

# **Mixed method systematic review: the relationship between breast cancer risk perception and health-protective behaviour in women with family history of breast cancer.**

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## ABSTRACT

### Aim

To investigate the relationship between risk perception and health-protective behaviour in individuals with family history of breast cancer.

### Background

Women with increased risk of breast cancer due to inherited predisposition can use health-protective behaviours to facilitate prevention or early detection of cancer.

### Data sources

Four scientific literature databases (CINAHL, Medline, AMED and PsychInfo) and three systematic review databases were searched.

### Design

Mixed method systematic review.

### Review methods

The systematic review of peer-reviewed literature was conducted following the method described by the Centre of Reviews and Dissemination. Research studies published in English between January 2004-December 2014 focussing on individuals with family history of breast cancer were included. Of 210 papers identified, ten studies were eligible for inclusion. Studies were assessed for their quality. Due to the diversity of the studies, a three-step analysis was undertaken involving narrative summary of quantitative data, thematic analysis and presentation of integrated results in narrative form.

### Results

A clear link between breast cancer risk perception and some health-protective behaviour was identified. Screening administered by health professionals (mammogram screening, chemoprevention) were appropriately adopted. However, behaviours requiring high individual input (breast self examination, lifestyle changes) were not as appropriately adopted and the decision process was not as clearly linked to risk perception.

## Conclusions

There is limited understanding about the complex relationship between risk perception and health-protective behaviour. Risk communication and health promotion need to be further developed to assist individuals to better engage with their actual risk and risk-appropriate behaviours, particularly those that require regular personal effort.

## Keywords

Nursing, systematic review, breast cancer, family history, risk perception, health-protective behaviour, literature review, Health Belief Model.

## SUMMARY STATEMENT:

Why is this review needed?

- Medical advances are increasing the knowledge about cancer genetics, but there is still only limited understanding of the complex relationship between breast cancer risk perception and health-protective behaviour in women with family history of breast cancer.
- It was important to systematically explore and collate recent literature on how breast cancer risk perception guides women's health related decision-making, in order to further develop risk communication and patient education.

What are the key findings?

- Health-protective behaviours requiring an input from a healthcare professional, such as appropriate use of mammogram screening and chemoprevention have strong links to high breast cancer risk perception.
- Breast self examination and making lifestyle changes, such as improving diet and lowering alcohol intake were found not to be dependent on the individual's risk perception. Women with high risk perception were knowledgeable about the impact of lifestyle on their risk, but still chose not to make the changes.

How should the findings be used to influence practice and research?

- Risk communication should be developed to improve the individual's association between perceived and actual breast cancer risk as this would lead to more appropriate health-protective decision-making.
- As well as factual information, health promotion programmes and patient education should acknowledge psychological factors, which influence women with family history of breast cancer when making health-protective behaviour decisions.

## INTRODUCTION

### Background

Breast cancer is the most common cancer occurring in women in the developed world, with approximately one in eight women being affected by the disease in their lifetime (CRUK 2013). The vast majority of breast cancers happen sporadically, but approximately 5-10% of breast cancers are due to an inherited genetic fault in one of the genes known to be associated with breast cancer; BRCA1 or BRCA2 (Claus *et al.* 1996). Early detection improves breast cancer survival and screening procedures are available, but the use of these may depend on the individual's perception of risk (Gross *et al.* 2005). Identifying individuals with an inherited predisposition to breast cancer is therefore important in order to inform them of their levels of risk, offer screening, psychological support and inform them of appropriate health-protective behaviours (Rahman 2014).

It is clear that growing scientific knowledge in oncogenetics has influenced cancer care (MacDonald *et al.* 2006). Therefore risk assessments incorporating family history information are becoming part of the standard care pathway for individuals with breast cancer in many countries (MacDonald *et al.* 2006). Family history risk assessment clinics can identify individuals who would most benefit from breast screening at an earlier age than usual, risk reducing interventions and information about healthy lifestyle choices (Santos *et al.* 2013). Appropriate cancer risk assessments can also help individuals in their health related decision-making process (Gomy & Estevez Diz 2013). However, it should be a concern for nurses that, despite the increase in breast cancer incidences in recent years and the wider availability of breast screening, women's health-protective behaviour has not advanced at the same rate (ChaeWeon & Suk Jeong 2013).

### Risk communication and accuracy of risk perception

Cancer risk perception has long been recognised as a factor that affects quality of life and health behaviour (van Dooren *et al.* 2004). Most individuals do not formulate their perception of risk purely based on facts and figures (Abraham & Sheeran 1997). Abraham and Sheeran (1997) suggested that risk perception is built over

time and influenced by individual experiences, emotional responses and sometimes selective memories. In addition, women do not always understand the common risk assessment terminology used by healthcare professionals (Buxton *et al.* 2003). Therefore, an individual's perception of risk may not conform to that presented by healthcare professionals. This can cause conflict for the individual, potentially leading to non-compliance with regard to screening or lifestyle (Cameron 1997).

It can be hypothesised that by helping individuals to have a realistic, evidence based risk perception and by increasing their knowledge and understanding about risk factors, they will be more likely to adopt appropriate health-protective behaviours. However, Dieng *et al.* (2014) found that there is lack of clear evidence about the efficiency of any of the educational tools currently available aiming to improve individuals' risk perception accuracy. ChaeWeon and Suk Jeong (2013) suggested that health professionals should develop risk communication styles that support women's formation of accurate risk perception. This could limit over or under screening and address appropriate cancer worry (ChaeWeon & Suk Jeong 2013).

Kreuter *et al.* (1995) suggested that perception of risk in general leads to behavioural change and helping individuals perceive their cancer risk accurately could have a positive influence on health behaviour. An individual with an inaccurate risk perception is unlikely to engage with optimal breast cancer screening or to adopt other appropriate health-protective behaviours (Katapodi *et al.* 2009).

### Breast cancer risk factors

Women's knowledge of breast cancer risk factors can be limited and this can affect their compliance with health-protective behaviour (Greco *et al.* 2010). In a study by Jones *et al.* (2011), women correctly recognised family history, poor diet, being overweight and high alcohol consumption as breast cancer risk factors, but failed to mention the bigger factors: age and gender. Murthy *et al.* (2011) however, noted that while poor diet and lack of exercise were identified as risk factors for breast cancer, participants were not aware of the relevance of family history. Women with family history of breast cancer often have knowledge about the health-protective

behaviours they should adopt, but this knowledge does not always translate in to actions (Demirelöz *et al.* 2010).

## Theoretical framework

It is clear that cancer risk perception affects health behaviour and it is therefore important for nurses to understand how individuals formulate their risk perception and construct their health behaviour strategies in order to develop illness prevention practices and health promotion programmes. The Health Belief Model initially proposed by Rosenstock (1974) identified factors that directly and indirectly affect an individual's engagement with health-protective behaviours, suggesting that individuals place different values on specific factors such as importance of perceived control over their own health. The Health Belief Model (Green & Murphy 2014) is based on the assumption that individuals are motivated to adopt health-protective behaviour as they have a desire to increase their own wellbeing.

## THE REVIEW

### Aim

The aim of this mixed method integrative review was to explore the relationship between breast cancer risk perception and health-protective behaviour in women with family history of breast cancer.

### Design

This was a mixed method systematic review of peer-reviewed literature. The use of this method ensures a systematic collection of all available evidence in a standardised and repeatable way, producing a balanced interpretation of the findings (Glasziou *et al.* 2001, Khan *et al.* 2011). Mixed method reviews can increase understanding of highly complex public health issues (Pluye & Nha Hong 2014).

### Search methods

The search strategy was agreed by two authors. The search was undertaken in January 2015. Four key electronic databases were searched: CINAHL, Medline, AMED and PsychInfo. Additional searches were performed on the databases of the Joanne Briggs Institute, Database for Abstracts and Reviews of Effects (DARE) and the Cochrane Collaboration database. Google Scholar was also searched for further material. The search terms used were: cancer family history AND risk perception. Studies were deemed to be eligible if they were published between 1st of January 2004 and 31st of December 2014 in English, in peer-reviewed journals, reported research conducted in any country, focussed on individuals with any family history of breast cancer, regardless of their genetic testing status and included data on risk perception and health-protective behaviours. Studies were excluded if they were interventional studies or if data on risk perception of individuals with family history of breast cancer could not be extracted.

### Search outcome

The identification and selection process for the appropriate papers was performed following the process described in the PRISMA flowchart (Moher *et al.* 2010) (Figure 1). After removing duplicates, 210 studies were identified from the initial searches. A total of 180 papers were excluded after reading the titles and/or abstracts as these did not fit the inclusion criteria. The remaining 30 papers were read in full and 21 were excluded. Nine papers were deemed eligible and included in the systematic review. Authors of one paper (Bennett *et al.* 2010) reported on two studies, making a total of ten studies included in the review.

### Quality appraisal

The Centre for Reviews and Dissemination (CRD) (2008) guidance does not favour a particular quality appraisal tool but states that tool selection should be based on methodological and pragmatic factors. All eligible papers were assessed for quality using the appraisal tool developed by Kmet *et al.* (2004). This tool enables the assessment of both quantitative and qualitative papers using separate but

comparable systems, and this has frequently been used for mixed methods systematic reviews on similar topics (Legare *et al.* 2008, Paneque *et al.* 2015, Cunningham *et al.* 2015). Two authors performed independent appraisals before discussing the outcomes. Minor differences of opinion between the two appraisers were resolved through discussion. The CRD guidance (Centre for Reviews and Dissemination 2008) indicates that studies should not be excluded on the basis of quality at this point and therefore all papers were included in the review. Notes on the quality appraisal of each paper are included in the supplementary table.

### Data abstraction

As recommended by the CRD (Centre for Reviews and Dissemination 2008), the data from the studies were extracted and these are presented in Table 1. Guidance on data abstraction is included in Box 1.

### Synthesis and thematic analysis

There was considerable heterogeneity in the papers with regard to sample, design and data collection method and outcomes measured, therefore neither a meta-analysis of the quantitative data nor a meta-synthesis of qualitative data could be performed. The findings were therefore synthesised and presented in a narrative form (CRD 2008), using a three-step approach. First we summarised the quantitative outcomes for each quantitative study using a narrative summary technique to determine the relationship between breast cancer risk perception and health-protective behaviour. The quantitative outcomes (p values and estimates of precision) are reported on a study by study basis in Table 1. Secondly we undertook a thematic analysis of the qualitative studies using Braun and Clarke (2006) to further explore and contextualise the relationship between breast cancer risk perception and health-protective behaviour. All papers were read by two authors several times and initial codes were identified. These were drawn from the data without attempting to make them conform to a pre-existing set of concepts: this method is consistent with that described by Braun and Clarke (2006). The codes were sorted into categories, refined and finally named under thematic labels. Finally, quantitative outcomes were integrated into the qualitative synthesis. Although we

did not conduct the analysis with pre-conceived themes in mind, we found that the findings segregated into one theme labelled 'cancer worry' and another focussed on risk reduction strategies, under which there were number of sub-themes (Table 2).

## RESULTS

### Description of the studies

Of the ten studies included in the review, five were conducted in the USA, two in the United Kingdom, one in Australia, one in Canada and one in France. Seven of the studies were quantitative and the remaining three were qualitative (Spector *et al.* 2009, Bennett *et al.* 2010, Keogh *et al.* 2011). In every study, all the participants were women and had family history of breast cancer, but they varied in age and ethnicity. In the study by Milhabet *et al.* (2013), all the women had had a negative BRCA gene test but these women still had family history of breast cancer, which may have an impact on risk perception.

The findings of all the studies are discussed further under two major themes identified through thematic analysis: 1) cancer worry and 2) health-protective behaviours related to risk perception. Cancer worry was often interlinked with the individual's breast cancer risk perception, while feelings of control over cancer were raised in several studies. It was therefore important to include cancer worry as a theme, even though it differs conceptually from the other theme and sub-themes.

#### *1. Cancer worry*

Cancer worry was related to risk perception and subsequent health-protective behaviours. For example, in the first study by Bennett *et al.* (2010) only one woman with high breast cancer risk perception reported psychological benefits from a breast cancer risk assessment, while the remaining 12 saw the main benefit being access to screening. For these women, having a breast cancer risk assessment did not lower their cancer worry and even though some reported initially feeling somewhat reassured this feeling had faded fairly quickly. The findings of the second study by

Bennett *et al.* (2010) confirmed that perceived susceptibility to breast cancer and high Breast Cancer Worry Score (BCWS) were statistically significantly associated with increased demands for mammograms, but not with engaging in BSE or other health-protective behaviours.

Milhabet *et al.* (2013) were the only researchers who investigated women who had strong family history but a negative BRCA gene test result. The authors reported a link between breast cancer worry and breast cancer risk perception. Women in their study expressed at least moderate breast cancer worry, but this did not lead to overscreening behaviour.

## *2. Health-protective behaviours related to risk perception*

### *Breast cancer risk perception and the use of mammograms*

In six studies, researchers found a clear link between breast cancer risk perception and the use of mammograms, whereas in one study (Martin & Degner 2006), this link could not be identified.

In their first study, Bennett *et al.* (2010) found that the 43% (n=13) of the women who reported high breast cancer risk perception were highly focused on their need for regular mammograms. These women described mammograms as a safety net, but failed to recall specific details about their actual risk. Haber *et al.* (2012) reported 761 women (11.3%) with family history of breast cancer had high breast cancer risk perception levels and were more likely to participate in mammogram surveillance than women with family history of other cancers.

Laing and Makambi (2008) found that women were more likely to have a mammogram if they had high breast cancer risk perception. In their study, 28/38 (74%) African-American women with high breast cancer risk perception reported having had a recent mammogram and 26 (72%) reported also having continuous regular screening, demonstrating good adherence to recommendations and awareness of the benefits of regular mammograms in this group.

Keogh *et al.* (2011) studied 24 women with family history of breast cancer and identified five risk management styles. These were labelled: “don’t worry about cancer risk, but do screening”, “concerned about cancer risk, so do something”, “concerned about cancer risk, so why don’t I do something”, “cancer inevitable” and “cancer unlikely”. None of the women in that study had received formal counselling about their actual breast cancer risk and many lacked confidence in their own interpretation of their risk. However, all were able to reflect on their health-protective behaviour decision-making process and to describe their breast cancer risk perception. Seven women (29%) acknowledged their increased breast cancer risk, but did not perceive it to be particularly high. These women had mammograms because of a health professional’s advice, rather than their risk perception. Six women (25%) with high perception of risk indicated that this guided their health-protective behaviour decision-making processes and all attended for regular mammograms. Two women (8%) in the study stated that, despite knowing that their actual risk of developing breast cancer was increased, they were convinced that they would never get breast cancer. One attended for regular mammograms, the other one did not. These women were aware that this was not a socially accepted attitude for someone with a strong family history of breast cancer and were reluctant to elaborate on their beliefs.

Milhabet *et al.* (2013) identified a significant link between high breast cancer risk perception and mammogram use. However, 66% of women in this study had adopted at least one screening behaviour that had not been recommended to them, such as having more mammograms than medically warranted. This suggests either some lack of understanding about health-protective behaviours and breast cancer risk management or inappropriate or limited delivery of information by the health professionals. The women in study by Milhabet *et al.* (2013) differ from women in other studies as they have all had a negative BRCA gene test. However, these women still had family history of breast cancer, which may influence their breast cancer risk perception and their health-protective behaviour decisions, therefore making them comparable with women in the other studies.

In contrast to the other six studies, Martin and Degner (2006) found no significant relationship between breast cancer risk perception and mammogram uptake in the

56 women that took part in their study. The participants were recruited from a genetics clinic where the women had been informed about their actual risk. Perhaps for this reason their risk perception was not the prominent guide for their health-protective behaviour decision-making processes. In fact, Martin and Degner (2006) reported that women with moderate breast cancer risk perception were more likely (90%) to have regular mammograms than women with high breast cancer risk perception (81%). In this study, the number of relatives affected by breast cancer was reported to be a major factor for women making health-protective behaviour decisions. It is notable however, that the study had a small sample and low response rate, which may have accounted for the difference in results compared to the other studies.

#### *Breast cancer risk perception and performing breast self examination (BSE)*

In two studies the researchers reported a significant correlation between high breast cancer risk perception and individuals' willingness to perform BSE as health-protective behaviour (Laing & Makambi 2008, Milhabet *et al.* 2013), but in neither study by Bennett *et al.* (2010) was this correlation found.

In their first study of 30 women, Bennett *et al.* (2010) found that women who reported low breast cancer risk perception felt confident about performing BSE. However, the 13 women with high breast cancer risk perception had strong focus on mammograms, but low reliance on other health-protective behaviours, such as BSE. Women with high breast cancer risk perception lacked confidence in their ability in taking responsibility of their own breast awareness. This was supported by similar findings from the second study by (Bennett *et al.* 2010), which had a much larger cohort of 263 women.

Laing and Makambi (2008) however, found that the 24 women (63% of the total of 38) who reported having high breast cancer risk perception performed regular BSE, whereas only 10 women (43%) out of 23 who considered their breast cancer risk to be low engaged with BSE.

The main focus of the study by Milhabet *et al.* (2013) was on what was described by the authors as 'overscreening behaviour' in women who had had BRCA gene testing, but had not inherited a gene mutation. The authors describe overscreening as "undergoing more screening tests for cancer than are medically warranted" (pp. 540). According to the authors, 43% of the 77 women who took part in their study adopted BSE as the type of overscreening behaviour. Milhabet *et al.* (2013) reported this as a statistically significant link between high breast cancer risk perception and performing BSE.

#### *Breast cancer risk perception and the use of breast ultrasound screening and the use of ovarian screening*

Milhabet *et al.* (2013) reported a significant relationship between high breast cancer risk perception and overscreening behaviour in the form of breast and ovarian ultrasound. In their study, based in France, 19% of women attended overscreening by breast ultrasound and 25% of women by ovarian ultrasound. The participants in this study were all unaffected members of families where a BRCA gene mutation had been identified, which may explain the high risk perception and overscreening behaviour.

#### *Breast cancer risk perception and attending clinical breast examination (CBE)*

Martin and Degner (2006) found no significant correlation between breast cancer risk perception and attending for CBE. However, the more relatives affected by breast cancer an individual had, the more likely they were to receive regular CBE. In this Canadian study, 63% of women who had three or more affected relatives reported having a recent CBE. Contrary to these findings, Milhabet *et al.* (2013) found that 10 (13%) out of the total of 77 women who took part in the study, reported high breast cancer risk perception and overscreening behaviour in the form of attending CBE.

#### *Breast cancer risk perception and the use of hormonal therapies*

In the study by Bober *et al.* (2004), 37 women (29%) out of the 129 decided to take chemoprevention (tamoxifen) and all these reported high breast cancer risk

perception. For individuals at increased risk of breast cancer, personal perception of risk was highly important when making health-protective decisions. Women were more likely to opt for chemoprevention if a health care professional had directly recommended it. Bober *et al.* (2004) also reported that 35 women (27%) chose to take part in a randomised study comparing two different types of chemoprevention (tamoxifen and raloxifen), 31 women (24%) decided against any chemoprevention and a notable number of women, 26 (20%) remained undecided. Women in these groups had lower breast cancer risk perceptions.

Spector *et al.* (2009) found that five (16%) of the 32 women who participated, reported low breast cancer risk perception and none of them had opted for chemoprevention. The actual breast cancer risk of these women was not low, but their behaviour seemed to be guided by their perceived risk. A vast majority (84%) of women in this study had elevated breast cancer risk perception and eight (30%) of these women had made hormone related changes: four women had stopped using HRT and four had begun chemoprevention therapy.

### *Breast cancer risk perception and making lifestyle changes*

Lemon *et al.* (2004) recorded five health behaviour changes in their study: exercise, fruit and vegetable consumption, fat consumption, alcohol consumption and smoking. Of the 600 women in their study, 456 (76%) considered their risk of developing breast cancer to be higher than women without family history of breast cancer. Most women (70%) felt that they had at least moderate control over developing breast cancer and that their health-protective behaviour choices made it possible to reduce their risk of developing breast cancer. However, only 42% reported to have made any lifestyle changes.

Lemon *et al.* (2004) also found that neither perception of severity of breast cancer nor personal breast cancer risk perception were factors affecting health-protective behaviour change. Women in this study appropriately recognised how the specific lifestyle changes affected their breast cancer risk and the key to encouraging women to change their health-protective behaviour seemed to be in education and offering them a sense of control over their risk.

Spector *et al.* (2009) found that three of the five women reporting low breast cancer risk perception had made at least one lifestyle change. However, of the 27 women who had elevated breast cancer risk perception, only eight (30%) had made some lifestyle changes.

## DISCUSSION

The findings of this systematic review indicate a clear positive relationship between breast cancer risk perception and some health-protective behaviours in women with family history of breast cancer. However it is also clear that these relationships are complex. For example, Bennett *et al.* (2010) found that women with high breast cancer risk perception had increased use of mammogram screening, but did not engage with other health-protective behaviours appropriately.

In two previous systematic reviews by McCaul *et al.* (1996) and by Katapodi *et al.* (2004), the researchers reported a positive association between breast cancer risk perception and mammogram adherence in 84% (n=27) of the 32 studies included. Considering these results in the framework of the Health Belief Model (Green and Murphy 2014), it is likely that women find the use of mammograms beneficial, thus explaining the high adoption rates reported. However, neither McCaul *et al.* (1996) nor Katapodi *et al.* (2004) offer much information about the relationship between breast cancer risk perception and other types of health-protective behaviours.

Katapodi *et al.* (2004) reported findings from four studies in which performing BSE and risk perception were investigated with inconclusive results. This was also found in the current review, where the results from two studies indicated a correlation between breast cancer risk perception and performing BSE, while a further two did not. It was notable that the studies conducted in the UK by Bennett *et al.* (2010) reported a link between risk perception and the use of mammograms, but not with BSE. However, studies undertaken in the USA (Laing and Makambi 2008) and in France (Milhabet *et al.* 2013) found that participants were able to complement their positive association of mammograms with good adherence to performing BSE in the appropriate context of their perceived risk. It is possible that risk communication,

knowledge about benefits of health-protective behaviours and acceptability of BSE varies in different countries, resulting in different behaviour.

Health-protective behaviour decisions are always made in the context of the environment of each individual (Rosenstock 1974). Demographic variables, such as age, race and socioeconomic status can also have an impact on how an individual views illness in general, how they recognise the benefits of certain behaviours and how likely they are, or indeed how able they are, to engage with them. In the Health Belief Model, Rosenstock (1974) spoke of direct and indirect elements that influence health behaviour: geographical location can certainly be seen as an indirect element. Screening recommendations, availability, ease of access and national attitudes often vary hugely in different countries and this is likely to influence how an individual develops their perception of cancer risk and view health-protective behaviours. For example, in a Spanish study by Montes *et al.* (2007) living near a referral centre increased adherence to the lung cancer screening program. Having family history of breast cancer potentially creates a specific context in which an individual develops their breast cancer risk perception.

Individuals who feel capable of controlling their own health are more likely to engage in appropriate health-protective behaviour (Rosenstock, 1974). It is therefore important to recognise that removing barriers of access of healthcare and empowering individuals with knowledge could produce more optimal health-protective behaviour. However, researchers in a number of studies in the review found that individuals with high risk perception and considerable cancer worry had appropriate knowledge about their actual risk and available health-protective actions, but still chose not to engage with certain health-protective behaviours. This suggests that personal barriers may make it difficult for individuals to form a connection between their knowledge, personal cancer risk perception and beneficial health-protective behaviour. It is therefore important that health professionals adopt new, innovative cancer risk communication methods. These should aim to improve acceptance and retention of actual risk information and to increase understanding about how different health-protective behaviours complement each other.

It is notable that in the current review interventions requiring a health professional to make a referral or prescribe a drug were almost unanimously and appropriately adopted. However, health-protective behaviours that required high personal input were not as appropriately adopted. Lemon *et al.* (2004) suggested that perception of the importance of the lifestyle change was important when making decisions. For example, if an individual perceives that high fat content in food will increase their risk of developing breast cancer, they are likely to make a dietary change regardless of scientific facts. Health professionals have an important but challenging role in offering the correct amount of information, support and social pressure to guide individuals to accept both the medically led interventions and those requiring more personal effort.

In the current review, rather surprisingly no link was found between breast cancer risk perception and making lifestyle changes. Women in some studies (Lemon *et al.* 2004, Spector *et al.* 2009) stated that if they felt that a lifestyle change would benefit them, they would be more likely to make the change. Rosenstock (1974) claimed that individuals hold different values and perceive certain actions as more beneficial to them than others, also emphasising the individual's perception of their own capability when making health-protective behaviour decisions. It is therefore possible that some individuals find that they are not capable of making certain lifestyle changes or attending certain types of screening, even when they recognise the potential benefit as these decisions are made in the context of their personality, environment, previous experiences and perceived barriers.

### Strengths and limitations

A strength of this review was the rigorous process undertaken to search for available evidence. The selection of papers, quality assessment and development of themes were undertaken by both researchers. However, it has to be acknowledged that unpublished studies were not represented, and this may be important, taking into account publication bias. All the papers included in this systematic review were rigorously assessed for their quality and found to be of high standard. However, they were mainly descriptive, which highlights the need for further research in this field using more experimental methods.

## CONCLUSION

### Clinical implications

Several clinical implications can be suggested from the findings of this systematic review. It was an especially interesting finding that breast cancer risk perception did not have an impact on individuals when making health related lifestyle changes. It therefore seems that the health-protective behaviours, such as increasing exercise, quitting smoking and making dietary changes, which are most economical from a health service perspective and the most widely beneficial to the individual's general state of health, are the ones with which women with family history of breast cancer find the most difficult to engage. Health promotion programmes and breast cancer information publications must tackle this issue and find ways to incorporate the factual messages with sensitivity about the psychological factors that influence women. It is clear from the findings of this review that breast cancer risk communication needs to be developed to further support individuals in understanding and accepting their actual risk. Due to the complex interplay of cancer worry, perceived cancer risk and health-protective behaviour, interventions, should also incorporate the psychological factors that influence individuals with family history of breast cancer.

### Suggestions for further research

The variability of some of the findings from this mixed method systematic review highlight the need for further research into the formulation of breast cancer risk perception and the disparities between actual and perceived risk, particularly in this specific group of women. It would also be beneficial to investigate in more depth the complexity of individuals' health-protective behaviour decision making processes. From a health economics point of view, it would be particularly interesting to find out whether an extended time spent with a specialist nurse discussing breast cancer risk, risk factors and risk management options would lead to better understanding and adoption of actual risk and appropriate health-protective behaviours. This may reduce cancer worry, demand for overscreening and inappropriate symptomatic clinic referrals.

This review has highlighted the need for health professionals to emphasise measures that can be taken by patients directly to reduce cancer risk or detect cancer at an early stage. As medical advances are made in cancer genetics and the public demand for more information about their options grows, cancer risk communication also needs to evolve to cater for this demand. It is only through rigorous research into understanding these decision making processes that we can satisfy ourselves as nurses that the patient is fully aware of the consequences their decisions may have.

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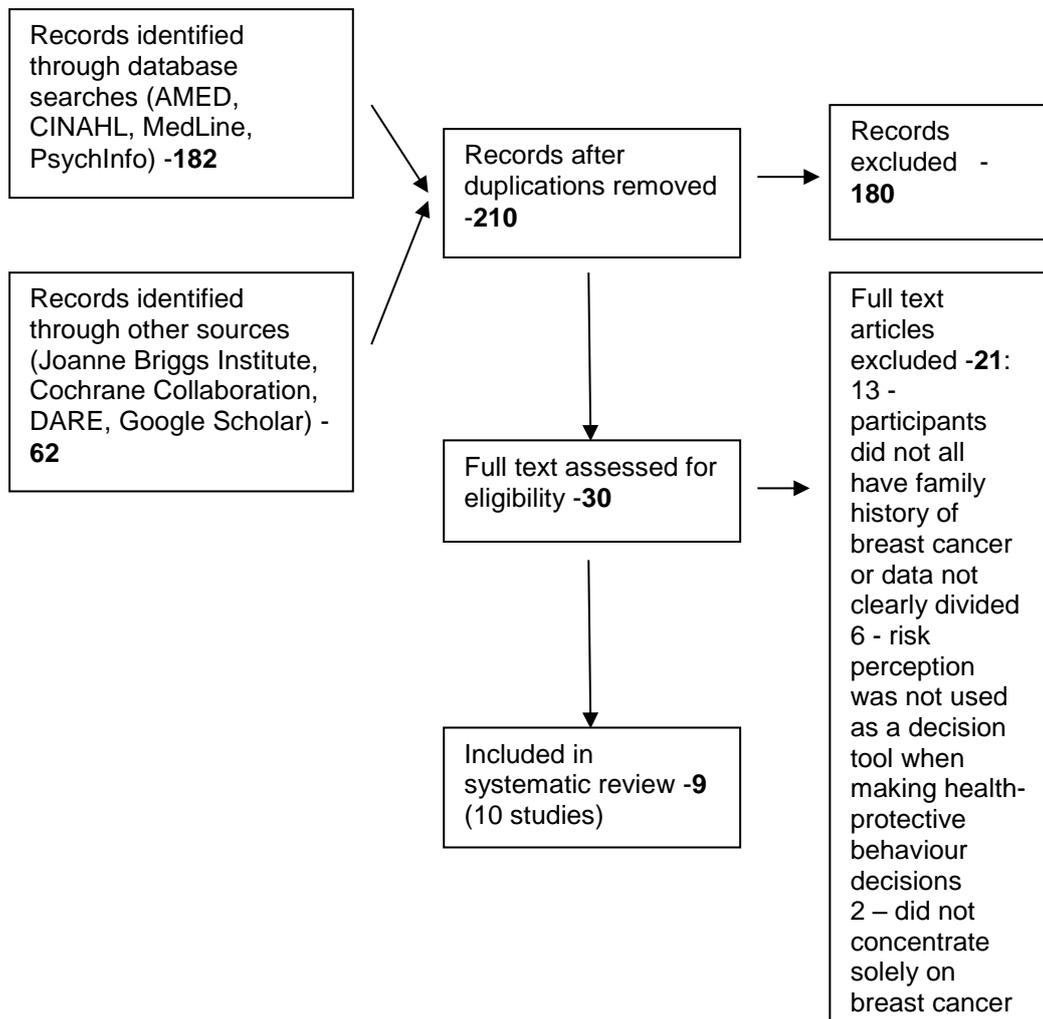
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**Figure 1 Summary of the selection process for systematic review based on PRISMA flowchart.**



**Table 1. Summary of papers included in the review**

Author, year of publication and country	Objective	Design and method	Participants	Data analysis	Main results
Bennett <i>et al.</i> (2010) -1 UK	To explore women's experiences of living with cancer risk and the use of health services.	Qualitative; semi-structured, face-to-face interview.	30 women with family history of breast cancer from TRACE study.	Interviews recorded, transcribed and thematically analysed by a coding group.	High risk perception leads to increased use of mammograms, but not of other health-protective behaviours.
Bennett <i>et al.</i> (2010) -2 UK	To explore women's experiences of living with cancer and the use of health services in a larger cohort.	Quantitative; cross-sectional postal survey.	263 women with family history of breast cancer from TRACE study.	Non-parametric methods: Spearman's correlation, Mann Whitney U statistics. Ordinal regression, Pearson's correlations, linear regression methods, T-test.	Confirmed findings of the smaller cohort in study 1. Women with high risk perception and high cancer worry are likely to request mammograms, even at older age. Actual risk may have little impact on this behaviour.
Bober <i>et al.</i> (2004) USA	To explore factors affecting chemoprevention decision making	Quantitative; survey, questionnaire, follow up telephone interview	129 women with high risk of breast cancer	Fisher's exact test, logistic regression, Student-Newman-Keuls, T-test.	Women with high breast cancer risk perception were more likely to take Tamoxifen than women with low risk perception (F=5.28, R <sup>2</sup> =0.11; p<0.001). Health professional's recommendation affected decision making (P<.0001).
Haber <i>et al.</i> (2012) USA	To examine associations between breast cancer risk perception and use of mammograms	Quantitative; cross-sectional survey.	6706 women from NHIS study, 761 (11.3%) with family history of breast cancer.	Structural equation modelling framework. Holm-modified Bonferroni method used to control possible error on risk perception.	Women with a family history of breast cancer were more likely to attend for repeat mammography (0.5 more mammograms in the previous 6 years (p<.001) when compared with women with no breast cancer history. When comparing numbers of mammograms in the past 6 years between women who had a mother, or mother and sister with breast cancer with women with no history of cancer, the odds ratio was 0.50 (95% CI 0.25, 0.77).
Keogh <i>et al.</i> (2011) Australia	To investigate relationships between breast cancer risk perception and screening practices.	Qualitative; semi-structured, face-to-face interview.	24 women with family history of breast cancer.	Interviews recorded and transcribed verbatim. Thematic analysis by two researchers. Data double-coded.	Cancer worry was linked to breast cancer risk perception and health-protective behaviour. Five risk management styles were identified: don't worry about cancer risk, but do screening; concerned about cancer risk, so do something; concerned about cancer risk, so why don't I do anything?; cancer inevitable; and cancer unlikely (p3). Risk perception guided screening behaviour
Laing and	To examine	Quantitative;	Community	Chi-squared	High breast cancer risk

Makambi (2008) USA	factors affecting breast screening behaviour.	cross-sectional survey.	sample of 61 African-American women with family history of breast cancer.	and Fisher's exact tests.	perception linked to increased use of mammograms and appropriate breast self examination activity. Access to regular health care (95% CI=1.01-42.79) and availability of health insurance (95% CI=1.05-23.52) were the most significant predictors for health-protective behaviour.
Lemon <i>et al.</i> (2004) USA	To describe perceived breast cancer risk and examine how it affects lifestyle.	Quantitative; longitudinal survey.	600 women with family history of breast cancer. Identified through affected relative.	Chi-squared and Fisher's exact test.	Women who believed exercise reduced breast cancer risk were more likely to increase physical activity (OR = 2.98; 95% CI = 1.72, 5.16). Those who believed the risk was reduced by eating fruit and vegetables were more likely to do so (OR = 2.34; 95% CI = 1.34, 4.11), while women who believed fat intake increased the risk were more likely to state that had decreased fat intake (OR = 2.67; 95% CI = 1.55, 4.58).
Martin and Degner (2006) Canada	To investigate breast cancer risk perception and surveillance activities.	Quantitative; retrospective correlational survey study.	56 women with family history of breast cancer from a hereditary breast cancer clinic	Chi-squared test.	No link found between risk perception and use of mammograms ( $X^2 = 0.850$ , $df = 1$ , $p = .356$ ) or having a clinical breast examination ( $X^2 = 2.204$ , $df = 1$ , $p = .138$ ). When comparing use of mammograms in women with different numbers of affected relatives, there was no significant difference ( $X^2 = 1.624$ , $df = 1$ , $p = .203$ ). However, women with more affected relatives were more likely to attend for CBE ( $X^2 = 7.381$ , $df = 1$ , $p = .007$ ).
Milhabet <i>et al.</i> (2013) France	To examine factors affecting breast screening behaviour.	Quantitative; cross-sectional survey.	83 women with family history of breast cancer and a relative with a BRCA gene fault.	Descriptive analysis. ANOVA calculated.	66.2% (n=51) of unaffected non-carriers used a form of screening that was not recommended for women at their level of risk. State anxiety was not correlated with overscreening behaviours ( $r = -0.04$ , ns; $n = 77$ ). Feelings of self-vulnerability were correlated with overscreening behaviours ( $r = 0.26$ , $P < 0.05$ ; $N = 77$ ).
Spector <i>et al.</i> (2009) USA	To explore breast cancer risk perception, screening and lifestyle behaviour.	Qualitative; descriptive interview.	32 women with family history of breast cancer identified through Sister-Study.	Interviews recorded and transcribed verbatim. Coding and constant comparative analysis performed.	High risk perception did not influence lifestyle decisions, but was a factor when making hormonal therapy choices. No link found between cancer worry and health-protective behaviours.

**Table 2. Prevalence of themes and relationships between breast cancer risk perception and health-protective behaviours.**

Theme/sub-theme	Number of studies in which data related to this theme/sub-theme were reported	Relationship between risk perception and health-protective behaviour identified	Relationship between risk perception and health-protective behaviour not identified
Theme 1- Cancer worry			
	7 (Bennett <i>et al.</i> 2010, Bober <i>et al.</i> 2004, Keogh <i>et al.</i> 2012, Laing & Makambi,2008, Milhabet <i>et al.</i> 2013, Spector <i>et al.</i> 2009)	4 (Bennett <i>et al.</i> 2010, Bober <i>et al.</i> 2004, Keogh <i>et al.</i> 2012)	3 (Laing & Makambi 2008, Milhabet <i>et al.</i> 2013, Spector <i>et al.</i> 2009)
Theme 2 –Health-protective behaviours			
a) Use of mammograms	7 (Bennett <i>et al.</i> 2010, Haber <i>et al.</i> 2012, Keogh <i>et al.</i> 2012 Laing & Makambi 2008, Martin & Degner 2006, Milhabet <i>et al.</i> 2013)	6 (Bennett <i>et al.</i> 2010, Haber <i>et al.</i> 2012, Keogh <i>et al.</i> 2012, Laing & Makambi 2008, Milhabet <i>et al.</i> 2013)	1 (Martin & Degner 2006)
b) Performing breast self examination	4 (Bennett <i>et al.</i> 2010, Laing & Makambi 2008, Milhabet <i>et al.</i> 2013)	2 (Laing & Makambi 2008, Milhabet <i>et al.</i> 2013)	2 (Bennett <i>et al.</i> 2010)
c) Making lifestyle changes	2 (Lemon <i>et al.</i> 2004, Spector <i>et al.</i> 2009)	0	2 (Lemon <i>et al.</i> 2004 Spector <i>et al.</i> 2009)
d) Having clinical breast examinations	2 (Martin & Degner 2006, Milhabet <i>et al.</i> 2013)	1 (Milhabet <i>et al.</i> 2013)	1 (Martin & Degner 2006)
e) Use of hormonal therapies	2 (Bober <i>et al.</i> 2004, Spector <i>et al.</i> , 2009)	2 (Bober <i>et al.</i> 2004; Spector <i>et al.</i> 2009)	0
f) Use of breast ultrasound scans and ovarian screening	1 (Milhabet <i>et al.</i> 2013)	1 (Milhabet <i>et al.</i> 2013)	0

### Supplemental Table: Quality assessment of qualitative studies

Criteria	Bennett <i>et al.</i> (2010) -1	Keogh <i>et al.</i> (2011)	Spector <i>et al.</i> (2009)
Question/objective sufficiently described	Satisfactorily addressed	Satisfactorily addressed	Satisfactorily addressed
Study design evident and appropriate	Partially addressed	Satisfactorily addressed	Satisfactorily addressed
Context of the study clear	Satisfactorily addressed	Satisfactorily addressed	Satisfactorily addressed
Connection to a theoretical framework/wider body of knowledge	Partially addressed	Partially addressed	Partially addressed
Sampling strategy described, relevant and justified	Satisfactorily addressed	Satisfactorily addressed	Satisfactorily addressed
Data collection methods clearly described and systematic	Satisfactorily addressed	Satisfactorily addressed	Satisfactorily addressed
Data analysis methods clearly described and systematic	Satisfactorily addressed	Satisfactorily addressed	Satisfactorily addressed
Use of verification procedure to establish credibility	Not addressed	Satisfactorily addressed	Satisfactorily addressed
Conclusions supported by results	Satisfactorily addressed	Satisfactorily addressed	Satisfactorily addressed
Reflexivity of the account	Partially addressed	Not addressed.	Partially addressed