**How do Women at Increased Breast Cancer Risk Perceive and Decide Between Risks of Cancer and Risk-Reducing Treatments? A Synthesis of Qualitative Research.**

**Hannah. G. Fielden1, Stephen L. Brown1, Pooja Saini1,2, Helen Beesley1, Peter Salmon1**

**1**Department of Psychological Sciences, University of Liverpool, Liverpool, L69 3BX, United Kingdom

**2** CLAHRC North West, University of Liverpool, Liverpool, L69 3BX, United Kingdom

***Corresponding author.*** Dr Stephen L. Brown (slbrown@liverpool.ac.uk)

**Abstract**

**Objective:** Risk-reducing procedures can be offered to people at increased cancer risk, but many procedures can have iatrogenic effects. People therefore need to weigh risks associated with both cancer and the risk-reduction procedure in their decisions. By reviewing relevant literature on breast cancer risk-reduction, we aimed to understand how women at relatively high risk of breast cancer perceive their risk and how their risk perceptions influence their decisions about risk reduction. **Methods**: Synthesis of 15 qualitative studies obtained from systematic searches of SCOPUS, Web of Knowledge, PsychINFO and Medline electronic databases (inception - June 2015). **Results**: Women did not think about risk probabilistically. Instead, they allocated themselves to broad risk categories, typically influenced by their own or familial experiences of breast cancer (BC). In deciding about risk-reduction procedures, some women reported weighing the risks and benefits, but papers did not describe how they did so. For many women, however, an overriding wish to reduce intense worry about BC led them to choose aggressive risk-reducing procedures without such deliberation. **Conclusions**: Reasoning that categorisation is a fundamental aspect of risk perception, we argue that patients can be encouraged to develop more nuanced and accurate categorisations of their own risk through their interactions with clinicians. Empirically-based ethical reflection is required to determine whether and when it is appropriate to provide risk-reduction procedures to alleviate worry.

*Keywords:* Breast cancer, risk-reduction, risk perception, qualitative research, meta-synthesis

**Background**

The development of technologies to identify and protect individuals at high risk of cancer or its recurrence is an area of continuing medical advance (1-4). However, risk-reducing procedures are often invasive and carry iatrogenic risk. For patients to make informed decisions about risk-reduction they therefore should understand and weigh risks of disease and the long and short-term risks and benefits associated with different treatments [5].

Breast cancer (BC) risk-reduction focuses the need to weigh risks and benefits acutely, because informed estimates of BC risk are available and risk reduction treatments are effective but carry risks [6]. Women with high BC risk can be identified from family history, with the latter often mediated by identified gene mutations [5]. Mutations in BRCA 1 or 2 genes and a history of affected first degree relatives confer an 80-90% lifetime risk, whilst mutations of other genes carry lower risks [6]. Ashkenazi, Icelandic, Swedish, Hungarian, and French-Canadian populations have higher rates of mutations [7]. Previous BC also increases a woman’s risk of developing a new BC [7]. Several risk-reduction procedures are available, with well understood risks and benefits. Screening, using radiographic mammography, ultrasound or magnetic resonance imaging [8], cannot prevent cancer but enables early detection which improves prognosis. However, screening can miss cancers, and false positive results cause unnecessary alarm [9]. Chemoprevention, through selective estrogen receptor modulators (SERMs) or aromatase inhibitors [10,11], can reduce incidence of estrogen receptor positive and negative cancer in post-menopausal women [12]. SERMs increase risk of endometrial cancer, thromboembolic events and menstrual and skin complaints, and aromatase inhibitors may reduce bone growth, and contribute to infertility and liver and kidney dysfunction [13]. Risk-reducing mastectomy (RRM) can improve life expectancy in women with BRCA mutations. In lower risk BC survivors RRM may reduce risk of new BC, but has not been shown to improve life expectancy because it cannot reduce the likelihood of metastatic disease [14]. RRM is irreversible, carries surgical risks, may require follow-up surgery, and can cause physical discomfort and emotional distress linked to breast appearance and feelings of damaged femininity [15,16]. Bilateral salpingo-oophorectomy (surgical removal of the ovaries and fallopian tubes) can reduce the risk of BC by up to 50% and risk of ovarian cancer by 90-95 %, although the extent of BC risk reduction has recently been questioned [17]. Oophorectomy is irreversible, risks surgical complications and causes infertility and premature menopause [17,18]. Therefore women at high risk of BC face complex choices about risk mitigation. Practitioners caring for women face corresponding challenges around how to help women weigh risks and benefits in making risk-reducing decisions.

According to early ‘likelihood-value’ theories of decision-making, people should weigh risks and benefits of different decision options by estimating the likelihood and personal value of potential outcomes and select the option that offers the optimal combination of these [19-20]. However, people do not, in practice, report thinking about risk in terms of continuous estimates of likelihood and value [21,22] and measures of these poorly predict behaviour [23,24]. The evidence suggests, instead, that people base risk perceptions and associated decisions on mental heuristics, i.e. ‘rules of thumb’ or approximations that allow easier decision-making [24]. Examples are the ‘affect heuristic’, whereby people’s inferences of risk are guided by their emotional feelings, and the ‘availability heuristic’, whereby people infer risk from the ease with which risk-related information can be recalled [25].

Whilst heuristics can reduce the extent to which people contemplate objective risks and logically integrate them into decision-making, they might also improve decisions by allowing people to respond to complex information that they would otherwise be unable to assimilate in a more rational way [26]. A large and diverse range of heuristics have been documented, but many are specific to the demands and contexts of particular decisions [27]. Thus, women’s risk-perception and decision-making in BC risk-reduction cannot be understood through merely appreciating that they use heuristics, but requires detailed understanding of the heuristics they use and the influence of these on decision-making. We are aware of no work that reviews this evidence in BC risk-reduction, and this was the aim of the present study. The measurement procedures of quantitative research in this context necessarily presuppose the main ways in which risk-perception and decision-making vary. Consistent with our inductive aim, we therefore focused on qualitative research. Our specific aims were, first, to synthesise qualitative literature concerning how women with elevated risk for BC perceive risk and how these perceptions influence decision-making about risk-reduction and, second, to draw implications for how clinicians can help women make these decisions.

**Methods**

*Inclusion and Exclusion Criteria*

We included peer-reviewed qualitative studies that examined risk perception or decision-making in adult women at high risk for BC. We used a broad definition of risk perception as ‘an individual’s personal understandings of BC risk and of the risks and benefits of risk-reduction options’. Higher risk groups included women with established genetic mutations (e.g. BRCA 1/2), or familial risk factors (affected first degree relatives), higher scorers on predictive scales derived from epidemiologic analyses of risk factors, members of ethnic populations characterized by higher risk and women who had previously been diagnosed with BC. Studies of women currently under treatment for BC were excluded. Inclusion was limited to English language reports. Databases (see below) were searched from inception to June 2015.

*Search Strategy*

Search terms and alternatives were initially identified using several reviews relevant to this area [22,23] and then augmented by scoping searches. Terms in the title, abstract or keywords relevant to breast cancer (“breast cancer” OR “breast carcinoma” OR “breast neoplasm”) AND risk perception (“risk perception” OR “risk understanding” OR “perceived risk” OR worry OR dread OR “anticipated emotion” OR “anticipatory emotion” OR emotion\* OR vulnerability) AND qualitative methodology (qualitative OR “Grounded Theory” OR IPA OR “Interpretative Phenomenological Analysis” OR “Thematic Analysis” OR “Content analysis” OR “Narrative Analysis” OR “Conversation Analysis” OR “Discourse Analysis” OR interview\* OR “focus groups”) were searched.

The electronic databases PsycINFO (1879-2015), Medline (1948-2015), Web of Knowledge (1900-2015), and Scopus (1960-2015) were searched. Reference lists from previous systematic reviews were also searched. Searches were combined and duplicates removed before study selection. Hand searches were also conducted of the reference lists of the included articles.

*Study Selection*

Using the electronic databases, search terms were identified from titles, abstracts and keywords. Following the search, identified studies were assessed for inclusion. Initially HGF screened all identified titles and then the abstracts of selected titles for potential inclusion. Then all papers identified as potentially relevant were read by HGF who assessed whether they met the inclusion criteria. When this was unclear, SLB also read the study and a joint decision was reached. Stage of exclusion and the reasons for exclusion were recorded (Table 1). Figure 1 describes study selection using the Preferred Reporting Items for Systematic reviews and Meta-Analysis [PRISMA] [28] flow diagram.

*Data Synthesis*

We wanted to develop new theoretical insights, grounded in the findings of individual studies but with general applicability across those studies and, therefore, potentially beyond them. Thus, we took an inductive approach, drawing upon grounded formal theory [29,30]. This approach starts with a descriptive analysis of data from the reviewed studies (including the research question, sample description, inductive categories arising from the authors’ analysis, and the illustrative data contained in the reports), but then progresses to a theoretical analysis. The key method of analysis is constant comparison within and across studies to detect convergences and resolve inconsistencies. Our synthesis was at the level of reported findings rather than the authors’ interpretations, and we sometimes drew different theoretical conclusions from the authors in the context of the developing analysis. HGF peformed a preliminary synthesis, first developing a descriptive analysis then a theoretical integration of this analysis. Then HGF and SLB interrogated this to identify consistencies and inconsistencies with the source data, and SLB provided a reformulated model. SLB and HGF then compared the reformulated model to the preliminary synthesis. The final synthesis arose through discussion amongst all authors.

**Results**

Table 2 summarises the ­­17 [31-47] included studies, each based on a unique sample. Countries of origin were USA, UK, Canada, Australia, Israel and the Netherlands. Sample sizes ranged from 17-123 (median 30, total 629). There was no overlap in samples between the studies. Six studies examined populations of women mainly defined by familial risk, three examined women with known genetic mutations (all had affected family members), three identified women by high scores on multivariate risk estimation tools (again, many women had affected family members) and two were studies of BC survivors.

*Overview*

Women generally perceived risk categorically rather than probabilistically, partly based on previous family experiences of BC. Decisions about risk-reduction arose in two very different ways, depending on how intensely women worried about BC.

*Women did not perceive risk probabilistically*

Only three of the 16 studies reported evidence that women viewed risk in likelihood-value terms. Of these, only Robertson [31] reported that women made probabilistic risk estimates. In this study many women spontaneously attempted to create their own personal risk estimate, anchoring this in a known population average and adjusting their estimate according to their personal risk factors. Robertson studied women with elevated Gail risk factor scores, but excluded any who had experienced cancer or had been referred for a genetic test. Thus, her sample may have a lower risk profile than other reviewed studies, which might explain her unique finding that women commonly used probabilistic risk perceptions. The other two studies reporting probabilistic estimates found these in only a few women. When asked to describe personal risk, only two of 24 women in Keogh et al’s [32] study of women at familial risk volunteered what could be regarded as continuous estimates (e.g. ‘one in three’). Beesley et al. [33] found, amongst 60 BC survivors requesting contralateral RRM, only five reported probabilistic estimates. Indeed, several studies showed that a proportion of women explicitly rejected the notion of trying to understand risk probabilistically or using objective risk estimates [33,34].

*Women perceived risk categorically*

Instead, when asked to describe personal risk, most women used verbal labels to describe risk categories to which they felt they belonged [34-39]. Categorisation was pervasive across the differing samples and analysis methods, and women were explicit about doing this. Category labels were diverse. Some, such as ‘probable’, ‘high risk’ or certain (of BC) could be seen as ordinal points across a spectrum of likelihood [34,38,39]. Others described positions relative to population risk, such as ‘a bit higher than population risk’ or ‘no higher than anyone else’ [34,36,39]. Other labels encompassed qualitative categories such as ‘vulnerable’ or ‘at risk’ [39]. Categorisations were generally realistic. Almost all women acknowledged being at high risk in either an absolute sense or in comparison with the wider population, and one study showed that women’s self-categorisations were largely consistent with the categorical estimates that they had been given by professionals [38].

Women were explicit about the ways that they developed these categories and about using category labels to help them to think about risk. Some spontaneously assigned themselves to categories, based on either their personal or family experiences related to cancer (see below), their theories about specific risk factors [32,34] or their emotional responses to risk [34]. Others reported that health professionals introduced them to the categories that they used [33,39]. In one study [38], BRCA1/2 mutation carriers wanted health professionals to provide them with risk ‘labels’.

*Family experiences defined risk perceptions*

Women’s perceived risk categories were informed by family experiences of BC [34,35,39]. Some women were explicit about how their family histories led them to believe that they were in a high risk category [39-41]. However, in most women the influence of family experiences was implicit [33,39-43]. Women assumed that their futures would follow the path of a family member’s illness with little consideration that their own cancer likelihoods or experiences might differ [35,39 -42]. The ages, sites, and stages at which relatives had been diagnosed and the outcomes of relatives’ illnesses defined expectations of their own fates, in that they expected to have cancers that would develop with the same trajectories [34,41,-42]. Relatives’ ages were particularly important. Dagan and Goldblatt [41] referred to this as the ‘family clock’, Werner-Lin [40] as a ‘danger zone’. Remaining healthy at the age at which their mothers developed BC provided hope for future health [41], and women felt profound relief when these landmarks had passed [34,36,41]. Thus, memories of the experiences themselves constituted risk perceptions by implicitly defining templates of expectations about personal futures. The dominance of family experiences in shaping risk perceptions was not, however, inevitable. Chalmers and Thomson [35] showed that some women moved away from an experience-determined view of BC risk toward more nuanced and objectively-based understandings over time. These women sought objective information about risk, reflected upon this and integrated it into their views of risk.

Family experiences sometimes led to a sense of inevitability about BC, inducing a ‘labelling’ error whereby BC risk was described as ‘certain’. This was evident in those whose mothers had been diagnosed with BC [44] and in some with affected first or second degree relatives [32,35]. After positive BRCA tests, many women in Werner-Lin’s [40] study felt that they were on a ‘*path towards cancer’*.

*Some women deliberated about risk, but worry impelled others toward aggressive risk-reduction procedures*

Women made decisions in two ways, largely depending upon their level of worry. Where worry was not intense, women generally reported weighing their risk of BC and iatrogenic risks associated with risk-reduction procedures. They also considered other factors, such as how engaging in research might help other women [34], how future childbearing and breast-feeding aspirations might militate against oophorectomy or RRM, and how current parental responsibilities militated against any such major surgery [35,39-41]. Sometimes they postponed decisions if they felt unready to make them [37]. Unfortunately, the reviewed studies did not reveal how women made comparisons between different risks to make their decisions. Therefore, whilst we know that women largely thought about risk categorically, we do not know how they weighed different risks in reaching decisions. Nonetheless, women who weighed risks and benefits were generally content with their decisions [37,41-43]. Often the decisions provoked strong emotions, but women did not describe these emotions as influencing their decisions [44,45].

Each study described women whose decisions were shaped by intense levels of worry about BC. Women described fears about BC as ever-present, intrusive, uncontrollable, and sometimes ‘*intolerable’* [31,32,36,41]. The threat of BC was a ‘*constant companion’* for these women [31,40] and induced a persisting sense of threat [44]. No study explicitly examined why these women worried so intensely, and worry was not clearly explained by the risk category to which women allocated themselves. Whilst some women attributed worry to being in a high risk ‘category’ or to recalling salient family experiences of BC [33,36-38], women who saw themselves as at high risk did not all worry so intensely [32,34]. Believing that cancer was inevitable could even reduce worry where women with family history of BC resigned themselves to this [39,45].

Worry resisted reassurance from professionals’ descriptions of objective risk or from good outcomes of clinical investigations [32,34,37]. Instead, minimising worry became the overriding and urgent goal that women pursued through their decisions about risk-reduction [32,33,36,41-43,46,47]. Women acknowledged that they were more worried than their objective risk warranted, but their decisions were nonetheless determined by worry [33,38,46]. The goal of minimising worry typically led women to eschew conservative options and choose the most aggressive available to them. Worry led women to prefer mammographic screening to self-care such as breast self-examination [46], participation in a chemoprevention trial to screening [36], and RRM to screening [33,44]. Many described needing to ‘do something’ and feared missing opportunities to reduce risk, but there was little indication that women had closely considered the iatrogenic risks associated with their chosen procedures, particularly RRM or oophorectomy [31,32,34,42,43,45].

**Discussion**

Women did not generally think probabilistically about risk. Instead, they perceived risk in terms of idiographic categorisations, influenced by family experiences. Some women deliberated about their decisions, whereby they weighed risks and benefits of different options. For others, worry excluded deliberation and drove choices of aggressive risk-reducing options.

Seen from the perspective of research showing that categorisation introduces error into risk-related health decision-making, the central role of categorisation in women’s perception of risk is potentially alarming. For example, Cameron et al. [48] showed that the categorisation of probabilistic risk estimates inevitably reduces accuracy by dividing a linear dimension into a restricted set of categories, Thus, miscategorisation can lead to incorrect inferences drawn from category labels. Reyna et al [49] showed that dependence on categories prevents people from acting upon category-inconsistent information. In our review, one potentially major source of error in categorical risk perceptions was that women inferred their risk category from memories of family experiences. Many categorised risk as ‘certain’ or saw themselves on an inevitable ‘path toward cancer’. These perceptions arose inductively, and women did not objectively assess the significance of family experiences. Family BC history does, in general, increase personal risk [6], but valid inferences should take account of the number of affected relatives and their ages and their genetic relationship to the individual. Women in the studies that we reviewed were influenced mainly by aspects of the familial experience unrelated to risk, such as the quality of family relationships and specific details of relatives’ experiences.

However, wider research in social psychology shows categorisation to be a fundamental aspect of how people interpret information and use it to make decisions [50,51]. Categorisation is a heuristic that allows people to remember, retrieve and use risk information more easily [52]. Thus, category labels such as ‘above average’ or ‘at risk’ provided easily accessible meanings that could help women to make decisions. Although categorisation of risk could be biased by family history, women wanted to use accurate categories. In particular, they sought accurate categorical information from health professionals [43] and were able to remember these when later asked [38]. Therefore, categorisation should not be regarded as an inherently inaccurate way for women to perceive risk.

Unfortunately, the reviewed studies did not illuminate how women compared different risks to make their decisions. Unlike probabilistic risk perceptions, where a common metric allows comparison of different outcome probabilities, categories used by women in the reviewed studies carry unique meanings that do not offer a common metric [48]. For example, patients considering surgery may use different types of category to describe risk of BC (e.g. ‘I am vulnerable’) and surgery (e.g. ‘I am at moderate risk’). One possibility suggested by the broader psychological literature is that some risk categories, such as feeling ‘vulnerable’, carry stronger emotional connotations than others, such as having ‘moderate’ risk. The risk associated with the stronger emotional connotation might therefore drive the decision [27]. Research is needed to elucidate how women compare categorical risk perceptions in decisions about risk-reduction.

The clearest evidence about decision-making in the reviewed papers arose where it was influenced by worry. Where worry was intense, women did not consider risks and benefits. Instead, they chose aggressive risk reduction to reduce worry, and they paid little attention to iatrogenic risk. That is, worry ‘hijacked’ decision-making. At first sight, this is consistent with evidence for widespread use of a heuristic whereby people infer risk from their emotional responses [53,54]. However, our review emphasised another mechanism: that worry reduction became a decision-making goal in its own right. That is, women pursued an ‘emotion-focussed’ coping strategy where they sought to reduce worry and were largely unconcerned with objective risk [54,55].

*Practice and research implications*

Our findings point to two challenges for practitioners working with women who are deciding about BC risk reduction. First, women’s categorical perceptions of risk may not closely correspond to objective risk and, second, worry might ‘hijack’ their decision-making by leading women to choose invasive procedures to reduce worry while disregarding objective risks and benefits.

Risk perception research shows that categorisations and other heuristics that people use to perceive risk are not static, but evolve toward greater nuance and accuracy if people engage with external evidence [24]. Our review shows that women sought accuracy in their categorisations and formed more nuanced categories over time by seeking information about the categories to which they belonged from health professionals [38]. Relevant information does not necessarily have to be presented didactically, and indeed didactic presentations may be counter-productive [56]. Street [56] and Elwyn et al [57] both emphasise the centrality of patient-clinician dialogue in enhancing the extent to which patients are able to make well-informed decisions based on risks and benefits; it allows clinicians to assess patients’ understanding and tailor information to patients’ needs, and patients to test and improve their understanding based on clinicians’ feedback. Thus, effective consultation with women considering risk reduction does not merely extend to providing information about risk, but involves clinicians eliciting and shaping women’s own idiographic categorisations of risk.

The influence of worry is harder to address. Where it is linked to perceiving oneself to be at high risk of BC, worry might be alleviated by helping women to question the risk perceptions that they have formed, as we describe above. However, cancer worry is not simply a product of high-risk perceptions, and indeed appears to be largely insensitive to reassurance about risk [54]. It is partly a consequence of unrelated factors, including general emotional state, negative life experiences and stressful or unsupportive environments [58]. While counseling or other interventions for worry might therefore prove helpful in some instances, it is unrealistic to expect that worry can be completely banished in clinical contexts in which patients are faced with the mortal threat of serious illness. Therefore, particularly when the clinical benefits of interventions are unclear, clinicians will face the dilemma of how to reconcile the normative expectations for them to respect patients’ *requests*, motivated by escape from worry, while simultaneously meeting their *needs*, which go beyond worry to encompass the balance between reduction of BC risk and avoidance of iatrogenic harm. The dilemma hinges on the ethical question as to whether and when it is appropriate for clinicians to provide invasive, and even surgical, responses to psychological need. Ethical analyses in the fields of cosmetic [59] and bariatric surgery [60] suggest surgical intervention for psychological benefit can be justified, but that a case always needs to be made that clinical and psychological benefits outweigh risk, that benefits are likely to occur and that benefits cannot be achieved with less risk.

Where solutions to ethical dilemmas cannot be derived from general normative principles, Kleinman [61] proposed that the starting point for reflecting on possible solutions should be detailed study of how practitioners and patients resolve these dilemmas in practice. Unfortunately, the studies that we reviewed provided little insight into this. Future research that examines, not only women’s accounts but also those of the clinicians caring for them, and which examines how decisions are negotiated between them in consultations, could provide evidence from which realistic and ethically robust solutions can be derived.

**Acknowledgement**: This research was part funded by the Economic and Social Research Council (UK) Grant ES/J008184/1. ESRC did not seek to influence the conduct of the investigation or this report.

**References**

[1] Reis-Filho JS, Pusztai L. [Breast Cancer 2 Gene expression profiling in breast cancer: classification, prognostication and prediction.](http://apps.webofknowledge.com.ezproxy.liv.ac.uk/full_record.do?product=UA&search_mode=MarkedList&qid=4&SID=U14@4PJIN8lI7e3fH7D&page=1&doc=2&colName=WOS) *Lancet* 2011;378:1812-23.

[2] Tan, M-H, Kanesvaran, R, Li H, Li H, Tan HL, Tan PH, Wong CF, Chia, KS, The BT, Yuen, J Chong, TW. [Comparison of the UCLA Integrated Staging System and the Leibovich Score in survival](http://apps.webofknowledge.com.ezproxy.liv.ac.uk/full_record.do?product=UA&search_mode=MarkedList&qid=4&SID=U14@4PJIN8lI7e3fH7D&page=2&doc=13&colName=WOS) [Prediction for Patients With Non metastatic Clear Cell Renal Cell Carcinoma](http://apps.webofknowledge.com.ezproxy.liv.ac.uk/full_record.do?product=UA&search_mode=MarkedList&qid=4&SID=U14@4PJIN8lI7e3fH7D&page=2&doc=13&colName=WOS). *Urology* 2010;75:1365-9.

[3] Wishart GC, Bajdik, CD, Azzato, EM, Dicks, E, Greenberg, DC, Rashbass, J, [Caldas, C](http://www.scopus.com.ezproxy.liv.ac.uk/authid/detail.url?origin=resultslist&authorId=7006688992&zone=), Pharoah, PDP. [A population-based validation of the prognostic model PREDICT for early breast cancer.](http://apps.webofknowledge.com.ezproxy.liv.ac.uk/full_record.do?product=UA&search_mode=MarkedList&qid=4&SID=U14@4PJIN8lI7e3fH7D&page=1&doc=7&colName=WOS) *European Journal* *of Surgical Oncology* 2011;37:411-7.

[4] Damato B, Eleuteri A, Taktak AF, Coupland S. Estimating prognosis for survival after treatment of Choroidal melanoma. *Progress in Retinal and Eye Research* 2011;**30**:285-95.

[5] Elwyn G, Miron-Shatz T. Deliberation before determination: The definition of good decision-making. *Health Expect* 2009;13:139-147. DOI: 10.1111/j.1369-7625.2009.00572.x

[6] Hartmann LC, Lindor NM. The role of risk-reducing surgery in hereditary breast and ovarian cancer. *New Engl J Med* 2016;374;454-68

[7] National Comprehensive Cancer Network. (2008). *NCCN clinical practice guidelines in* *oncology. Genetic/familial high-risk assessment: breast and ovarian*. Retrieved from <http://www.nccn.org/professionals/physician_gls/PDF/genetics_screening.pdf>.

[8] [Kim, S.J.](http://www.scopus.com.ezproxy.liv.ac.uk/authid/detail.url?authorId=8583033000&amp;eid=2-s2.0-84916920082), [Chung, S-Y](http://www.scopus.com.ezproxy.liv.ac.uk/authid/detail.url?authorId=28567545200&amp;eid=2-s2.0-84916920082), [Chang, J.M.](http://www.scopus.com.ezproxy.liv.ac.uk/authid/detail.url?authorId=56157112200&amp;eid=2-s2.0-84916920082), [Cho, N.](http://www.scopus.com.ezproxy.liv.ac.uk/authid/detail.url?authorId=16416850000&amp;eid=2-s2.0-84916920082), [Han, W.](http://www.scopus.com.ezproxy.liv.ac.uk/authid/detail.url?authorId=8588073500&amp;eid=2-s2.0-84916920082), [Moon, W.K.](http://www.scopus.com.ezproxy.liv.ac.uk/authid/detail.url?authorId=7102860983&amp;eid=2-s2.0-84916920082) Ultrasound screening of contralateralbreastafter surgery for breastcancer. *Euro J Radiology* 2015;84:54-60.

[9] Aro, AR, Pilvikki Absetz, S, van Elderen, TM, van der Ploeg, E, van der Kamp, L J. False-positive findings in mammography screening induces short-term distress-breast cancer-specific concern prevails longer. *Euro J Cancer* 2000;*36*:1089-1097.

[10] Bao, T, Prowell, T, Stearns, V. Chemoprevention of Breast cancer: Tamoxifen, raloxifene, and beyond. *Am J Therapeutics* 2006;13:337-348.

[11] National Institute of Clinical Excellence. (2013). *Familial breast cancer: Classification and care of people at risk of familial breast cancer and management of breast cancer and related risks in people with a family history of breast cancer*. Retrieved from <http://www.nice.org.uk/guidance/index.jsp?action=byID&o=14188>

[12] Cuzik J, Sestak I, Cawthorne S, Hamed H, Holli K, Howell A, Forbes JF. Tamoxifen for prevention of breast cancer: Extended long-term follow-up of the IBIS-I breast cancer prevention trial. *Lancet Oncol* 2015;16:67-75.

[13] Nelson, H. D, Fu, R, Griffin, JC, Nygren, P, Smith, M B, Humphrey, L. Systematic review: Comparative effectiveness of medications to reduce risk for primary breast cancer. *Ann Internal Med* 2009;**151**:703-715.

[14] Rebbeck, TR, Friebel, T, Lynch, HT, Neuhausen, SL, van’t Veer, L, Garber, J E Weber, BL. Bilateral prophylactic mastectomy reduces breast cancer risk in *BRCA1* and *BRCA2* mutation carriers: The PROSE study group. *J Clin Oncol* 2004;**22**:1055–1062.

[15] Payne, DK, Biggs, C, Tran, K, Borgen, PI, Massie, M J. Women's regrets after bilateral prophylactic mastectomy. *Annals Surg Oncol* 2000;**7**:150-154.

[16] Hopwood, P, Lee, A, Shenton, A, Baildam, A, Brain, A, Lalloo, F, Howell, A. Clinical follow-up after bilateral risk reducing (‘prophylactic’) mastectomy: mental health and body image outcomes. *Psycho-Oncology* 2000;**9**;462-472.

[17] Domchek, S. M, Rebbeck, T. R. Prophylactic oophorectomy in women at increased cancer risk. *Current Opinion Obstetrics Gynecol* 2007;**19**:27-30.

[18] [Heemskerk-Gerritsen, B.A.M.](https://www-scopus-com.liverpool.idm.oclc.org/authid/detail.uri?authorId=16942492000&amp;eid=2-s2.0-84928421635),  [Seynaeve, C.](https://www-scopus-com.liverpool.idm.oclc.org/authid/detail.uri?authorId=7004064207&amp;eid=2-s2.0-84928421635)a, [Van Asperen, C.J.](https://www-scopus-com.liverpool.idm.oclc.org/authid/detail.uri?authorId=28168088300&amp;eid=2-s2.0-84928421635) et al. Breast cancer risk after salpingo-oophorectomy in healthy BRCA1/2 mutation carriers: Revisiting the evidence for risk reduction. J Nat Cancer Inst 2015;**107** (5).

[19] Rogers, RW. (1983). Cognitive and physiological processes in fear appeals and attitude change: A revised theory of protection motivation. In J. Cacioppo & R. Petty (Eds.), *Social Psychophysiology* (pp.153-177). New York: Guilford Press.

[20] Weinstein, N.D. Testing four competing theories of health-protective behavior. *Health Psychol* 1993;**12**:324–333.

[21] Lipkus, I. M., Samsa, G, Rimer, BK. General performance on a numeracy scale among highly educated samples. *Med Decision Making* 2001;**21**:37–44.

[22] Milne S, Sheeran P, Orbell S. Prediction and intervention in health-related behavior: A meta-analytic review of protection motivation theory. *J Appl Soc Psychol* 2000;**30**:106-143.

[23] Katapodi, MC, Lee, KA, Facione, NC, Dodd, MJ. Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: A meta-analytic review. *Prev Med* 2004;**38**:388-402.

[24] Reyna, VF. How people make decisions that involve risk: A dual-process approach. *Current Directions Psychol Sci* 2004;**13**:60-66.

[25] Pachur, T, Hertwig, R. Steinmann, F. How do people judge risks: Availability heuristic, affect heuristic or both? *J Experimental Psychol Appl* 2012;**18**:314-330.

[26] De Vries, M, Fagerlin, A, Witteman, HO, Scherer, L D. Combining deliberation and intuition in patient decision support. *Patient Educ Couns* 2013;**91:**154-160.

[27] Gigerenzer, G, Gaissmaier, W. Heuristic decision-making. *Ann Rev Psychol* 2011;**62:**451-482.

[28] Moher D, Liberati A, Tetzlaff J, Altman DG. Et al.. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. [*PLoS Med* 2009;**6**:e1000097.](http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1000097)

[29] Kearney MH Ready-to-wear: discovering grounded formal theory. *Res Nursing Health* **21**:179-186.

[30] Finfgeld-Connett D. Metasynthesis findings: Potential versus reality. *Qualitative Health Res* 2014;**20**:1581-1591.

[31] Robertson, A. Embodying risk, embodying political rationality: Women's accounts of risks for breast cancer. *Health, Risk Soc* 2000;**2**:219-235.

[32] Keogh, LA, McClaren, BJ, Apicella, C, Hopper, JL. How do women at increased, but unexplained, familial risk of breast cancer perceive and manage their risk? A qualitative interview study. *Hereditary Cancer Clin Prac* 2011;**9**:1-11.

[33] Beesley, H, Holcombe, C, Brown, SL, Salmon, P. (2013). Risk, worry and cosmesis in decision-making for contralateral risk-reducing mastectomy: Analysis of 60 consecutive cases in a specialist breast unit. *Breast* 2013;**22**:179-184.

[34] Heiniger L, Butow PN, Charles M, kConFab Psychosocial Group, Price MA. Intuition versus cognition: A qualitative explanation of how women understand and manage increased breast cancer risk. *J Behav Med* 2015;**8**:727-739. DOI 10.1007/s10865-015-9632-7

[35] Chalmers, K., & Thomson, K. Coming to terms with the risk of breast cancer: Perceptions of women with primary relatives with breast cancer. *Qual Health Res* 1996;**6**:256-282.

[36] Altschuler, A, Somkin, CP. Women's decision making about whether or not to use breast cancer chemoprevention. *Women Health* 2005;**41**:81-95.

[37] Howard, AF, Balneaves, LG, Bottorff, J L, Rodney, P. Preserving the self: The process of decision making about hereditary breast cancer and ovarian cancer risk reduction. *Qual Health Res* 2011;**21**:512-519.

[38] Van Dijk, S, Otten, W, van Asperen, CJ, Timmermans, DRM, Tibben, A, Zoetweij, MW, Breuning, MH, Kievit, R. Feeling at Risk: How women interpret their familial breast cancer risk. *Am J Med Genetics* 2004;**131A**:42-49.

[39] Raveis, VH, Pretter, S. Existential plight of adult daughters following their mother's breast cancer diagnosis. *Psycho-Oncology* 2005;**14**:49-60.

[**40**] Werner-Lin, A. V. Danger zones: Risk perceptions of young women from families with hereditary breast and ovarian cancer. *Fam Process* 2007;**37**:335-349.

[**41**] Dagan, E., & Goldblatt, H. The twilight zone between health and sickness: A qualitative exploration with asymptomatic BRCA1 and 2 mutation carriers. *Women Health* 2009;**49**:263-279.

[**42**] Kenen, R, Ardern-Jones, A, Eeles, R. Living with chronic risk: Healthy women with a family history of breast/ovarian cancer. *Health, Risk Soc* 2003;**5**:315-331.

[**43**] Hoskins, LM, Roy, K M, Greene, MH. Toward a new understanding of risk perception among young female BRCA1/2 "previvors". *Fam Systems Health* 2012;**30**:32-46

[**44**] Kelly, PT. Counselling needs of women with a maternal history of breast cancer. *Patient Counsel Health Educ* 1980;**2**:118-124.

[**45**] Hallowell, N, Foster, C, Eeles, R, Ardern-Jones, A, Watson, M. Accommodating risk: Responses to BRCA1/2 genetic testing of women who have had cancer. *Soc Sci Med* 2004;**59**:553-565.

[**46**] Bennett, P, Parsons, E, Brain, K, Hood, K. Long-term cohort study of women at intermediate risk of familial breast cancer: Experiences of living at risk. *Psycho-Oncology* 2010;**19**:390-398.

[**47**] Sheinfeld Gorin, S, Albert, S M. The meaning of risk to first degree relatives of women with breast cancer. *Women Health* 2003;**37:**97-117.

[**48**] Cameron, LD, Sherman, KA, Marteau, TM, Brown, P M. Impact of genetic risk information and type of disease on perceived risk, anticipated affect, and expected consequences of genetic tests. *Health Psychol* 2009; **28**: 307.

[49] Reyna, VF, Lloyd, FJ. Physician decision making and cardiac risk: Effects of knowledge, risk perception, risk tolerance, and fuzzy processing. *J Exp Psychol: App* 2006;**12**:179–195.

[50] Zhong, CB, Phillips, KW, Leonardelli, GJ, and Galinsky, AD. Negational categorization and intergroup behavior. *Pers Soc Psychol Bull* 2008;**34**:793–806. doi: 10.1177/0146167208315457

[51] Mulvey, K.L., Hitti, A., Killen, M. The development of stereotyping and exclusion. *Wiley Interdisciplinary Rev: Cog Sci* 2010;**1**: 597-606.

[52] Reyna, VF, Lloyd, FJ. Physician decision making and cardiac risk: Effects of knowledge, risk perception, risk tolerance, and fuzzy processing. *J Exp Psychol: Appl* 2006;**12**:179–195.

[53] Dillard, AJ, Ferrer, D, Ubel, PA and Fagerlin, AJ. Risk perception measures’ associations with behavior intentions, affect, and cognition following colon cancer screening messages. *Health Psychol* 2012;**31**:106-113.

[54] van Dijk, S, W Otten, W, Zoeteweij, MW, Timmermans, DRM, van Asperen, CJ, Breuning, MH, Tollenaar, R A E M, Kievit, J. Genetic counselling and the intention to undergo prophylactic mastectomy: Effects of a breast cancer risk assessment. *Brit J Cancer* 2003;**88**:1675 – 1681.

[55] Luce, MF. Decision making as coping. *Health Psychol* 2005;**24**(4S):S23.

[56] Street, R L. Aiding medical decision making: a communication perspective. *Med Decis Making* 2007;**27**:550-553.

[57] Elwyn G, Lloyd A, May C, et al. Collaborative deliberation: A model for patient care. *Patient Educ Couns* 2014;**97**:158-164.

[58] Hay, JL, Buckley, TR, Ostroff, JS. The role of cancer worry in cancer screening: A theoretical and empirical review of the literature. *Psycho-Oncology* 2005;**17**:517-534.

[59] de Roubaix JAM. Benificence, non-maleficence, distributive justice and respect for patient autonomy – reconcilable ends in aesthetic surgery? *J Plastic Reconstruc Aesthetic Surg* 2011;**64**:11-16.

[60] Persson K. Why bariatric surgery should be given high priority: An argument from law and morality. *Health Care Anal* 2014;**22**:305-324.

[61] Kleinman A. Moral experience and ethical reflection: Can ethnography reconcile them? A quandary for ‘The new bioethics’. *Daedalus* 1999;**128**:69-97.

*Figure 1.* PRISMA flow diagram of article selection process.

Records identified through database searching  
(n = 2794)

Additional records identified through hand searching  
(n = 15)

Records after duplicates removed  
(n = 1458)

Records excluded  
from title (n = 314)

Full-text articles assessed for eligibility  
(n = 122)

Records excluded from full-text  
(n = 106)

Studies included in synthesis  
(n = 16)

Records excluded  
from abstract (n = 1022)

**Included**

**Eligibility**

**Screening**

**Identification**

*Table 1* Reasons for exclusion of studies by stage of selection

|  |  |  |  |
| --- | --- | --- | --- |
|  | Title screening | Abstract screening | Full text screening |
| Sample (e.g., not a high risk sample) | 282 | 380 | 29 |
| Topic (e.g., not about risk perception) | 0 | 423 | 57 |
| Method (e.g., not qualitative) | 3 | 183 | 6 |
| Study type (e.g., not primary data - review or commentary) | 1 | 27 | 12 |
| Duplicate not previously identified | 28 | 9 | 2 |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Reference**  Table 2: *Summary of Included Studies* | **Country** | **Sample characteristic of interest** | **Sample** | **Data Collection Method** | **Analysis** | **Aim(s)** |
| Altschuler and Somkin (2005) | USA | Invitees to chemoprevention trial with Gail scores 1.66% or greater. | n=51  **Age**: 40-80+ yrs  **Ethnicity:** 93.4% White, 2.5% African American, 2.0% Latina, 2.1% other  **FH**: unclear  **PH:** unclear  **BRCA:** not stated | Semi-structured interview | Grounded theory | Understand why eligible women at similarly high calculated risk, made different choices about whether or not to join a hormonal therapy trial. |
| Beesley, Holcombe, Brown, and Salmon (2013) | UK | Women considered for CRRM | n= 60  **Age:** 24-68yrs  **Ethnicity:** not stated  **PH:** all  **FH:** not stated  **BRCA:** not stated | Case series | Constant comparative | Understand how CRRM decisions are made in practice and identify factors that influence these decisions. |
| Bennett, Parsons, Brain, and Hood (2010) | UK | High or intermediate risk Claus scores.  . | n=30  **Age:** 48.1 mean (range not stated)  **Ethnicity:** not stated  **FH:** all  **PH**: not stated  **BRCA:** unknown | Semi-structured interview | Thematic analysis | Explore factors associated with cancer worry and utilisation of services. |
| Chalmers and Thomson (1996) | Canada | First degree relative with BC. | n=55  **Age:** 20-69yrs  **Ethnicity:** not stated  **FH**: all  **PH:** none  **BRCA:** not stated | Semi-structured interview | Latent content analysis and constant comparison techniques within symbolic interaction framework. | Describe risk perceptions, identify self-care needs and practices, identify factors influencing self-care practices. |
| Dagan and Goldblatt (2009) | Israel | Asymptomatic BRCA 1/2 carriers | n=17  **Age:** 37-55yrs  **Ethnicity:** Israeli Ashkenazi Jewish  **PH:** none  **FH:** all  **BRCA:** all positive | Semi-structured interview | Thematic content analysis | Understand lived experiences of asymptomatic BRCA mutation carriers. |
| Hallowell, Foster, Eeles, Ardern-Jones, and Watson (2004) | UK | Breast or Ovarian Cancer survivors who completed genetic testing. | n= 30  **Age**: 39-71yrs **Ethnicity:** not stated  **PH:** 27  **FH:** 26 FDR  **BRCA:** 10 positive, 12 inconclusive, 8 awaiting results | Semi-structured interview | Constant comparative | Explore perceptions and experiences of genetic testing and establish information and support needs before and after result. |
| Heiniger, Butow, Charles, et al. (2015) | Australia | Family histories of BC or ovarian cancer | N=36  Age: Mean=46  Ethnicity: Mixed  PH: Not stated  FH: All  BRCA: 8 positive BRCA1/2 or P53,  8 negative, 20 untested | Semi-structured telephone interview | Grounded theory | Explore how risk perceptions are formed  in both tested and untested women unaffected by BC but at increased familial risk of breast and/or ovarian cancer and how risk perceptions affect risk management |
| Hoskins, Roy, and Greene (2012). | USA | Young (age 36 or below) BRCA carriers | n=60,  **Age:** 21-36yrs  **Ethnicity:** 3% Hispanic, 97% White, 20% Jewish  **PH:** not stated  **FH:** not stated  **BRCA:** all positive | Semi-structured telephone interview | Grounded theory | Investigate how, and how much, risk perception become entangled with partner, children, and interpersonal relationship issues. |
| Howard, Balneaves, Bottodorf & Rodney (2010) | Canada | BRCA carriers | n=22,  **Age:** 28-80  **Ethnicity:** Diverse – not stated  **PH:** 5  **FH:** All  **BRCA:** all positive | Semi-structured interview | Grounded theory | Understand women’s decision-making processes and the social contexts that influence these processes. |
| Kelly (1980) | USA | Maternal history of BC | n=39.  **Age:** 28-73yrs  **Ethnicity:** 34 White, 3 Oriental, 2 Black  **PH**: none  **FH:** all  **BRCA**: not stated | Semi-structured interview | Grounded theory | Determine needs, concerns, and health practices pertaining to BC. |
| Kenen, Ardern-Jones, and Eeles (2003) | UK | Family history of BC. | n=21  **Age:** 24-61yrs  **Ethnicity:** not stated.  **PH:** none  **FH:** all  **BRCA:** all unknown | Semi-structured interview | Thematic | Report on risk perception, family history, life stages, biographical interruptions and women’s attempts to control their risk |
| Keogh, McClaren, Apicella, and Hooper (2011) | Australia | 1 first or second degree relative diagnosed with BC before 50yrs. BRCA1/ 2 not identified in family. | n=24,  **Age**: 35-70yrs  **Ethnicity:** not stated  **FH**: all  **PH:** none  **BRCA:** all unknown. | Semi-structured interview | Thematic | Explore how women perceive their risk of breast cancer and how this perception influences their screening decisions. |
| Raveis and Pretter (2005) | USA | Daughters of BC survivors | n=50.  **Age:** 21-62yrs,  **Ethnicity:** 70% White, non-Hispanic, 24% Hispanic 4% Black, non-Hispanic.  **PH:** not stated,  **FH**: all  **BRCA:** not stated | Semi-structured interview | Content analysis | Describe daughter’s experience and elucidate reactions to mother’s BC diagnosis. |
| Robertson (2000) | Canada | Breast Health Clinic attendees, aged 30 -50 (pre-menopausal); no PH of BC.  Only presents data of women indicated to be at increased risk by Gail assessment tool. | n=20  **Age**: 30-50yrs  **Ethnicity:** mostly northern European  **PH**: none  **FH:** not stated  **BRCA:** excluded women who had undertaken gene testing | Semi-structured interview | Thematic | Explore notion of 'phenomenology of risk' to explore women's accounts of their own individual risks for BC. |
| Sheinfeld Gorin and Albert (2003) | USA | At least one close female relative diagnosed with BC | n=26.  **Age** Normalizer 49yrs, Adopter 42yrs (mean)  **Ethnicity:** majority whi**te**  **PH:** not stated  **FH**: all  **BRCA:** suggest ‘some’ but no % | Semi-structured interview | Thematic | Understanding of the effect of risk perception on screening adherence in a woman’s natural language |
| Van Dijk, et al. (2004) | Netherlands | Increased risk attributable to FH | N=123  **Age** 47yrs (mean)  **Ethnicity:** majority whi**te**  **PH:** not stated  **FH**: all  **BRCA:** 9.8% | Semi-structured interview | Content analysis with coding for frequency analysis. | Examine how women describe their risk, and describe cognitions, emotions, and beliefs associated with risk information in genetic counseling for breast cancer. |
| Werner- Lin (2007) | USA | Young age (22-36) BRCA positive | n= 22, **Age**: 22-36 **Ethnicity:** White, mixed Eastern/ Western European **PH**: none **FH:** 20  **BRCA:** all positive | Semi-structured interview | Listening guide | Explore connections between family history and beliefs about susceptibility. Understand how family histories/experiences with health care professionals integrate to inform beliefs. |