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Intuition versus cognition: a qualitative exploration of how women understand and manage their increased breast cancer risk

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Abstract Risk comprehension in individuals at increased familial risk of cancer is suboptimal and little is known about how risk is understood and managed by at-risk individuals who do not undergo genetic testing. We qualitatively studied these issues in 36 unaffected women from high-risk breast cancer families, including both women who had and had not undergone genetic testing. Data were collected through semi-structured interviews and data analysis was guided by Grounded Theory. Risk comprehension and risk management were largely influenced by the individual's experience of coming from a high-risk family, with both tested and untested women relying heavily on their intuition. Although women's cognitive understanding of their risk appeared generally accurate, this objective risk information was considered of secondary value. The findings could be used to guide the development and delivery of information about risk and risk management to genetically tested and untested individuals at increased risk of hereditary cancer.

Keywords Familial risk · Oncology · Genetic testing · Risk comprehension · Risk perception

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Introduction

The identification of genetic mutations that confer an increased risk of disease has revolutionized risk assessment by providing specific genetic risk information that can be used to tailor risk management (Etzioni et al., 2003; Siegel et al., 2014). However, the majority of unaffected at-risk individuals do not undergo genetic testing, either because they are not eligible for testing, they delay testing for a period of time, or they decline testing altogether (Finlay et al., 2008; Lerman et al., 1999; Sharaf et al., 2013).

In Australia, testing for genetic mutations in breast cancer susceptibility genes is not covered by the universal health care scheme (Medicare) and costs approximately AU$2000, except for individuals who have a 10 percent or greater risk of carrying a mutation. Unaffected women, however, are typically not offered testing unless a mutation has been identified in an affected family member, as a 'normal' result in an unaffected person is impossible to interpret (Lau & Suthers, 2011). Until recently, the majority of genetic tests performed in Australia have been research-based, often providing no-cost testing (and compulsory genetic counseling) to eligible individuals and/or families members. However, direct-to-consumer genetic testing is increasingly being accessed, and consequently, unaffected individuals at increased risk of breast cancer who do not undergo genetic testing, and others those who seek direct-to-consumer genetic testing, may have little or no contact with genetic services; thus risk perceptions are formed and risk management decisions are made in the context of uncertainty about risk.

Risk perception is complex and often inaccurate. In general, women with a family history of breast cancer tend to overestimate their risk (Caruso et al., 2009; Sivell et al., 2008). While genetic counseling aims to improve accuracy

of risk perceptions (Biesecker, 2001), a significant proportion of counselees continue to overestimate or underestimate their risk (for reviews see Braithwaite et al., 2004; Butow et al., 2003; Smerecnik et al., 2009). Furthermore genetic testing does not always have the intended effect on perceived risk and risk management. Dawson et al. (2008) reported that about half of women who were found *not* to carry a genetic mutation, such as BRCA1/2, continue mammographic screening at a frequency appropriate for high-risk women. Since screening and prevention behaviours are often associated with variables other than objective risk levels (McInerney-Leo et al., 2006; Meiser et al., 2013; Price et al., 2010; Schwartz et al., 2005) there is a need to understand what information is being used to inform risk perceptions and risk management strategies (Pilarski, 2009), particularly in women who do not access genetic services (Keogh et al., 2011).

Factors thought to affect risk perception and interpretation include the inherent complexity of risk estimates (Cameron et al., 2009; Hallowell et al., 1997), persistent beliefs in lay theories of risk and inheritance (McAllister, 2003; Sanders et al., 2007), and difficulties in reconciling new risk information that is inconsistent with existing beliefs (Bottorff et al., 1998; Michie et al., 2002). Most studies investigating how risk is conceptualized focus on at-risk individuals who have undergone genetic counseling or testing (Bakos et al., 2008; Carlsson & Nilbert, 2007; Dagan & Goldblatt, 2009; van Dijk et al., 2004). These studies have highlighted inconsistencies between participants' and counselors' evaluations of risk level and risk relative to peers (Bjorvatn et al., 2007), and between participants' interpretations of risk level and their causal explanations (Ersig et al., 2010). Inconsistencies have also been reported between risk perception and behavior. For example, some women who were ineligible for testing knew they were at increased risk for breast cancer, and acknowledged their concern over this, but did not engage in recommended screening (Keogh et al., 2011). Thus research shows that even when individuals hold relatively accurate beliefs about their risk level, they may fail to take appropriate action to manage their risk.

For individuals who do not undergo a formal risk assessment, risk perceptions may be wholly subjective or based on information communicated by relatives (Vos et al., 2011). Knowing how women understand or interpret their risk both in the presence and absence of accurate objective risk information is vital for improving risk communication and comprehension, and thus optimizing risk management in at-risk individuals (Pilarski, 2009; Sivell et al., 2008). Therefore the primary aim of the current study was to explore how risk perceptions are formed in both tested and untested, unaffected women at increased familial risk of breast and/or ovarian cancer. A secondary aim was to examine the impact of these perceptions on risk management.

Method

Design

A qualitative approach was used. Data were collected through semi-structured telephone interviews, with data collection and analysis guided by Grounded Theory. The style of Grounded Theory employed in the present study adopts the methodology of Strauss (Strauss & Corbin, 1990), which accommodates the inevitable influence of existing knowledge about the topic on the research process (Charmaz, 2003).

Study context and participants

The participants were unaffected women at increased familial risk of breast cancer who were participating in the Kathleen Cunningham Foundation Consortium for Research into Familial Breast cancer (kConFab) Psychosocial Study, aged 18–75, with sufficient English language skills to complete a semi-structured interview. Details of kConFab and the Psychosocial Study are reported elsewhere (see Phillips et al., 2005), but in brief, kConFab is a population-based research registry of Australian and New Zealand families with a strong history of breast cancer. Individuals who had been referred to one of 13 familial cancer clinics, based on their family history of breast and/or ovarian cancer, were invited to participate in kConFab. The Psychosocial Study collected stressful life events, social support and coping data from unaffected women at 3-yearly intervals. Participants were aware of being at increased risk although many had not attended genetic counseling or undergone clinical genetic testing.

Sampling and recruitment

Ethical approval was obtained from participating sites (Westmead Hospital NSW, King Edward Memorial Hospital WA, Women's and Children's Hospital SA) and The University of Sydney.

Women were selected from the pool of psychosocial study participants based primarily on their genetic testing status. The aim was to recruit approximately equal numbers of women from each genetic testing status. Purposive sampling was then utilized to maximize variation across demographic and genetic variables, including marital status, parity, recency of genetic testing result (if applicable), uptake of risk-reducing surgery, cancer-related distress and genetic mutation testing status (ineligible for testing,

declined testing, delaying testing, tested carrier or tested non-carrier—reported by participants as part of the kConFab psychosocial study assessment and verified against kConFab data). In this research setting, women were considered to be ineligible for testing if there was no living affected relative to provide a blood sample for mutation searching or if mutation searching of an affected relative's sample did not identify a known pathogenic mutation. Mutation searching involves examining the entire length of the relevant genes for mutations. Once the location of a familial genetic mutation has been identified, unaffected relatives may undergo predictive testing, which requires that only the gene location in which the mutation was previously identified be examined. This is typical of most research-based genetic testing as mutation searching of all members of a high-risk family can be costly. Thus the women in this study were ineligible for predictive genetic testing (herein 'ineligible for testing'). This is different to being ineligible for genetic testing due to the family history not being strong enough to warrant it. Women from families with an identifiable mutation who have indicated they do not wish to be tested are classed as decliners, while women who have indicated they wish to be tested at a later date (e.g., when they are older or have completed childbearing) are classed as delayers.

Family history data were obtained from kConFab. Cancer-related distress was indicated by women's level of intrusive thoughts about being at increased risk for breast cancer, as measured by the intrusion subscale of the Impact of Event Scale (IES; Horowitz et al., 1979) at the women's most recent kConFab psychosocial study assessment (above or below IES established 'low' distress cutoff). Other sampling variables were obtained from the Psychosocial Study database.

Selected women were mailed an introductory letter about the current study, an information statement and consent form, and a reply-paid envelope. Consenting women were interviewed via telephone.

Data collection

Each telephone interview started with the interviewer (LH) asking for demographic information (age, marital status, parity, employment status, occupation, education level). Open interview questions were then used to avoid leading the interview content (Allan, 2003). The interview schedule, of which slightly different versions were used depending on testing status, included questions designed to elicit a rich description of the participants' understanding of their risk level and approach to risk management:

- What do you understand about your risk?
- What does that mean for you?
- What sorts of information do you draw on to understand your risk?
- What kind of thoughts do you have about your personal risk?
- From whom have you received information about your risk from?
- What do you understand about your risk in light of any information you have received about it?
- What do you do to manage or minimize your risk?

Each interview, lasting between 20 and 70 minutes, was audio-recorded and transcribed.

Data analysis

Demographic, family history, risk-reducing surgery and testing status data were analyzed descriptively using SPSS (version 20). Interview transcripts were coded using NVIVO software (version 10). The codes were validated through constant comparison within and between interviews and through cross-coding (by LH, MP, PB), until saturation was achieved. The criteria used to determine the point at which additional data did not generate any new information or add to the emerging theory (the saturation point) (Glaser & Strauss, 1967; Guest et al., 2006), namely incident exhaustion, category saturation, overextension and stabilization of coding definitions (Bowen, 2008; Guest et al., 2006), were established prior to data collection. Saturation is inherently linked with the method of constant comparison (Bowen, 2008; Strauss & Corbin, 1990), a key component of Grounded Theory methodology, and Glaser and Strauss (1967) propose that saturation should be used to determine sample size. It has been suggested that the concept of saturation is often too loosely defined, that "researchers should make explicit the steps they take to ensure data or theoretical saturation. They should provide clear descriptions of the saturation process in their research reports" (Bowen, 2008, p. 137) and "a general yardstick is needed … to estimate the point at which saturation is likely to occur" (Guest et al., 2006, p. 61). Thus establishing criteria for assessing the data saturation point prior to data collection was undertaken in the interests of methodological rigor.

Results

Participants

Of 63 eligible women invited onto the study, 36 completed the interview, 13 declined (two carriers, two non-carriers, seven delayers, two ineligible for testing), 10 were non-contactable, and four women were not pursued as the data

saturation point had been reached. The mean age of participants was 46 years, most were married or cohabiting (81 %) and had children (83 %), and a third (33 %) had completed university education (Table 1). Over a third (39 %) of participants had more than one first-degree relative (FDR; e.g., mother, daughter, sister) with breast or ovarian cancer and over half (59 %) had more than one second-degree relative (SDR; e.g., grandmother, aunt) with breast or ovarian cancer, comparable with other samples of women at increased familial risk of breast cancer (den Heijer et al., 2012; Meiser et al., 2002). Sixteen women had been genetically tested and 20 had not. Key characteristics and pseudonyms used for untested and tested participants are listed in Tables 2 and 3, respectively.

Table 1 Summary of participant characteristics (N = 36)

	n (%)
Mean age	46
Married or cohabiting	
Yes	29 (81)
No	7 (19)
Children	
Yes	30 (83)
No	6 (17)
Education	
High school	19 (53)
TAFE	5 (14)
University	12 (33)
Mutation testing status	
Ineligible	12 (33)
Carrier	8 (22)
Non-carrier	8 (22)
Declined	6 (17)
Delayed	2 (6)
Risk-reducing oophorectomy	5 (14)
Risk-reducing mastectomy	2 (6)
Familial mutation	
BRCA1	10 (28)
BRCA2	8 (22)
P53	2 (6)
BRCA2_np[a]	1 (3)
First degree relatives with breast/ovarian cancer	
0	3 (8)
1	18 (56)
2	8 (22)
3	6 (14)
5	1 (3)
Second degree relatives with breast/ovarian cancer	
0	6 (19)
1	10 (25)
2	14 (42)
3	4 (11)
5	2 (6)

[a] BRCA2_np—this mutation is non-pathogenic

Findings

The analysis revealed that women's risk perceptions and subsequent decisions about risk management were primarily driven by an *intuitive* understanding of risk, which was a product of women's experiences associated with coming from a high-risk family and their reactions to these experiences. In many cases, objective risk information, leading to a *cognitive* understanding of risk, was considered of secondary value. Women's intuitively-derived risk perceptions often contradicted their cognitive understanding of risk. These categories and their properties are reported below, in order from the most to least frequently endorsed, along with associated risk management strategies.

Intuition

Four key properties of intuition were identified—feelings of expectation, affective understanding of risk, theories about cancer and heredity, and assumptions about carrier status. Almost all women drew on their intuition, describing risk as intricately linked with experiences, emotions, and personally-derived theories and assumptions. Exemplifying this, Casey (ineligible for testing) said "with regards to statistics … I don't understand anything, but going with gut feeling, I do have a feeling that I do have a high chance of getting (breast cancer)". Similarly, Karyn (ineligible for testing) said "I tend to just go on my own instincts about things… I guess I have some intuitive feeling that maybe it would be positive".

Expectation

Many participants expected to be identified as a mutation carrier or diagnosed with breast cancer, even if their objectively-defined risk was low. For example, Yolanda (non-carrier) said "you kind of expect that you're going to get diagnosed with it… because of the family history". Patty's expectation of being a carrier made it harder for her to process her non-carrier status; she said "that was a big shock, because I'd honestly thought it would come back positive… I think I was actually more honestly ready to hear the positive result". Expectation facilitated preparation for bad news, was often explained by repeated exposure to cancer in the family, synonymous with elevated risk perceptions, and a barrier to comprehending low-risk information.

Table 2 Individual characteristics of untested participants

Pseudonym	Age	Family mutation	FDRs[a]	SDRs[b]
Ineligible				
Ann	67	N/A	3	2
Hannah	47	N/A	1	2
Indie	66	N/A	1	2
Jill	57	N/A	1	2
Karyn	38	N/A	1	1
Casey	36	N/A	1	2
Jean	62	N/A	2	3
Kath	34	N/A	1	1
Lee	60	N/A	2	2
Ella	29	N/A	1	0
Vicki	34	N/A	1	0
Wendy	39	N/A	1	2
Declined				
Bella	59	BRCA1	3	2
Gemma	50	BRCA1	2	1
Cate	58	BRCA1	0	5
Denny[c]	59	BRCA2	0	5
Onda	50	BRCA2_np[d]	3	1
Rita	36	Ineligible	1	1
Delayed				
Nina	34	BRCA1	1	2
Diane	41	Ineligible	1	2

[a] FDRs: number of first degree relatives with breast or ovarian cancer

[b] SDRs: number of second degree relatives with breast or ovarian cancer

[c] Participant underwent risk-reducing oophorectomy 12 months ago

[d] BRCA2_np—this mutation is non-pathogenic

Affective understanding of risk

Many women's risk perceptions were closely linked with emotions elicited by past experiences. Ella (ineligible for testing) felt at high risk "because my mum got it and she was so young, and by the time that they found it, it was already too late … (so) me and my sister both have fears that we're going to get it one day". Casey's (ineligible for testing) "gut feeling" was related to having a breast cyst biopsied more than 10 years ago. The potency of affective understanding of risk was evident in women's belief that a hypothetical non-carrier result "still doesn't lower my chances (of developing breast cancer), I don't think" (Ella, ineligible for testing), with Karyn (ineligible for testing) explaining that "even if I did get a negative result… I wouldn't a hundred percent trust it anyway". Affective understanding of risk impacted women's risk management strategies. For instance Tina (carrier), who had undergone both bilateral risk-reducing mastectomy and oophorectomy, had "made the decision to go ahead with the surgeries anyway, regardless of the testing" and said that if she'd received a non-carrier result, the only difference would be that she "probably wouldn't have done the operation so quickly". Three non-carriers who expressed a high affective understanding of risk all continued with annual or twice-yearly MRIs and/or mammograms after receiving their non-carrier result. Of note, Medicare covers the cost of mammograms and ultrasounds but not the cost (about AU$500) of screening MRIs, except for women aged under 50 years who have a very high risk of breast cancer.

A minority of women's affective understanding was that they were at low risk, including a carrier who had not undergone risk-reducing surgery, three decliners and two women who were ineligible for testing. Zara (carrier) said "I'm quite positive that there's a chance that I may never develop it … even though I am a BRCA1". Zara's approach to screening was appropriate for her high-risk status, even though her intuitively derived low-risk perception seemed to have overridden her cognitive understanding of risk. Similarly, Onda (decliner) explained she did not feel her risk was elevated despite breast cancer being "so prevalent in my family, and I was a smoker, and I was on

Table 3 Individual characteristics of tested participants

Pseudonym	Age	Months since result	RRO[a]	RRM[b]	Family mutation	Previous decline or delay	FDRs[c]	SDRs[d]
Carrier								
Gina	42	16	Planned	Planned	BRCA1	No	2	2
Sally	53	15	12	4	BRCA1	No	2	1
Zara	37	30	Planned	N/A	BRCA1	No	2	3
Fran	40	126	48	N/A	BRCA2	No	0	2
Helen	52	17	N/A	N/A	BRCA2	Decline	3	0
Tina	39	22	12	64	BRCA2	No	1	3
Abi	63	5	Planned	N/A	BRCA2	Decline	1	2
Fiona	46	60	24	N/A	BRCA2	No	2	0
Non-carrier								
Erica	58	108	N/A	N/A	BRCA1	No	5	1
Yolanda	52	65	N/A	N/A	BRCA1	No	1	0
Patty	33	8	N/A	N/A	BRCA1	Delay	1	2
Ulrika	44	71	24	N/A	BRCA2	No	2	3
Iris	56	120	N/A	N/A	BRCA2	No	3	1
Beth	48	21	N/A	N/A	BRCA2	No	1	1
Mary	67	124	N/A	N/A	P53	No	3	0
Xia	30	20	N/A	N/A	P53	No	1	1

[a] RRO: number of months since risk-reducing oophorectomy

[b] RRM: number of months since risk-reducing mastectomy

[c] FDRs: number of first degree relatives with breast or ovarian cancer

[d] SDRs: number of second degree relatives with breast or ovarian cancer

the pill for a long time". While Onda said that managing her risk through lifestyle was not a priority, she attended annual screening, as did the other five women who felt at low risk, with most making conscious efforts to maintain a healthy lifestyle as a preventative measure. Five of the six women with an affective understanding of low risk had low levels of intrusive thoughts and all six women cognitively understood their risk to be above average or high.

Theories

About half of the women had formed theories about various aspects of risk such as the causes of cancer, their chances of having inherited a genetic mutation, and/or their chances of developing breast cancer. Stress and negative emotions, in particular "bottling up emotions" (Jean, ineligible for testing), were thought to increase cancer risk, while Zara (carrier) said that her low levels of stress were partly why she felt at low risk despite being a carrier. Some theories had no logical basis. For instance, some women assumed they had inherited 'good' or 'bad' genes, although there was no genetic information to support this, and two women who were ineligible for testing believed that the vulnerability to cancer had 'skipped' them. Interestingly, the women actively sought confirming evidence, while contradictory evidence was often dismissed (e.g., "I don't know why it skipped me but not my sister, I just can't work that out"—Iris, non-carrier).

A number of women expressed social comparison theories. For instance, physical or personality similarities to individuals who were affected or mutation carriers were thought to increase the risk of developing cancer or being a mutation carrier. Women's tendency to compare themselves to the age or life stage of affected relatives, to gauge how at risk they were, was exemplified by Bella (age 59, decliner), who felt her breast cancer risk was at its peak. She said "you know my sister was 61 and my mum was 64… I guess I'm in that bracket". Indie (ineligible for testing), on the other hand, had passed the age at which her relatives were diagnosed and felt at low risk because "if I was going to get it, I would have gotten it by now, surely". These theories influenced women's affective understanding of risk and thus the impact of theories on risk management could be mediated by whether the comparison resulted in feeling at high or low risk.

Assumptions

Women who were eligible for testing but remained untested often made assumptions about their carrier status, as exemplified by four currently untested women (three decliners and a delayer). Two decliners assumed they did

not carry the mutation, although both reported engaging in behaviors aimed at reducing risk and facilitating early detection. Interestingly, one of these women had an affective understanding of being at high risk, while the other had an affective understanding of being at low risk. Thus assuming non-carrier status did not necessarily translate into feeling at low risk. Two women assumed they were carriers and reported "living like I do have it", indicating their risk management was congruent with being at increased risk. In addition, three tested women had made assumptions about their carrier status prior to receiving their result. One non-carrier who previously delayed testing had assumed she was a carrier, while two carriers who both previously declined testing, had assumed they were non-carriers. Thus decliners generally assumed non-carrier status while delayers assumed carrier status.

Only one participant, who was ineligible for testing, explicitly stated she had no intuition about her risk level. When directly asked, she replied "no, it's a scientific thing; that's my view. I mean I don't have any feelings about whether I'm more likely than someone else in my family to develop breast cancer". Further probing revealed that her understanding of her risk was wholly based on factual information derived from the family pedigree.

Cognitive risk perception

Most of the women expressed a cognitive understanding of risk, although only four women recalled numerical risks.

Above average or high

The majority of women who expressed a cognitive understanding of their risk stated this as above average or high. This group included two women who currently assumed they did not carry a mutation and all women who intuitively felt that their risk was low. Beth (non-carrier), who had a cognitive above average risk perception, explained that this was because the genetic counsellors

> said to both my sister and I that we're not BRCA2 carriers, but then they went on to say that that doesn't mean not to be careful and, you know, making sure everything's being checked all the time because there is something obviously happening within our family…

Thus Beth's cognitive understanding of above average risk was based on the information she had received. Three women with a perceived above average or high risk used a percentage to describe their risk level. One carrier stated her breast cancer risk was 80 percent and her risk for ovarian was less than this but still high. Another carrier understood that her risk-reducing oophorectomy had reduced her breast cancer risk by about 50 percent. One woman who was ineligible for testing said "I'm in the 98 percent high risk category or whatever—it is because my mother and grandmother passed away of cancer".

Low or average

Of the seven women coded as having a cognitive low or average risk perception, two were carriers who had undergone risk-reducing surgery and five were non-carriers. Three of the non-carriers, who also had an affective understanding of low risk, had relaxed their screening regimens since learning their results. One used a percentage to describe her risk, saying her risk is "less than the normal population—at about, I don't know, it's about a five percent risk or something, of getting breast (cancer)".

Six women did not have a cognitive understanding of their risk. Five of these women were untested and they all understood their risk intuitively. The remaining participant was a non-carrier who also did not report an intuitive understanding of her risk. This participant did not understand the meaning of her non-carrier result for her cancer risk and expressed a high level of uncertainty.

Discussion

This study found that unaffected women at increased familial risk of breast cancer formed their risk perceptions based on both intuition and cognitive understanding, with few differences evident in this process between those who had and had not undergone genetic mutation testing. The data suggest that while women may cognitively understand their objective risk, many intuitively feel that their risk is higher or lower than their objectively-defined level of risk. In some cases this can have a detrimental effect on risk management, more usually causing over- rather than under-screening. These findings have important implications for the process and content of risk communication and the provision of emotional support and information about risk management.

Other studies support the components of intuitive risk perception reported here, including the sense of expectation (Bakos et al., 2008; Persson et al., 2012; Rees et al., 2001; van Dijk et al., 2004), affective understanding of risk (Dawson et al., 2008), use of lay theories to explain risk (McAllister, 2003; Sanders et al., 2007), and assumptions about carrier status (McAllister, 2003). The current study extends these findings by showing that these intuitively-derived risk perceptions are not held in lieu of objective risk perceptions, but instead sit parallel to objective risk information received.

The apparent contradictions evident in some women's understanding of their risk may be somewhat explained by the central tenets of fuzzy-trace theory (Brainerd & Reyna, 1990). Fuzzy-trace theory is a dual-process model of cognition that integrates disparate approaches in both reasoning and memory research in an effort to explain disparities within individuals in the way they process information and the resulting memory-reasoning dissociations (Brainerd & Reyna, 2001). Brainerd and Reyna's research findings suggested that it was the background facts, or gist, rather than the exact content of memories that were employed in reasoning and that "reasoning accuracy was largely independent of memory accuracy" (Brainerd & Reyna, 2002, p. 164). Thus it may be the case that the women in this study who reported seemingly contradictory accounts of their risk have the gist that they are at high (or low) risk and this gist continues to guide their perceptions of risk and reasoning about their risk level despite maintaining memories of specific facts about their risk that are inconsistent with this gist.

Our findings also show that overall emotional representations of genetic risk tend to be driven by familial and personal experiences with cancer, such as affected relatives or personal health scares (Ersig et al., 2010; Evers-Kiebooms et al., 2000; Rees et al., 2001). Further, we found that more weight was given to this experientially-derived understanding of risk than to objective information about risk, and that individuals who remain ineligible for testing, and therefore have less objective information about their risk, may rely solely on their intuition.

Our findings regarding assumptions about carrier status suggest that individuals may be more likely to make assumptions when they are eligible for predictive testing, but have not yet taken up this option. This may be because their uncertainty is more salient in this situation and their assumption is used as an attempt to reduce the uncertainty. If this is the case, then it is possible that assuming that they carry a mutation may in part contribute to the delay of testing. For instance, if a woman has decided that she will undergo risk-reducing surgery if identified as a carrier, she may want to delay testing until she has completed childbearing or feels otherwise able to cope with the physical and psychological impacts of this type of surgery.

The affective understanding of risk appeared to be related to, but not synonymous with, cancer-related distress. Research has consistently found a positive relationship between general and cancer-related distress and risk perception (Audrain et al., 1997; Erblich et al., 2000; Hay et al., 2006; McGregor et al., 2004; Price et al., 2007), and there is evidence of a positive correlation between the intensity of women's emotional reaction to their breast cancer risk and their perceived risk (Katapodi et al., 2004). In light of the findings of the present research and a study which found that affective risk perception was more closely related to distress than cognitive risk perception (van Dooren et al., 2004), assessment of risk perceptions both for research and in clinical practice should aim to differentiate between affective and cognitive risk perceptions. In addition, management of the distress associated with being at increased risk may help to bring subjectively-perceived risk closer to objectively-defined risk.

The theories women held about their cancer or mutation risk have been noted before (McAllister, 2003; Sanders et al., 2007). Despite a widespread belief in the role of psychosocial factors such as stress and personality in the development of breast cancer, research on this topic has produced mixed findings (Price et al., 2001). The commonly held belief or lay theory, that genetic inheritance is directly related to physical similarities, has been acknowledged as a potentially maladaptive source of bias due to the impact these beliefs may have on thoughts, feelings and health-related decision-making (Ersig et al., 2010; Rees et al., 2001). The current findings add to our understanding of how such beliefs/theories affect risk perceptions by demonstrating the relationship between these lay theories and affective risk perceptions. What remains unknown is what comes first—whether lay theories lead to affective risk perception or are employed to justify it. Regardless, correcting unsubstantiated theories about risk, through education, may reduce reliance on an affective understanding of risk and increase trust in cognitive risk perceptions.

Women simultaneously held intuitively- and cognitively-derived risk perceptions that were not necessarily consistent with each other. Thus some women's accounts of their risk were somewhat incoherent and contradictory, confirming previous studies of individuals at increased familial risk of cancer (Bjorvatn et al., 2007; Ersig et al., 2010). Keogh et al. (2011) concluded that lack of contact with genetic services may force women to rely on their own interpretation of their risk. It may therefore be that this kind of inconsistent account of risk is more often seen in untested individuals, where objective risk information is less explicit and less definitive than for tested individuals. However, we found inconsistent accounts of risk in women across the range of testing statuses, and this inconsistency was actually more pronounced in women who had received a personal genetic result at odds with their intuitively-derived risk perception.

Other studies have also found that some non-carriers continue feeling as though they are still at higher than population risk (Bakos et al., 2008; Jacobsen et al., 1997; van Dijk et al., 2004). However the case of the carrier who feels at low risk in the current study is intriguing, particularly as the participant had a risk-reducing oophorectomy planned for the coming months, which would indicate

that she did feel at increased risk. In addition, three decliners (who objectively have a 50 % chance of carrying the mutation identified in their family) also felt at low risk. These findings highlight the discord between what women *know* about their risk, and how they *feel* about their risk. In this study, feeling at low risk did not appear to have a detrimental impact on risk management behavior, supporting Shiloh et al.'s (2009) conclusions that downplaying risk may not reflect actual beliefs about risk but rather attempts to manage the distress that may be triggered by openly acknowledging elevated risk.

Intuition was often prioritized over cognitive risk perceptions. There are a few explanations for this. First, individuals may have difficulty understanding risk information. Some of our women found it difficult to understand or recall the probabilities and numerical risk estimates communicated in genetic counseling, consistent with past research (Cameron et al., 2009; Hallowell et al., 1997). Few of the tested women cited the percentage lifetime risks or probabilities typically communicated during familial risk assessments, and this supports research which has found suboptimal longer-term retention of personalized risk estimates for individuals who have undergone counseling (Smerecnik et al., 2009).

Second, individuals may cognitively understand information about their risk but have difficulty reconciling it when it is substantially incongruous with their existing beliefs or theories about their risk (Bottorff et al., 1998; Michie et al., 2002). The Cue Adaptive Reasoning Account model (Renner, 2004) asserts that "unexpected information may be considered less trustworthy and less accurate than information that is concordant with existing beliefs" (Bennett et al., 2009, p. 160). Thus although theories and beliefs may be used as coping strategies (McAllister, 2003) they may also interfere with comprehension of risk information, an important issue to consider during pre- and post-test genetic counseling. The women in the present study also experienced shock and disbelief when unexpected results were communicated, supporting previous findings that genetic test results that are inconsistent with expectations require more psychological adjustment, even if results confer a decreased risk (Croyle et al., 1997; Lynch et al., 1997).

There was no evidence that having an affective perception of low risk or assuming non-carrier status had a negative impact on risk management; however our sample was small and decliners have been less likely to engage in early detection behaviors than tested individuals in previous research (McInerney-Leo et al., 2006). Thus it is possible that others who assume they do not carry a mutation may under-screen. However two non-carriers still felt at high risk and continued to screen as though they were at high risk. Concern has been expressed with regard to over-screening for breast cancer in non-carriers who have a high affective risk perception (Dawson et al., 2008). Of particular concern, one 33-year-old non-carrier participant in our study continued to undergo regular mammograms against evidence-based recommendations. Mammographic screening is not risk-free (NBOCC, 2010) and repeated radiation exposure may increase risk of cancer for subgroups of women at increased risk (Pijpe et al., 2012).

We found no evidence of underscreening in the current study, unlike earlier studies (Keogh et al., 2011), and this might be explained by differences between the samples. Women in the current study were kConFab registry participants and, as such, received regular newsletters and communication from registry staff (Phillips et al., 2005). The women in the study by Keogh et al. were taking part in the Australian Breast Cancer Family Study and had not, to our knowledge, received ongoing communication. Thus the salience of their risk and access to information may have been less compared to the women in the current study.

Limitations

Although this study's qualitative design permitted an in-depth examination of the complex and multifaceted phenomenon of risk perception, a number of limitations should be noted. The findings are drawn from a select group of women at increased familial risk for breast cancer and this group is unlikely to be representative of the population from which they were drawn. However, few studies have been able to shed light on the experiences of decliners, delayers and women who remain ineligible for testing and these findings are valuable for demonstrating similarities and differences between the mental strategies these women use to self-assess their risk level compared with those used by women who have received conclusive results.

The classification of participants according to their testing status in the present research was based on women's subjective understanding of this status. Discrepancies between participants' understanding of their status and clinical results have been reported elsewhere (Price et al., 2007). There were several instances of women's reported status varying from clinical records. The subjective classifications were retained because the current study was concerned with the participant's experience in light of their subjective assessment of their testing status.

Recruitment of delayers and decliners was challenging. A number of participants who had been classified by the psychosocial study as delaying or declining were found, at interview, to be ineligible for testing or had subsequently undergone testing. In addition, just over half of the women who elected not to take part in this study were delayers. Although this limited the number of decliners and delayers in the sample, the qualitative nature of this study allowed

the women who had previously been declining and delaying to discuss this experience retrospectively. Nevertheless, the views and experiences of delayers may be underrepresented by these data and further research on risk perception in individuals who delay testing is needed.

Clinical implications

The findings of this study suggest that supportive and educational interventions may improve the way individuals perceive and manage their risk. We agree with the assertion that "counseling approaches which are grounded in the patient's own experience of the disease may lead to more effective communication of genetic risk" (Pilarski, 2009, p. 307). Our findings show that women draw heavily on their own experiences (i.e., health scares and cancer in the family) to inform risk perceptions. Since elevated distress may compromise comprehension of risk information (Kash et al., 1995; Lerman et al., 1995), interventions designed to acknowledge these experiences and alleviate associated distress prior to the presentation of risk information may facilitate better comprehension. Our findings suggest that results of risk assessment that confer decreased risk may require interventions of a similar intensity to those employed with individuals receiving results that confer an increased risk, in order to facilitate a smooth transition from high-risk to population-risk status. Although clients may absorb risk information and cognitively understand the meaning of their personal risk estimates, checking how people feel about the information and whether it is congruent with their existing beliefs about their risk may provide opportunities to explore contradictions between different aspects of risk perception.

Evidence from randomized controlled trials shows that educational interventions have not been effective in improving accuracy of risk perceptions (Dieng et al., 2014). Our findings suggest that educational interventions aimed at acknowledging and correcting personal or lay theories of cancer and risk may improve affective risk perceptions, and that the emotional and behavioral correlates of risk perceptions may be more amenable to change.

Future research

Our findings suggest that future research and interventions could focus less on the accuracy of perceived risk and more on the relationships between conceptualizations of risk and their associated emotions and behaviors. The reliance on theories to inform risk perceptions has implications for information provision that warrant further exploration. Qualitative studies investigating acceptable approaches to dispelling unhelpful theories about cancer or mutation risk would provide critical insights to inform development of educational interventions.

At-risk individuals who decline, delay or remain ineligible for genetic testing are understudied groups, despite their substantial numbers in the population of at-risk individuals. Further research on risk perceptions and risk management behaviors in a large, representative sample of decliners and delayers is needed. Research aimed at identifying sources of risk information commonly used by untested women may also prove useful, so that appropriate channels for the dissemination of information can be established.

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Conflict of interest Louise Heiniger, Phyllis N. Butow, Margaret Charles, Melanie A. Price declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent All procedures followed were in accordance with ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

Appendix

The kConFab Psychosocial Group includes the following in addition to the authors listed in the author group: B Bennett, B Meiser and K Tucker, Department of Medical Oncology, Prince of Wales Hospital, Randwick, Australia. S-A McLachlan Department of Oncology and Department of Medicine, St Vincent's Hospital, Melbourne, Australia; K-A Phillips, Division of Cancer Medicine, Peter MacCallum Cancer Centre, Melbourne, Australia; Department of Medicine, St Vincent's Hospital, The University of Melbourne, Melbourne, Australia; Sir Peter MacCallum Department of Oncology, The University of Melbourne, Melbourne, Australia; School of Population and Global

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