients' coping responses (i.e. uncertainty management strategies) may be to maintain, increase, reduce, or adjust to that uncertainty (Brashers, 2007). Research informed by RUIT suggests that patients appraising uncertainty as danger will experience negative emotions and poor health outcomes (Clayton et al., 2018; Kang, 2006), whereas patients

appraising uncertainty as opportunity are likely to self-reflect on the situation and even restructure one's life and priorities (Mishel, 1990; Mishel & Clayton, 2008). These appraisals inform their uncertainty management decisions.

Previvors need to manage uncertainty (and enhance health) in the present moment (particularly given distressful chronic risk/uncertainty) as well as in the long term by reducing disease risk. However, their appraisals will vary and, therefore, inform which risk management option they choose differently. The uncertainty theoretical constructs of UMT and RUIT, specifically appraisal and coping strategies (i.e. medical decisions), can help illuminate how previvors' make risk-reducing decisions.

Research inquiry

To date, no study has examined – from their perspective – how uncertainty informs previvors' risk-reducing medical decisions and the impact of those decisions. By further examining this process, we can develop tools practitioners could use to aid women's decision-making and uncertainty management and, ultimately, enhance previvors' present well-being and long-term survival. As such, the following inquiry is posited:

RQ: How does uncertainty inform women's medical decision-making process after testing positive for a *BRCA1/2* mutation?

Methods

Procedures and recruitment

Participants were recruited using theoretical, purposive sampling (Hesse-Biber & Levy, 2006) as *BRCA1/2* genetic variants are only responsible for causing 5–10% of HBOC, and most do not know they are at high risk for HBOC (Friedman, Sutphen, & Steligo, 2012). Participants were recruited via social media pages of Facing Our Risk of Cancer Empowered's (FORCE) – a non-profit organization that coined the term 'previvors' – as well as other Facebook HBOC or BRCA groups. This approach optimized the potential to recruit women who experienced this decision-making process.

Participants

A total of 46 previvors, women never diagnosed with HBOC but testing positive for a *BRCA1* or *BRCA2* genetic variant, participated (25 tested positive for *BRCA1*, 21 tested positive for *BRCA2*). On average, previvors were 36 years old (range 23–67). Most ($n = 36$, 78%) identified as Caucasian, while one previvor identified as Chinese-American, one as Caucasian and Colombian, two as Caucasian and Hispanic, and six Caucasian and Ashkenazi Jewish.

Data collection

Upon Institutional Review Board (IRB) approval, previvors participated in an audio-recorded, semi-structured interview via phone lasting between 30 and 90 min. Questions

included ‘After testing positive for *BRCA1/2* mutation, what health decisions have you made, and how have those decisions assisted you in coping with your hereditary cancer risk?’ ‘Reflecting on your [personal health decision], in what ways did the decision help you manage your concerns about a future diagnosis of cancer?’ ‘Why did you pick that preventive health behavior over the other options that are available?’ This approach facilitated narratives prioritizing their voice (Lindlof & Taylor, 2011). Questions were broad to allow for constructs of uncertainty to emerge naturally. Professional transcriptions resulted in 701 single-spaced pages. For confidentiality, pseudonyms were used.

Data analysis

Data collection, transcription, and analysis were concurrent to ensure thematic saturation (Morgan, Fischhoff, Bostrom, & Atman, 2002). Data were analyzed using an iterative approach whereby emerging themes were informed by sensitizing constructs (Tracy, 2013). The uncertainty theoretical constructs of appraisal (danger and opportunity) and coping strategies/decisions (surgery, surveillance, and chemoprevention) guided the analysis of women’s decision-making process. Special attention was also paid to the implications (outcome) of women’s decision-making.

The primary author read transcripts observing patterns prior to beginning first-level coding – categorizing data into codes (Tracy, 2013). Incident-with-incident coding – using the constant comparison method – was used noting interpretations in transcript margins (Charmaz, 2014). The analysis was shared with colleagues with related expertise (Creswell, 2007) to refine themes and validate the application of theory. The primary author then conducted axial coding of each theme (appraisal, decision, outcome) for each decision-making pathway to capture how uncertainty informed decisions distinctively. The second author confirmed data matched themes and emergent properties. Together, the authors developed visual representations of the decision-making pathways to illustrate women’s experiences to both showcase the critical role of uncertainty and provide clinicians with a translational tool to enhance understanding of factors impacting women’s decisions.

Verification

To increase the credibility, consistency, and transferability (Lindlof & Taylor, 2011), the primary author kept a reflexivity journal recording methodological and analytical memos (Hesse-Biber & Levy, 2006; Lincoln & Guba, 1985). Member checks ensured findings reflected participants’ experiences (Hesse-Biber & Levy, 2006). During analysis, negative cases were also examined to fully capture previvors’ divergent experiences.

Results

Two uncertainty management (risk-reducing) decision-making pathways emerged: (1) *preventive surgery* and (2) *increased surveillance*. Women’s unique decisions/pathways are presented and informed by the theoretical framework, which illustrated a three-part decision-making process of (1) *uncertainty appraisal*, (2) *medical decision (i.e. uncertainty management strategy)*, and (3) *outcomes*. Themes and associated properties are presented for each phase highlighting the uncertainty in women’s divergent decision-making

pathways. The third decision option available to previvors (chemoprevention) did not emerge. A few women did discuss it. An analysis of their reports informs why chemoprevention may not have been chosen.

Pathway 1: preventive surgery

Most participants ($n = 31$) chose preventive surgeries (PBM or BSO). Previvors who appraised their uncertainty as a *danger* chose *preventive surgery* as their risk-reducing medical decision (which served as an uncertainty reduction strategy) and resulted in *health-enhancing outcomes* (see Figure 1). Their description of this risk-reducing decision-making pathway was characterized by a more linear experience of uncertainty.

Appraisal: danger

Previvors noted two characteristics informing their danger appraisal. First, women perceived uncertainty as a *gamble and/or risk*. To these previvors, testing positive for BRCA increased their risk of developing HBOC so much that it felt like they were gambling with their lives and, as such, required immediate, extreme action in the form of surgery. Sophia (BRCA2, age 33, PBM) explained it this way:

If I got cancer, whether it's next year or ten years from now, I would really be pissed at myself for not having taken care of it. That's the reason I want to do [PBM]. I think I would be happier saying I made this decision. I consciously made this decision, so that I don't have to suffer. My kids don't have to suffer. My husband doesn't have to suffer. Rather than [betting] on not getting cancer and hop[ing] that it works out because I would just be pissed if I didn't. I don't even gamble in Vegas. Why on earth would I gamble with this?

Women's danger appraisal was also characterized by *heightened/extreme distress*. They described overwhelming emotions, at times suggesting the shock of learning their BRCA test results was too much to handle. As Addison (BRCA1, age 33, PBM) stated,

At 25, I didn't have a care in the world. I was happy-go-lucky. I really didn't think a lot about my health. I was in great shape. I was invincible. I guess, at that point, I had it in my mind, 'Oh, it should be fine. I'll have to take the test, and I know I'm negative.' And so, the shock, finding out that, 'Oh my God, I'm positive ...' My genetic counselor walked me through the risks meant for that and [I realized], 'Oh my God, I have [a high risk] of having breast cancer.'

Similarly, Samantha (BRCA2, age 35, PBM and BSO) expressed, 'I cried at first. It just it never occurred to me. It's like before that I wasn't at any at risk. I've always been healthy, and I take care of myself, and it never even occurred to me.' Previvors noted that the

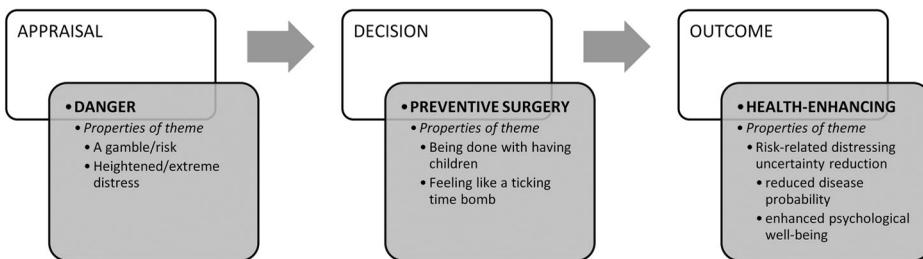


Figure 1. Pathway 1: preventive surgery.

distress was immediate and extreme. Lacy (*BRCA2*, age 51, BSO) recalled, '[Testing positive] impacted my life a lot just as far as how I view my own health and also to where I am in life. I was pretty anxious about it all at first and very overwhelmed.'

Decision: preventive surgery

Previvors noted two factors informing their preventive surgery risk-reducing decision. First, women described *being done with having children*. For instance, Jenelle (*BRCA1*, age 41, BSO) explained she had a BSO soon after learning her BRCA status saying, 'I had my ovaries removed within a year after I had my last child, and I had planned to do that. So soon as I knew my family is complete, I moved to remove that.' Some previvors indicated their healthcare providers' recommendation for surgery influenced their decisions but that recommendation was still considered in conjunction with whether they were certain they were done with family planning, as Lacy (*BRCA2*, age 51, BSO) relayed:

I spoke with the genetic counselors, and they said their recommendation for me was have my ovaries and tubes removed. I honestly was done having kids, and I was at an age where they would have liked me to have done [BSO] a little sooner, but I didn't know it at that time. It felt like, okay. Let's do something to move along with.

Previvors choosing surgery also indicated they were *feeling like a ticking time bomb*. Multiple previvors used this exact phrase to describe the uncertainty they felt about their risk and their subsequent risk-reducing decision. As Tiffany (*BRCA1*, 38, PBM) described:

You've heard the ticking time-bomb. That's really how I felt. So, for me, it really wasn't a question. Once, I had all the information with me, I was going to have surgery. I just felt like, why am I going to wait and get [cancer]? I valued my life more than I did my body parts.

Likewise, Camille (*BRCA2*, age 47, PBM) said, after testing positive for BRCA, 'You feel like a ticking time bomb on your shoulders. Just finding out that I might have been positive and not been ready to do something about it, I just, I couldn't really wrap my brain around that.'

Outcome: health-enhancing

Previvors choosing surgery also reported inter-connected health-enhancing outcomes, which highlight the complexity of chronic risk-related uncertainty. They described how their decision *reduced risk-related uncertainty*, which thereby *eliminated disease probability* and *enhanced psychological well-being*.

By choosing surgery, previvors emphasized they *reduced their HBOC risk* as much as clinically possible, which ultimately *reduced their uncertainty*.¹ Shauna (*BRCA2*, age 67, PBM) underwent her PBM because 'you've taken your probability of getting cancer down to almost nothing in today's numbers.' In addition, Tara (*BRCA2*, age 28, PBM) underscored she was a '100% glad' she did a PBM because she 'did all the steps to prevent [cancer].' Similarly, Theresa (*BRCA2*, age 34, BSO with intended PBM) articulated, 'I'm still moving forward with the preventive mastectomy because I think it will save my life. I don't want to waste any more of my life. ... I don't want to know that I could have prevented my own death.'

These women also linked uncertainty and disease probability reduction with eliminating extreme distress. Women said they experienced ‘relief,’ ‘less stress,’ and ‘peace of mind’ after their decision. That is, the psychological chronic uncertainty (and distress) they described when appraising uncertainty as a danger was alleviated by choosing surgery. The following previvors illustrate how their medical decision resulted in *enhanced psychological well-being*:

Since I’ve had [PBM], I felt so much less stressed. It’s been really such a relief, and I don’t have to worry about [getting cancer] every day. (Madison, BRCA1, age 32, PBM)

This is for my own peace of mind because I’d never be at peace if I [didn’t] do it. ... I knew that if I was constantly going through the surveillance of MRI, mammograms every 6 months or so, I would be panicking ... (Nancy, BRCA2, age 40, BSO and PBM)

The number one feeling I felt when I woke up [after PBM] was relief. ... A huge weight lifted! (Anna, BRCA1, age 44, PBM and BSO)

Pathway 2: increased surveillance

Fifteen participants chose increased surveillance. Previvors who appraised their uncertainty as an *opportunity* chose *increased surveillance* as their risk-reducing medical decision (which served as an uncertainty management, as opposed to reduction, strategy) and resulted in both *health-enhancing and health-inhibiting outcomes* (see Figure 2). Their description of this risk-reducing decision-making pathway was less linear than the surgical decision-making process and characterized by a cyclical experience of uncertainty.

Appraisal: opportunity

Women noted two characteristics informing their opportunity appraisal. First, they described an opportunity for *personal control*. They could control uncertainty by choosing a plan. This helped women manage uncertainty about developing HBOC. For example, Hannah (BRCA2, age 35, surveillance) described how taking control gave her an opportunity to ‘shelf’ distressing uncertainty:

Having a plan to do something about it gives me some of that control back. It does. I feel like the time between my surveillance I don’t have to worry because I have these set times and set screenings in place. And outside of that, unless there’s something really weird that I notice with my body, I don’t have to worry about it, which is really nice. I can kind of put it on the shelf.

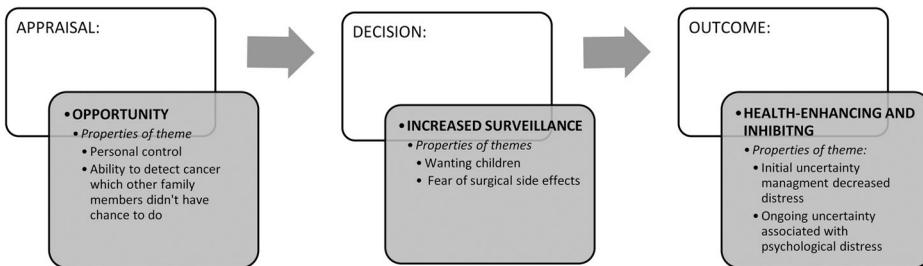


Figure 2. Pathway 2: increased surveillance.

Jordan (*BRCA2*, age 30, surveillance) took this idea of control further by connecting her knowledge of her genetic mutation with her ability to engage in surveillance, which otherwise she would not have been able to do. She positively appraised her opportunity for control and its impact on both her and her family's risk:

I just thought, well, I could find out that I don't have that risk or if I found out that I have the risk, at least then I'll know for sure, and I'll know that I need to have increased surveillance. I was just excited to think that knowing in advance could help make decisions or especially knowing in advance that we didn't have the gene for certain members in the family could all be such a big relief taking that weight off our shoulders and why I really wanted to have testing for myself personally.

Relatedly, women who appraised uncertainty as an opportunity also stressed the importance of having the *ability to detect cancer which family members did not have the chance to do*. While they struggled with risk uncertainty, by knowing their BRCA status they recognized they also had more certainty than their loved ones, giving them an opportunity to do something unlike other family. Elena (*BRCA1*, age 26, surveillance) shared this emotional guilt saying,

I feel sad about it that my mom didn't get the chance to find out that stuff, and she found out too late. Sometimes I just feel like bad about that, and then sometimes I feel happy to know because at least I get to know. Like my mom said, I would be able to possibly save myself or catch it really early if I do develop cancer or anything like that.

Likewise, Claudia (*BRCA1*, age 30, surveillance) expressed,

I was upset that I even knew because my mom didn't get the chance to know. So, part of me felt guilty for going to the doctor's appointment and stuff like that ... I do it for my mom because I almost feel, bratty if I don't because I know, and I can make the cancer potentially prevented, so I just kind of go along. I do it because I'd [feel] bad if I didn't because my mom didn't get the chance to know ... Because she didn't get the chance. So, I would be really selfish to not be on top of it since I know I have it.

Decision: increased surveillance

Women described two factors informing their surveillance risk-reducing decision. First, unlike previvors choosing surgery, they *wanted to have children*. They emphasized having biological children and noted surveillance gave them that opportunity. For instance, Hannah (*BRCA2*, age 35, surveillance) stated, 'I would like to have my own, carry my own child, and be pregnant, and breastfeed.' Some previvors who already had children emphasized how surveillance enabled them to complete their family. Julianna (*BRCA1*, age 34, surveillance) remarked, 'I was going to have more children, so [preventive surgery] wasn't really an option for me.' Some previvors acknowledged surveillance was riskier than surgery but their desire for children was prioritized, as Amelia (*BRCA2*, age 28, surveillance) explained:

My main thing is I want to have a family. That's what I want. We're trying now. We want to have kids. Once we're done having a family, I think I'll listen to it [the preventive surgery option]. But right now, just getting the checkups and getting the surveillance is the best route for me that I feel.

Previvors opting for surveillance did indicate that they planned to do surgeries in the future (given the risks with surveillance), when they were done with family planning.

Similarly, they described complex uncertainty regarding children, making this decision pathway complex as Claudia (*BRCA1*, age 30, surveillance) explicated:

The kid situation is what is keeping me from the major surgeries right now because I just don't know if I want kids. So, I know eventually I am going to do the surgeries. But right now, I'm just kind of like going through with the surveillance to make sure that things are okay. [But] then, part of me sometimes is like I'm just done with all this ... If I'm not sure about the kid situation, then, you know, obviously the surveillance is the way to go.

Women's desire to have children was also related to wanting control over other maternal experiences like breastfeeding. Increased surveillance helped them protect maternal opportunities and maintain control. Lindsey (*BRCA1*, age 27, surveillance) summarized this saying, 'If BRCA has control over my ultimate dream of motherhood, and of breastfeeding, and of being able to carry a child, [then] BRCA is taking away everything else in my life.' Amelia (*BRCA2*, age 28, surveillance) articulated this further stating:

I decided that having my kids a little closer together rather than going through with the mastectomy first was more important to me ... I will be moving on surgical measures as quickly as I feel like I can. But for me, it was about finishing my family and not kind of letting BRCA rule my life. [No one] will make my decisions for me.

Second, previvors choosing surveillance were *concerned about surgical side effects*. This concern was linked to wanting maternal experiences because a surgical side effect was losing their breasts if they underwent a PBM. Previvors like Hannah (*BRCA2*, age 35, surveillance) described breasts as an important – part of their identity: 'This may sound very superficial, but I really like my breasts, and I'm not ready to let go of that part of myself.' Also, breast removal impacted breastfeeding. For example, Elena talked about her decision for surveillance indicating she was not interested in losing the opportunity to breastfeed saying it was 'one of the most important parts of having children' because it facilitated bonding. For these previvors, uncertainty was especially complex. They struggled with the tension between managing uncertainty about risk as well as uncertainty related to being/becoming a mother. As Melissa (*BRCA1*, age 26, surveillance) revealed,

I'm 26, and I've been married for 4 years. I would like to have children at some point, but I'm personally just not ready to cut off my breasts yet, and I have to be okay with that right now. It's difficult, but it's the best decision for me at this point.

This complex uncertainty was further amplified when previvors described concerns about not just losing breasts but associated outcomes like breast implants. Julianna (*BRCA1*, age 34, surveillance) explained it best when she said,

I [am] really petrified of having implants. I'm like so scared of them. If I really go through [with] this radical surgery so I can prevent cancer, it's really unlicensed against putting something torn into my body ... Then I also feel like it's not a permanent thing. You can't just get implants, and then have them the rest of your life. They need maintenance, so I think every what, every 10 or 20 years or something, you have to ... I don't like that. I just don't, and I mean ultimately if I were ever to get breast cancer, I would absolutely have my breast removed. No questions asked ... But right now, I would ultimately like to avoid implants.

Yet in addition to breast loss, previvors expressed concern about the surgical side effect of a BSO – menopause. Medically induced menopause is a more extreme process than natural menopause, and multiple previvors admitted they feared it. For instance, Angela (*BRCA1*, age 36, surveillance) explained, ‘I am terrified to go into medical-induced menopause. It scares me, and it makes me nervous.’

Outcome: health-enhancing and inhibiting

Previvors choosing surveillance reported both health-enhancing and inhibiting outcomes, tied to their uncertainty. They described how initially when they made their decision it helped them *manage risk-related uncertainty*, which was health promoting by *reducing distress*. However, because their uncertainty persisted (it was managed but not reduced as was the case when choosing surgery), they encountered *psychological distress associated with the chronic uncertainty*.

For instance, as noted above, Audrey (*BRCA1*, age 23, surveillance) explained that surveillance originally provided her with ‘peace of mind’ (a phrase also utilized by previvors choosing surgery). Yet, Audrey did not ‘feel any better about her risk.’ Previvors, like Audrey, who chose surveillance initially felt ‘calmer’ about cancer probability but undergoing surveillance did not reduce uncertainty completely. Instead, previvors in the surveillance pathway reported persistent uncertainty that caused them ongoing distress. Audrey explained saying she ‘started having like this recurring thought of “if I do nothing [by doing surveillance not surgery],” and then I wait, and then get sick – I [had] all this knowledge, and I wasted it.’

Unlike previvors choosing surgery, previvors undergoing increased surveillance encountered cyclical uncertainty and distress. Their experiences suggest women were coming full circle to the beginning of their decision-making process by having to re-appraise uncertainty. Given this, we extended the analysis of this pathway and identified that women indeed experienced a cyclical decision-making process characterized by ongoing uncertainty.

Extension of pathway 2: increased surveillance

Re-appraisal: danger

After choosing surveillance, previvors re-appraised uncertainty. Their re-appraisal somewhat mirrored previvors’ appraisal in pathway 1. Their uncertainty was no longer described as an opportunity and instead appraised as a *danger*. However, their danger appraisal was different than previvors selecting surgery.

For these women, the danger appraisal was informed by the *experience of distressful uncertainty triggers*. They described being able to ‘shelf’ the uncertainty initially but realized the uncertainty returned with triggers. Triggers included surveillance appointments and family planning. While they did not describe thinking about risk daily, they did report heightened stress and uncertainty at screening appointments (e.g. breast MRIs, mammograms, and transvaginal ultrasounds). They felt like ‘I may have cancer.’ That distressful uncertainty could also trigger other emotions, such as grief. Claudia (*BRCA1*, 30, surveillance) shared,

Every doctor’s appointment is just a constant reminder of this gene that I have that I lost my mom to. The appointments are so hard because I have the whole issues and stuff where they

[doctors] want to follow up on it. So, the one person in this world that I want to be there for me isn't there for me because of this gene, and so it's hard because it's a constant reminder that this is the gene that took her and the only person in this world that could comfort me through all these checkups and follow-ups and stuff is my mom, and she's not here. It's really hard. The doctor's appointments and everything that I go through is really tough. It's not like [I] can go to [my] mom, and she is cheering me on and those kinds of things. And so, the appointments are just horrible.

Melissa (*BRCA1*, age 26, surveillance) talked about experiencing panic attacks during breast MRIs. She struggled with the uncertainty of her risk mentioning 'that loud voice,' – a persistent voice in her head saying this could be the day she was diagnosed. Triggers of distressful uncertainty also occurred when family inquired about appointments. Katie (*BRCA1*, age 31, surveillance) stated,

If my husband asks me about when my next MRI is, [my anxiety] just shoots up. I kind of forget about it when no one is ever bringing it up. It's always there at the back of my mind. But when someone brings it up or something has in my life, it just gets more and more prevalent.

Additionally, previvors described heightened distressful uncertainty when making family planning decisions. Hannah (*BRCA2*, age 35, surveillance) talked about how she 'could go for a while without thinking about [her risk]' but when she considered family planning options it would trigger uncertainty and distress. Marisol (*BRCA1*, age 29, surveillance) further explained how this escalated during pregnancy (screening halts during pregnancy): 'It makes me worried about being pregnant and now breastfeeding. It's like such a long time that I don't get screened. I feel more stressed about it this time.'

Decision: reconsidering options

After re-appraising uncertainty as a danger, previvors described *reconsidering options*. Though they did not change their decision, they did constantly re-consider options, including surgeries. This ongoing contemplation helped them manage ongoing uncertainty and was informed by *time passed and older age*, factors associated with increasing risk. For instance, Hannah tested positive for *BRCA2* in 2011. She stated she 'start[ed] to think about doing preventive surgery as an option especially as I get older, and I feel like the more times that I go in to get surveillance, the higher my chances are of coming out with something, a not so good outcome.' Similarly, Angela tested positive for *BRCA1* in December of 2012. During the interview she was 36 years old, which is during the recommended age timeframe for removing one's ovaries if finished having children.² Reflecting on the past few years, she said,

I [now] have to be a little bit more aggressive and sort of say this is what I want to do. I don't want to push it off forever. I'd like to do it within a year. I just wanted to buy myself a year when my children are a little bit older.

Outcome: health-inhibiting

Previvors' re-appraisal and subsequent ongoing contemplation of options was health-inhibiting and embedded in chronic uncertainty. Women described *false hope as masked anxiety/worry* as well as *feeling like it was a gamble/risk*. As Julianna (*BRCA1*, age 34, surveillance) explained:

I kind of have this false sense of like nothing happen to me because – like nothing [has] happen to me. But in the back of my mind, I'm essentially waiting for cancer, but I can't feel like I'm just going to catch it. ... I'm really just hoping that's the right decision. I'm petrified that it's not.

Previvors recognized the limitations of surveillance, intending to do preventive surgery in the future (but again dealing with uncertainty about when). This was distressful. They described *feeling like it was a gamble/risk* – that undergoing several rounds of surveillance was too risky to continue for long when a preventive surgery could reduce risk, uncertainty, and distress. Julianna (*BRCA1*, age 34, surveillance) stated:

I'm really just gambling here. I'm gambling that I can live my life happy enough for a few more years or, as many more years as I can push it, and I pray to God that I don't get ovarian cancer because if I get ovarian cancer, I'm just going beat myself up for not doing the surgery and for being selfish and not wanting to go through menopause. I mean, I would probably have so much more of struggle with the actual diagnosis because I could have prevented it.

These previvors acknowledged they were not able to eliminate their uncertainty through surveillance. They described having to reconcile with the psychological distress and chronic uncertainty of their 'gamble,' while constantly reassessing it, knowing that one day they would choose an alternative risk management option (i.e. surgery).

Although previvors choosing surveillance initially experienced a decision-making pathway distinct from those choosing surgery, once their decision was made their ongoing experience with uncertainty (and thus, entrance back into the decision-making process) seemed to somewhat mirror the experiences of previvors in pathway 1 (surgery). However, they also experienced chronic uncertainty (and associated distress). They seemed to recognize that uncertainty and distress would persist until they made the decision to do surgery (or enter pathway 1). To further illustrate the unique cyclical nature of this complex uncertainty in women's surveillance decision-making process, [Figure 3](#) combines the full analysis.

Non-emergent pathway: chemoprevention

Although no previvors in this study chose chemoprevention, a small number ($n = 2$) did acknowledge it was an option. A pattern emerged in their discussions that inform our understanding as to why this third decision-making pathway did not emerge even though it is a risk-reducing option for previvors. Their reports capture a *lack of knowledge/understanding about chemoprevention*.

Lack of knowledge/understanding about chemoprevention

These women reported that they lacked knowledge about chemoprevention, which was tied to it not being discussed by their healthcare providers. This lack of knowledge informed previvors' perception of it not being a risk-reducing option.

For instance, two participants described having no knowledge about chemoprevention and, yet, also expressed interest. Marisol (*BRCA1*, age 29, surveillance) said, 'I don't really know that much about it I guess. But I'm actually going in a FORCE Conference³ this year, and that's one of the sessions I signed up for because I don't really feel like I know a lot

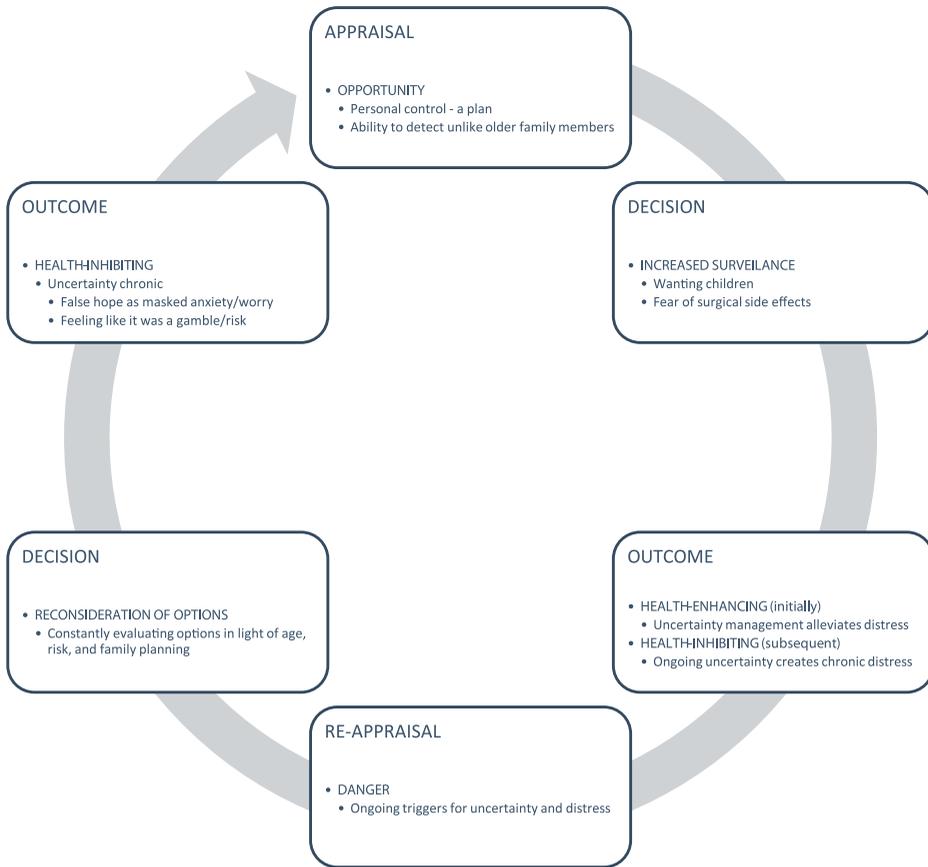


Figure 3. Extended surveillance pathway – chronic uncertainty.

about it.’ Another previvor did not consider chemoprevention because her doctors did not bring it up in their conversations. Hannah (*BRCA2*, age 35, surveillance) reported, ‘Basically, my doctors have not brought it up to me, and so I haven’t seen it as an option to myself.’

This lack of knowledge and communication about chemoprevention may also contribute to confusion. Hannah stated,

I don’t know a lot about it. My understanding is that it involves taking chemo in order to kind of reduce the risks. I have a friend right now who is going through breast cancer treatment, and I don’t understand enough about it. To me, it sounds like the chemo is so – like the side effects are just a lot worse than the risk reduction, but I haven’t looked into it enough to really [decide] on that.

Hannah’s experience suggests there may be confusion about how chemoprevention to reduce risk is different from undergoing chemotherapy after diagnosis. Although most women in the entire sample did not discuss chemoprevention, many talked about chemotherapy negatively – noting it was something they would not want their children to witness them undergoing. Their perceptions of chemotherapy were informed by personal observations (prevalent family history) of having witnessed many family members suffer

from negative chemotherapy side effects. Thus, women may be both uninformed (possibly due to a lack of healthcare provider communication) and have misperceptions about chemoprevention (related to their unique family medical history), which may contribute to it not emerging as decision pathway in this sample.

Discussion

This study captures the complex decision-making process of previvors – an at-risk population whose experiences may inform other individuals living with chronic risk and uncertainty. Our findings show that women can encounter two distinct uncertainty management (i.e. risk management) decision-making pathways – preventive surgery and increased surveillance. Most notably, the analysis brings to the surface life-span phenomena (e.g. age, developmental milestones like giving birth, family planning) that play a significant role in women's decisions. Women's decision pathway included a three-part process of (1) appraising their uncertainty, (2) making the medical decision (uncertainty management strategy), and (3) experiencing outcomes associated with the decision. This three-part process, however, manifested differently depending upon the decision (uncertainty management choice) women made.

For instance, previvors choosing surgery appraised uncertainty as a danger, and after making their medical decision, experienced health-promoting outcomes associated with reduced uncertainty. In contrast, women appraising uncertainty as an opportunity opted for surveillance. These women encountered a mixture of health-promoting and health-inhibiting outcomes as their uncertainty was not managed in the long term. These previvors eventually viewed uncertainty as a danger and encountered ongoing, cyclical uncertainty and distress as they constantly reassessed their decision and described feeling like they were gambling with their lives. Ultimately, women in this pathway exhibited persistent distress – heightening the practical need for intervention in assisting these women across time rather than just at the time of their risk-reducing decisions.

With this in mind, we highlight the important role of life-span phenomena in women's decision-making and discuss the implications of these results in theory and practice.

Chronic uncertainty and risk management decision-making

Uncertainty has been explored in patients' illness experiences (e.g. diabetes, HIV/AIDS, cancer) as well as genetic counseling. Our study extends this by capturing how uncertainty informs the decision-making process of individuals without illness/disease but coping daily with life-threatening risk. The theoretically informed visuals bring to light the different pathways women's uncertainty management can take them and how each decision has variant health implications. These visuals provide practitioners a translational tool that can be used to help women compare options, a clinical intervention direly needed in practice (Padamsee et al., 2017).

These pathways also bring to the forefront a serious issue impacting women's chronic risk/uncertainty – the importance of understanding how uncertainty informs a health decision not just at one point in time but *across* time. In other words, the life-span theoretical lens should be integrated to better attend to women's chronic psychological distress.

By highlighting life-span issues or phenomena impacting women's experiences, we move several issues to the front of uncertainty and risk management.

First, previvors selecting surveillance are at risk for extreme distress and must learn to cope with complicated emotions. As previous research shows, women living with a psychological chronic risk encounter detrimental psychological and physiological effects (Berlin et al., 2013; Cohen et al., 2002). Women in the present study described extreme distress not just prior to making the decision (both surgery and surveillance pathways) but also after making a decision (surveillance pathway). Unlike previous research that links positive emotional responses with opportunity appraisals of uncertainty (Mishel & Clayton, 2008), women who appraised their uncertainty as an opportunity and subsequently chose surveillance described conflicting positive and negative emotions (e.g. happy for control but emotionally guilt ridden about their opportunity). Moreover, they initially experienced relief but ultimately, because their risk continued, faced ongoing negative emotions after making their decision.

Second, life-span issues complicated women's uncertainty and distress. Life-span factors influencing their decision were unpredictable, heightening uncertainty and stress. Life-span issues certainly play a prominent role in women's illness experiences (e.g. Fisher, 2010, 2014; Pecchioni, Wright, & Nussbaum, 2005), and clinician-researchers have long argued for this approach when treating individuals (e.g. Rolland, 1994). It is likely that previvors' ongoing uncertainty will further persist across their life span, meaning additional life course issues are of concern. This will even be true for those women who opted for surgery as generational concerns can arise as they reface this decision-making process for their children who are also of increased risk.

Last, and somewhat related to this, science is a life-span phenomenon. Science is constantly evolving and hard to keep up with. Chemoprevention did not emerge as a part of previvors' decision-making process, which may be in part because it is a newer option and, therefore, less understood or even considered by healthcare providers and practitioners. Risk-reducing options constantly evolve especially in the age of precision medicine (see Scherr et al., 2017), affording women with new options (but also unpredictability as to what those options may be down the line). Relatedly, the changing nature of science is sometimes used as a hopeful lens. Genetic counselors note the 'uncertainty of science' to help elevated and high-risk women manage uncertainty (e.g. science will bring a cure) (Bylund et al., 2012).

Implications for theory

With these findings in mind, we argue that a life-span theoretical lens highlighting an ongoing experience of uncertainty and risk-related medical decisions can help emphasize critical factors like life course/developmental transitions (e.g. family planning), age and increased risk, generational factors (e.g. offspring's risk), family history/memories, and the evolving nature of science – factors these previvors identified as critical to their decision-making. To date, research focused on uncertainty management and medical decision-making (with both acute and chronic conditions) typically addresses one point in time, with a heavy focus on treatment decisions, making certain people have the knowledge/skills needed to decrease uncertainty and to make a decision (e.g. Mishel et al., 2009). Our study shows that even after a medical decision has been made in a high-risk context,

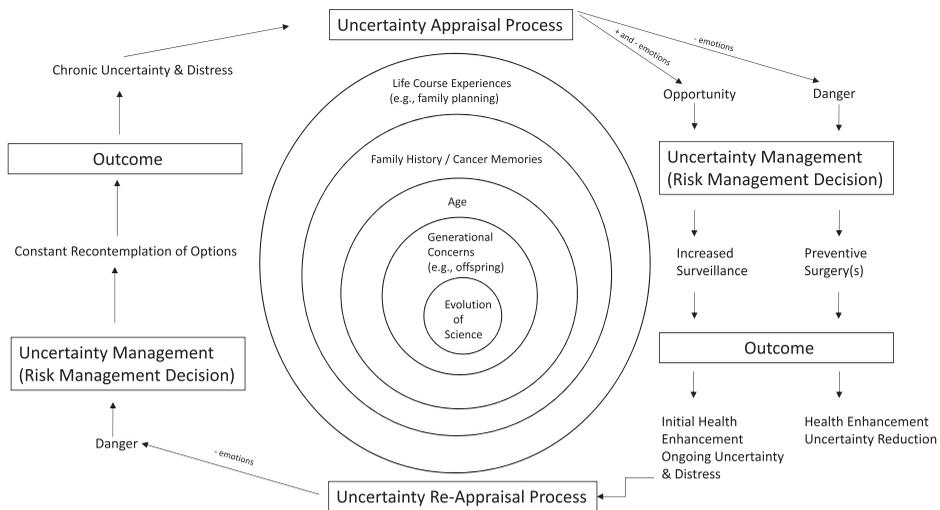


Figure 4. Life-span model of previvors' chronic uncertainty and risk management decision-making.

uncertainty and risk distress do not necessarily end, particularly when riskier medical options (e.g. surveillance) are chosen. Women may continue to experience uncertainty when risk is managed as opposed to reduced, meaning their decision-making process is ongoing. Moreover, their initial appraisal of that uncertainty can be mixed (both positive and negative), which extends Brashers' theorizing of appraisals as either positive or negative and reinforces recent work on risk appraisals (see Cohen et al., 2016). Furthermore, women's appraisals of uncertainty can change and become more negative, as was evidenced with women choosing surveillance.

To enhance the translational potential of our findings for theory and practice, we propose a life-span model of previvors' chronic uncertainty that considers the variant decision-making pathways they may experience in the context of life-span factors that influence their ongoing decision-making process (see Figure 4). With this model, we argue two theoretical points about uncertainty for individuals facing high disease risk or chronic risk of some kind. First, uncertainty as a theoretical construct should be viewed as a life-span phenomenon, one that is fluid with potential for change with both health-promoting and health-inhibiting appraisals and decision-making consequences. Second, uncertainty management decisions should be focused more as a life-span process as appraisals can change, management strategies can change, and the uncertainty management process (or risk-reducing process) is informed by ongoing changes that are inherently life-span phenomena (e.g. age, life course developmental tasks). Given our findings, it seems critical that scholarship that theorizes about uncertainty and risk also integrate or utilize a blended lens that incorporates life-span theory.

Implications for practice

Finally, we offer some suggestions for future practice. A recent systematic review examined 68 educational tools (from the U.S., Canada, Australia, the U.K., France and Ireland) currently used to counsel women undergoing and receiving *BRCA1/2* genetic testing (Dorval,

Bouchard, & Chiquette, 2014). Collectively these practice tools focused on the meaning of test results and educating women about their risk-reducing options. Reviewers noted that none addressed women's psychosocial experiences that impact their decision-making. As such, they identified the lack of psychosocial support in any tool as a major shortcoming. Our findings warrant the need for ongoing biopsychosocial decision-making support services for previvors, and our model provides the first psychosocially focused educational tool that could be translated to practice.

Specifically, genetic counselors could present these visual tools to women facing this decision-making process as the pathways provide them with a preview of what they may experience with each decision. For example, genetic counselors could share these visual tools during (1) the pre-genetic testing consultation when the patient is deciding to undergo genetic testing and (2) the post-genetic testing consultation after the patient receives positive genetic test results. Furthermore, because women choosing surveillance exhibit ongoing psychological chronic distress, genetic counselors could provide decision support beyond the usual genetic counseling and genetic testing process. Potential points in time for offering such psychosocial support services include when women are considering having children and when women are between the ages of 35 and 40 years old given current NCCN guidelines for considering preventive surgeries. Genetic counselors could also revisit the life-span model (see [Figure 4](#)) during these support sessions to facilitate conversations for re-evaluating decisions throughout previvors' life-span, which may assist women managing their uncertainty/distress on an ongoing basis. At the same time, the life-span model helps clinicians and practitioners identify critical factors influencing women's decisions. These tools could be integrated into a decision-making intervention that helps women cope across their life span (as opposed to just addressing one acute decision). Likewise, this tool could be used to help women who choose surveillance as they continuously re-evaluate options and face an ongoing decision-making process.

Future directions

Future research could design and test the effectiveness for both managing women's uncertainty and buffering harmful distress as they live with psychological chronic risk. Our model is just a beginning. Future research should explore the cyclical nature of women's uncertainty as they embark on increased surveillance which persists through years and multiple life transitions (e.g. becoming an adult; getting married; family planning; being pregnant without surveillance). It is also likely that women who choose surgery experience a return of uncertainty when offspring face risk. Future research that incorporates more longitudinal methods could extend our model to comprehensively address chronic risk decisions.

Limitations

Several limitations exist. First, most participants were Caucasian. While recruiting previvors is challenging, the experiences of women of other ethnicities are unique and missing in research, especially within high-risk families. In addition, the majority of women were 30–40 years old. Given current clinical recommendations suggest previvors remove their ovaries between ages 35 and 40 and to remove breasts around age 35 (Friedman et al.,

2012; NCCN), it is not surprising that more women in this sample had selected preventive surgery. Women who are notably younger (e.g. 18–30) and likely to select surveillance should also be sampled given their extended experience of surveillance and, thus, longer experience of ongoing psychological chronic risk/distress.

Notes

1. For example, undergoing a preventative mastectomy reduces one's breast cancer risk by 90% or more (Metcalf et al., 2004).
2. The National Comprehensive Cancer Network (NCCN) recommends removal of ovaries and fallopian tubes between age 35 and 40 and upon completion of family planning.
3. 'Joining FORCES Against Hereditary Cancer' is an international conference hosted by the non-profit organization called FORCE (Facing Our Risk of Cancer Empowered) and is designed for individuals and families affected by hereditary cancer or a genetic mutation associated with an increased risk of hereditary cancer.

Acknowledgments

A previous version of this manuscript received a top paper award from the Health Communication Division at the annual meeting of the International Communication Association Conference in Washington, D.C. in 2019. The authors would like to thank Facing Our Risk of Cancer Empowered (FORCE) for their recruitment assistance and express immense gratitude to the previvors who shared their decision-making experiences.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by the Texas A&M University's College of Liberal Arts Vision (2020) Dissertation Enhancement Award; University of South Florida's College of Arts and Sciences' Pilot Research Internal Grant.

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