Padamsee et al. Breast Cancer Research (2017) 19:34
DOI 10.1186/s13058-017-0826-5

Breast Cancer Research

REVIEW Open Access

Decision making for breast cancer prevention among women at elevated risk

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Abstract

Several medical management approaches have been shown to be effective in preventing breast cancer and detecting it early among women at elevated risk: 1) prophylactic mastectomy; 2) prophylactic oophorectomy; 3) chemoprevention; and 4) enhanced screening routines. To varying extents, however, these approaches are substantially underused relative to clinical practice recommendations. This article reviews the existing research on the uptake of these prevention approaches, the characteristics of women who are likely to use various methods, and the decision-making processes that underlie the differing choices of women. It also highlights important areas for future research, detailing the types of studies that are particularly needed in four key areas: documenting women's perspectives on their own perceptions of risk and prevention decisions; explicit comparisons of available prevention pathways and their likely health effects; the psychological, interpersonal, and social processes of prevention decision making; and the dynamics of subgroup variation. Ultimately, this research could support the development of interventions that more fully empower women to make informed and values-consistent decisions, and to move towards favorable health outcomes.

Background

Current risk estimation models enable the identification of women who are at elevated risk for breast cancer through genetic testing for *BRCA1*, *BRCA2*, and other mutations, as well as other potential genetic susceptibilities made evident by family histories of the disease. These high-risk women face a lifetime likelihood of breast cancer of between 20% and 80% depending on family history and genetic findings, significantly greater than the average 12% risk for women in the US. A subset of high-risk women face additional stresses related to genetic findings that do not correspond to a very specific risk estimate, or have unclear clinical implications, due to limitations of existing genetic science and risk quantification.

Several risk management options are available to support women at higher than average risk of breast cancer. Most of these are significantly underused by women who may benefit in terms of reduced cancer risk and cancer-related worry. Only about half of *BRCA* mutation carriers undergo the recommended prophylactic oophorectomy [1] and fewer than 5% of the high-risk women likely to benefit from chemoprevention use it [2, 3]. Underuse may be driven by multiple factors: lack of physician or patient information or understanding; lack of clinician confidence discussing preventive interventions or identifying women who could benefit from them; psychological or social dynamics that shape women's preferences, deliberations, or ability to act on their decisions; and fully informed choice. Ultimately, it is women who make the choices—often with the help of health professionals and personal connections—about which prevention options to implement. These individual choices have significant impact on utilization of prevention options, breast cancer incidence, and health outcomes. Nevertheless, little is known about the processes women navigate as they make these decisions.

This article summarizes what is known and unknown about the various drivers of women's decisions about breast cancer risk management methods. It begins with a brief overview of breast cancer prevention options for high-risk women, followed by a review of the current literature regarding decision making about these options by specific populations of women, and possible

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explanations for these patterns. This review also highlights important areas for future research, which could support the development of interventions that more fully empower women to make informed and values-consistent decisions and contribute to favorable health outcomes. It focuses solely on the prevention decision making of women at elevated risk of breast cancer due to identified genetic mutations or familial history. The prevention behavior of average risk women, decisions relevant after a breast cancer diagnosis, and the psychological sequelae of prevention interventions are outside the scope of this discussion.

Breast cancer prevention pathways

Women at elevated risk for breast cancer are those who either have a known predisposing genetic mutation, or have a family history of breast or related cancers sufficient to raise calculated lifetime chance of breast cancer above a certain benchmark—usually 20–25% [4–13]. Studies of breast cancer patients and early population-based screening studies suggest that between 10% and 15% of women with a substantial family history likely carry *BRCA1/2* mutations [14, 15], and about half of *BRCA* mutation carriers are unaware of this status [16, 17]. Current evidence indicates that specific mutations in other genes (*ATM*, *CDH1*, *CHEK2*, *NBN*, *NF1*, *PALB2*, *PTEN*, *STK11*, and *TP53*) also confer increased breast cancer risk, and testing for these mutations is becoming increasingly available. Positive findings for these mutations are currently associated with recommendations to add magnetic resonance imaging (MRI) screenings and, for a subset of these genes, to consider prophylactic surgery, but other aspects of appropriate clinical management for these patients remain under investigation [13, 18–20]. Guidelines recommend that women with a family history of breast or related cancers be screened, receive genetic counseling and testing if indicated, and receive counseling to discuss chemoprevention, risk-reducing surgery, and enhanced surveillance options if found to meet familial or genetic risk criteria [13, 21, 22]. Four biomedical prevention options form the basis for women's individual prevention pathways.

Bilateral prophylactic mastectomy (BPM; the surgical removal of both breasts for breast cancer risk reduction), the single most effective prevention method, reduces breast cancer risk by about 90% [23–31] and breast cancer-specific mortality by upwards of 80% [25, 26]. It may not improve overall survival, however, relative to routine mammography and MRI use, particularly for women who have had their ovaries removed [27]. Contralateral prophylactic mastectomy (CPM; surgical removal of the nonaffected breast for women with unilateral breast cancer) has not been shown to improve survival rates, but may decrease the risk of contralateral cancers in certain high-risk women; it is considered a clinically appropriate option for breast cancer patients with known *BRCA1/2* mutations, significant family history, or high-risk histology [32–38].

Prophylactic surgical removal of ovaries and fallopian tubes (bilateral prophylactic salpingo-oophorectomy; BPSO) is recommended for all *BRCA* mutation carriers between the ages of 35 and 40 years (or when childbearing is complete). For this group, it reduces the risk of ovarian, fallopian tube, or peritoneal cancer by 80% [39], likely halves the risk of breast cancer [33, 36, 40–43] (but see [44] for a counter-argument), and strongly reduces breast cancer mortality, ovarian cancer mortality, and all-cause mortality [27, 39]. However, adverse effects include induction of menopause, as well as increased risk of cardiovascular disease, osteoporosis, and cognitive impairment. Treatment with hormone replacement therapy (HRT) is controversial due to increased breast cancer risk [27, 45].

Two selective estrogen receptor modulators are approved for use as chemoprevention agents in the US. A 5-year course of tamoxifen by premenopausal women at elevated risk reduces their risk of breast cancer by 30% to 50%. Side effects include increased risk of endometrial cancer and venous thrombosis during the treatment period, while the protective benefits of chemoprevention last for at least 20 additional years [23, 46–52]. Raloxifene (approved for postmenopausal women) is estimated to be 76% as effective as tamoxifen in reducing the risk of invasive breast cancer, with significantly lower risks of thromboembolic events and uterine cancers [53–55]. Aromatase inhibitors show substantial promise as chemoprevention agents but are not yet approved for this use in the US or Europe; other potential chemoprevention agents including nonsteroidal anti-inflammatory drugs (NSAIDS), aspirin, metformin, cyclooxygenase-2 (COX-2) inhibitors, and poly-adenosine diphosphate-ribose polymerase (PARP) inhibitors have shown promise in early clinical research [27, 53, 56–59].

Enhanced surveillance is designed to facilitate early detection and treatment of breast cancer in women at high risk. Recommendations include: 1) increasing the frequency of clinical breast examinations to biannual checks; 2) initiation of radiologic screening at younger ages, such as 5 to 10 years prior to the youngest age of breast cancer diagnosis in a woman's family; 3) annual bilateral screening mammograms, combined with targeted ultrasound examinations as indicated; and 4) the addition of breast MRI for women with a lifetime risk of breast cancer of 20% or greater [13, 60]. These methods substantially increase the probability of early cancer detection in high-risk women, but require sustained adherence, involve regular (and sometimes substantial) expenditures, and raise distress rates associated with false-positive tests [61–66].

Lifestyle changes that reduce the risk of breast cancer in the general population are considered wise but insufficient for those with higher, familial risk [30, 56, 67]. These include increased intake of vegetables, fruit, and fiber, increased exercise, weight management, smoking cessation, reductions in alcohol use, prolonged lactation, and minimizing exogenous hormone therapy [56, 68].

It is likely that high-risk women commonly compare the effectiveness and consequences of methods and consider particular combinations of prevention options. There is, however, a sparse evidence base for these comparisons and combinations [69, 70]. It is known that *BRCA* mutation carriers can achieve greater risk reduction by undergoing both BPM and BPSO than either alone [27, 71], and that prophylactic surgeries generally reduce both cancer risk and anxiety about cancer [28]. BPSO is likely the single intervention with the best risk-benefit ratio for *BRCA* mutation carriers [72, 73]. Prophylactic surgeries may be more cost-effective than other methods, but enhanced surveillance yields the most quality-adjusted life years [74, 75]. Given the serious ethical and practical impediments to randomized controlled trials, prospective observational studies that take into account adherence to chemoprevention and enhanced surveillance could be useful in comparing morbidity, mortality, and psychological consequences in the context of various prevention strategies across various subgroups of women [30, 76].

Women's prevention choices

Uptake of prevention methods

Most research on uptake of biomedical prevention methods pertains specifically to *BRCA* mutation carriers, and less is known about women with apparent hereditary risk who are negative for *BRCA* mutations, those known to carry other risk-increasing genetic mutations, and those who have not undergone genetic testing. The rate of BPSO in *BRCA* mutation carriers ranges from 55% to 90% in various populations over periods ranging from 6 months to 10 years after receipt of genetic testing results [1, 77–81]. BPSO is performed on many additional women with hereditary risk each year, although the risk-reduction potential is less certain for women not known to have a *BRCA* mutation [42, 82]. Most studies find the rate of BPM among cancer-free *BRCA* mutation carriers to be about 20% and gradually rising [1, 77, 78, 83, 84], although it varies from as low as 11% to as high as 50% in specific samples [78, 81]. Overall, up to 80% of *BRCA* mutation carriers in some populations may undergo at least one risk-reducing surgery within 5 years of genetic testing [70], but this rate is likely much lower in other groups. BPSO is likely more common than BPM among *BRCA* mutation carriers because ovarian cancer treatment has poorer success rates than breast cancer treatment, because BPSO reduces risk of both ovarian and breast cancer, and because some women find mastectomy more psychologically difficult due to its potential effects on body image and sexuality [85]. CPM rates have risen substantially in recent decades, mostly among women who are *BRCA*-mutation negative or do not know their genetic status, and who are therefore unlikely to benefit [32, 38, 41, 43, 82, 86–89]. More than 5% of these women currently undergo CPM even as rates of contralateral breast cancer and regional breast cancer recurrence are both dropping; this raises concerns about surgery-related health risks, the need for new methods of communication about surgical options, and over-utilization of health services [42, 82, 89].

Population studies suggest that only 1–5% of women eligible to use tamoxifen for primary prevention actually do so [3, 67, 90–92]. Only 15% of *BRCA* mutation carriers approached for a chemoprevention trial enrolled [2], and only 8.5% of *BRCA* mutation carriers offered chemoprevention started such a regimen within 4 years of receiving genetic test results [77]. These usage rates fall far short of the proportion of women *interested* in chemoprevention, which one study found to be upwards of 40% [93] of those with familial risk. Chemoprevention also poses the challenge of long-term adherence: a large study of women at familial risk found that almost half of those who started tamoxifen chemoprevention did not complete the 5-year regimen [59, 94]. Additional studies are needed to fully understand the barriers to chemoprevention use, but they include: research gaps (limited risk prediction at the individual level and questions about risk-benefit profiles for specific subgroups); physician challenges (insufficient knowledge, difficulty identifying chemoprevention candidates, lack of training and confidence in risk assessment and counseling, and lack of time); and patient challenges (fear of side effects, predicted stress associated with chemoprevention, inaccurate or incomplete information, weighing witnessed experiences more heavily than statistical probabilities, and concerns about insurance coverage or cost) [3, 93–101]. It is important to understand low uptake better and to address the associated challenges, particularly in light of the recent review panel estimate that up to 50% of breast cancers among women at elevated risk could be prevented using currently available chemoprevention [56].

Between 20% and 50% of *BRCA* mutation carriers, and probably more high-risk women without known mutations, engage in surveillance alone, without specific intervention for biomedical risk reduction [70, 77]. Despite the widespread adoption of this 'watchful waiting' approach and recent increases in the use of screening MRI among women with familial risk [102], studies indicate that fewer than 70% of women are adherent to evidence-based

screening recommendations, and that the use of screening varies by race and ethnicity [103–106]. Effective screening also requires access to accurate and personalized information about the appropriate screening schedule and to clinical, radiologic surveillance that is financially and logistically feasible.

The general relationship between lifestyle factors and breast cancer has been extensively studied, but the specific extent to which high-risk women use lifestyle changes to reduce breast cancer risk has not yet been explored. Future research should examine women's perceptions and use of dietary and exercise changes as prevention behaviors, and how lifestyle choices relate to women's other preventive decisions.

Which women choose which prevention options?

Understanding which women are likely to make particular prevention choices is a key basis for efforts to facilitate informed, values-consistent, health-protective decisions. This involves understanding how uptake rates do or do not fit specific subgroups of women, as well as how psychological and social dynamics may affect the preferences and actions of individuals. Existing knowledge relevant to this area comes primarily from retrospective studies, usually of *BRCA1/2* mutation carriers and women who have completed preventive surgeries. This research is largely descriptive and correlational, and does not explore decision-making processes or other factors that affect women's preferences and choices on a prospective basis.

Severity of risk, family history, and psychological health

Severity of cancer risk (both diagnosed and perceived) strongly affects prevention behavior. Higher perceived risk of breast cancer is positively associated with considering chemoprevention, BPM, and BPSO among high-risk women in general [83, 107, 108]. Known *BRCA* mutation carriers choose BPM more frequently than other women at elevated risk, and are more likely to believe that BPM is the best way to reduce both breast cancer risk and worry [109]. *BRCA* mutation carriers who believe ovarian cancer to be incurable are more likely to undergo BPSO [110]. Women with *BRCA1* and *BRCA2* mutations may behave differently with respect to BPM and BPSO, but this merits additional investigation [77, 111]. Among breast cancer patients, those who have clinical correlates of recurrence (larger tumors, lobular histology, known *BRCA 1/2* mutations) are in fact significantly more likely to choose CPM [111, 112]. The most influential correlates of CPM choice, however, are not these clinical factors but other patient factors: cancer worry, socioeconomic factors, and demographic factors [34, 89, 113].

Several studies point to strong but complex relationships between family history and surgical choice [114, 115]. *BRCA* mutation carriers with a first-degree family history of breast or ovarian cancer—particularly in a mother or sister—are more likely to undertake prophylactic surgery, and breast cancer patients with a family history are less likely to choose breast-conserving surgery and are more likely to undergo CPM [77, 108, 111]. Future research might clarify these relationships by disentangling two possible causes for the effects of family history on surgical choice: objective differences in cancer risk depending on a woman's specific family history, and the personal impact of directly witnessing a close relative experiencing cancer.

Some evidence suggests that women's psychological well-being may also affect their prevention choices. Among women with hereditary risk, BPM is more often chosen by those who experience high anxiety and/or exaggerated perceptions of their risk [116]. *BRCA* mutation carriers with poorer self-perceived health may be more likely to choose prophylactic surgery [110]. The choice to undergo CPM is also associated with psychological motivations, including higher cancer-specific distress, worries about recurrence or the efficacy of surveillance, and the concerns of significant others [34, 117–122].

Demographic characteristics

Existing research indicates that breast cancer morbidity and mortality, access to treatment, and decisions regarding a range of related screening, diagnostic, and treatment questions all differ substantially by race and ethnicity [103–106, 123–128]. It is thus likely that racial-ethnic variation also exists in the processes and outcomes of women's prevention decision making. A few studies support this hypothesis, establishing that both BPM and CPM are most often chosen by white *BRCA* mutation carriers [82], and that African-Americans are less likely to participate in genetic risk assessment [129]. It would be helpful to know the extent to which use of BPSO and chemoprevention differ by race, how decision making and prevention choices vary among groups of non-white women, and which mechanisms (e.g., healthcare access, cultural differences, relationships to providers) underlie these racial-ethnic variations.

The significant body of research that relates socioeconomic status (SES) to healthcare access, general prevention behavior, and health outcomes suggests that cancer prevention decisions may also be systematically related to SES. However, the sparse research on this potential relationship has so far yielded conflicting findings on relationships between prevention-related choices and SES indicators including employment, education, and health insurance status [82, 130]. The lack of direct attention to relationships between SES and prevention decisions, and

the prominence of attention to financial considerations in the work of patient advocacy organizations [131], also suggest that this is an area that merits further investigation. The influence of SES on decision making could operate through both direct mechanisms (e.g., women considering what they can afford) and indirect mechanisms (e.g., if SES influences the degree to which healthcare providers engage in shared decision making).

Prevention decisions also vary by age. Both BPM and CPM are associated with younger ages among *BRCA* mutation carriers [132], while the choice of BPSO is associated with older ages [1, 26, 109, 111, 133] (but see [81] for an exception). The effects of age on chemoprevention or enhanced surveillance behavior have not been well studied, but it is clear that decision making is particularly complex for young *BRCA* mutation carriers who are often single, childless, and not yet confident making life-altering decisions [134–137].

Prophylactic surgery is more often chosen by *BRCA* mutation carriers who have at least one child [112], and those with multiple children are even more likely to undergo BPM and/or BPSO [1, 26, 81, 109, 138]. Marital status could also affect prevention decisions, but this relationship has rarely been investigated [87].

Large geographic differences have been observed in the uptake of preventive surgeries, across both nations and subnational regions [81]. Uptake of chemoprevention and adherence to enhanced surveillance recommendations could vary geographically as well, and this should be investigated. The reasons for geographic variation are as yet unclear and also merit study; potential mechanisms include cultural differences, provider education or behavior, availability and policies relevant to specific risk management options within a healthcare system, and financial and geographic access to specialist healthcare and genetic testing.

Women's prevention decision making

Information and communications

The acquisition and processing of accurate information are necessary conditions for appropriate decision making. Women's physicians are a trusted but insufficiently studied source of information about cancer risk and prevention [139, 140]. Better informed patients make different decisions to others, and a substantial proportion of variation in the use of medical procedures can be attributed to a lack of solid information transfer from practitioner to patient, and lack of opportunities for patients to engage in shared medical decision making [45, 91, 141–147]. With respect to breast cancer prevention specifically, physicians vary in the provision of information and recommendations [148], often provide less information than high-risk women want [149, 150], frequently struggle to assess individual risk and eligibility for preventive procedures [67], and have difficulty navigating variations in patient preferences about the ideal degree of shared decision making [107, 148]. Intervention design research is warranted to improve physicians' confidence in providing information [151], women's confidence in making decisions based on that information, and the overall quality of information transfer. Future investigations should also examine whether confidence in risk information differentially affects women's choices to pursue particular risk management behaviors.

For women with access to them, genetic counselors provide more thorough information about risk and prevention than generalist physicians or oncologists, combined with support to process information and make decisions [152]. Although the health information they provide can also vary [153], these interactions are associated with higher uptake of risk reduction methods [154]. Family, friends, patient communities, and survivor groups also have varied impact on women's information gathering and processing [131, 148, 155], but additional research is needed about the conditions under which these relationships best support health-protective decision making.

Decisional timing and complexity

For many women, prevention decisions are developed through complex processes that can involve explicit deliberation, objective information, intuitive and affective elements, and/or input from others [149, 156]. Perceptions of personal risk and prevention decisions evolve over a variable period of time [107, 140, 157–159]. Studies of *BRCA* mutation carriers who choose prophylactic surgery indicate that they may take several years to do so [63, 110], and that they are likely to make quicker decisions if they anticipate choosing surgery in the event of positive results before genetic testing, have first-degree relatives with cancer, experience higher psychological impacts of genetic findings, are older, have children, and/or experience specific triggering events [133, 160].

Qualitative studies have revealed that women's conceptualizations of risk and prevention differ substantially from those of healthcare providers [161–163]. These distinctions reflect decision-making complexities far deeper than mere incomplete information or irrational decision making. The difficulty of prevention and surveillance choices for women at elevated risk likely reflects a range of normal cognitive patterns described by Daniel Kahneman, wherein intuitive and emotional decision making, shaped by personal experiences and instincts, is usually dominant over the conscious, analytic style of decision making. High-risk women report actively striving to make careful, deliberative breast cancer prevention decisions, but the cognitive dominance of the more reflexive decision-making mode may make this exceptionally

difficult unless women have access to both thorough information and the cognitive skills necessary to process it [164]. Hesse-Biber and An further describe how prevention decision making in *BRCA* mutation carriers involves filtering genetic information through a complex framework of diverse psychological, social, and emotional factors [165]. Other research suggests some of the specific complexities that may shape women's choices (nonlinear movement toward a decision [162]; acting to both maximize survival and preserve a sense of self [166, 167]; processing cancer experiences of primary relatives [157, 159, 168]; interpreting *BRCA* mutations as pressure to act [169]; and experiencing the uncertainties and interventions associated with elevated risk) are similar to those associated with breast cancer itself [96, 145, 163, 168, 170, 171]. These preliminary observations suggest that deeper attention to the meanings women construct around levels of risk, prevention options, diseases, and treatments may be an important element in understanding their decision making.

Emotions

The stress associated with uncertainty is a central part of coping with health risks, and may be triggered at many stages of decision making [61, 148, 149]. Cancer-related worry or anxiety strongly motivates most women to take preventive action [109, 172–175]; particularly high levels of worry may also impede adherence to surveillance recommendations among some groups [176–178]. Some women are motivated to undertake preventive action through fear of abandoning their children, but others avoid surgeries that might cause their children to worry [140, 159]. Decisions can be changed or delayed by fear of surgery or side effects [67, 159]. Women's decisions are also shaped by aspirations for their future (e.g., desire to have children), predictions about future emotions, perceived control over health, self-worth, experiences in high-risk families, risk fatigue, and cancer-related stigma [28, 97, 159, 164, 179]. Affective influences merit more thorough attention, and socio-emotional factors so far absent from the academic literature may also exert powerful influence on women's decisions [164]. For instance, the broad body of research on patient-centered care, anecdotal news reports, and comments posted in online support communities all indicate that the desire to take control of one's health can be a profound, but as-yet unstudied, part of the decision-making journey for women facing elevated risk of breast cancer [131, 180].

Interactions among drivers of prevention choice

Finally, the impact of the drivers of decision making discussed above may not be consistent across subgroups of women, and a comprehensive understanding of interactive effects may be critical to the design of effective decision-support interventions. Relevant examples can be found in studies of race and ethnicity in decision making; for instance, subgroups of Asian-American women differ in their use of mammogram screening by ethnicity, health insurance, and SES [105, 181]. Minority populations also include a high proportion of the medically underserved [182], which suggests that understanding decision making may require attention not just to individual-level factors, but also to the communities in which women live and the resources they can access.

Future research

Many of the most substantial gaps in the research literature have to do not with breast cancer risk reduction options themselves, but instead with how women make sense of and utilize these measures. Key gaps in existing knowledge of women's prevention decision making are summarized in Table 1. Future research should focus on four key areas.

Table 1 Key gaps in current knowledge concerning breast cancer prevention decision making by women at elevated risk

- Which prevention options and combinations women consider viable (prevention pathways)
- Women's reasons for low uptake of biomedical prevention interventions
- Explicit comparisons of prevention options and their effects
- How prevention behavior varies among subgroups of women, who differ according to:
  - Medically-defined or self-perceived level of risk
  - Geographical and cultural context
  - Race-ethnicity or socioeconomic status
  - Access to medical information or care
- Mechanisms that account for variation in prevention choices across subgroups
- Effects of emotions and psychological factors on women's prevention decision making
- Effects of spouses, children, family, and friends on decision making
- Effects of exposure to cancer patients, support groups, or advocacy organizations on decision making
- Effects of exposure to genetic counseling and quality of communication with other healthcare providers on decision making
- Effects of previously unstudied factors on decision making: stigma, self-worth, desire to take control of health, personal exposure to experience of cancer
- Interactions among various drivers of prevention choice
- How women at elevated risk explain their own decision-making processes and needs
- Key methods to help women attain informed and empowered decision making

Women's own perspectives

Prior research on women's use of prevention interventions has been largely quantitative and deductive. This research has provided a powerful foundation for understanding women's prevention behavior, but has also missed key dynamics such as the potential roles of financial resources, social support, and desire to control one's health. The ability to support improved decision making will hinge on accurate understanding of women's own perspectives, which can be illuminated by systematic qualitative research that offers women more space to articulate perspectives on their own experiences, rationales, and challenges.

Explicit comparison of prevention pathways

The ability of women to compare their options would be facilitated by research that explicitly documents the effects of various choices on physical, psychological, and social well-being. One potential outcome of such research may be improved decision aids, which have been shown to positively impact knowledge, expectations, distress, and decisions among patients facing multiple medical options with complex pros and cons [183–189]. Initial steps have been made toward developing such tools for women at elevated risk (particular with respect to chemoprevention) [185, 190–200], but considerable work remains to incorporate all possible prevention pathways, and to consider psychological, social, and demographic factors in the construction of decision aids [97].

Processes of decision making

Inductive research from women's own perspectives may illuminate previously unstudied processes important to women's decisions, and thereby offer new potential approaches for designing prevention-supportive interventions. At a minimum, these dynamics are likely to include: psychological factors from cancer-specific distress and fear for children to the desire to take control of health; social dynamics of support from spouses, family, and friends; exposure to cancer patients, survivors, and advocacy groups; the need to bolster both information acquisition and skills-building to facilitate deliberative decision making; and interactions among the drivers of prevention choice.

Dynamics of subgroup variation

Existing research in and beyond the area of breast cancer prevention indicate that decision-making processes and prevention choices are likely influenced by the severity of medical risk, geographical context, race-ethnicity, SES, and access to medical information or care. These distinctions may have important implications for tailoring supportive interventions.

Conclusions

One key conclusion of this review is that we must broaden our research agenda beyond the medical components of prevention interventions themselves, to focus also on social questions and women's perspectives relevant to breast cancer prevention. Such research will help resolve crucial mismatches between the biomedical interventions researchers have developed to mitigate cancer risk and women's real-life prevention behavior, and will ultimately provide critical support for the objective of preventing breast cancer among women at elevated risk.

Abbreviations

ATM: Ataxia-telangiectasia mutated gene; BPM: Bilateral prophylactic mastectomy; BPSO: Bilateral prophylactic salpingo-oophorectomy; *BRCA1*: Breast cancer gene 1; *BRCA2*: Breast cancer gene 2; CDH1: Cadherin-1 gene; CHEK2: Checkpoint kinase 2 gene; COX-2: Cyclooxygenase-2; CPM: Contralateral prophylactic mastectomy; MRI: Magnetic resonance imaging; NBN: Nibrin coding gene; NF1: Neurofibrimin 1 gene; NSAIDS: Nonsteroidal anti-inflammatory drugs; PALB2: Partner and localizer of BRCA2 gene; PARP: Poly-adenosine diphosphate-ribose polymerase; PTEN: Phosphatase and tensin homolog gene; SES: Socioeconomic status; STK11: Serine/threonine kinase 11; TP53: Tumor protein p53

Acknowledgements

The authors would like to thank Anne Esacove and Gene Deerman for their comments on an early draft of this piece, Megan Hils for her editorial assistance, and Robert Pilarski for his assistance in verifying information related to genetic risk and testing.

Funding

Development of this manuscript has been supported by National Cancer Institute Award no. CA181547-01.

Availability of data and materials

Not applicable.

Authors' contributions

As primary author, TJP conceived of, researched, and wrote the initial draft of this review article. CEW, LDY, and EDP contributed to the content of the article by providing substantive content for particular sections, contributing to multiple critical revisions, and approving the final submitted version.

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Competing interests

The authors declare that they have no competing interests.

Consent for publication

Neither this article nor portions of it have been previously published elsewhere. This manuscript is not under consideration for publication in another journal and will not be submitted elsewhere until the *Breast Cancer Research* review process is complete. All authors consent to the publication of this article in *Breast Cancer Research*, should the article be accepted at the conclusion of the review process.

Ethics approval and consent to participate
Not applicable.

Publisher's Note

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Published online: 24 March 2017

References

1. Friebel TM, Domchek SM, Neuhausen SL, Wagner T, Evans DG, Isaacs C, et al. Bilateral prophylactic oophorectomy and bilateral prophylactic mastectomy in a prospective cohort of unaffected BRCA1 and BRCA2 mutation carriers. Clin Breast Cancer. 2007;7:875–82.
2. Pujol P, Lasset C, Berthet P, Dugast C, Delaloge S, Fricker J-P, et al. Uptake of a randomized breast cancer prevention trial comparing letrozole to placebo in BRCA1/2 mutations carriers: The LIBER trial. Familial Cancer. 2012;11:77–84.
3. Waters EA, Cronin KA, Graubard BI, Han PK, Freedman AN. Prevalence of tamoxifen use for breast cancer chemoprevention among U.S. women. Cancer Epidemiol Biomarkers Prev. 2010;19:443–6.
4. American Cancer Society. American Cancer Society recommendations for early breast cancer detection in women without breast symptoms. American Cancer Society. 2015. http://www.cancer.org/cancer/breastcancer/moreinformation/breastcancerearlydetection/breast-cancer-early-detection-acs-recs. Accessed 21 Mar 2017.
5. Antoniou AC, Pharoah PPD, Smith P, Easton DF. The BOADICEA model of genetic susceptibility to breast and ovarian cancer. Br J Cancer. 2004;91:1580–90.
6. Antoniou AC, Cunningham AP, Peto J, Evans DG, Lalloo F, Narod SA, et al. The BOADICEA model of genetic susceptibility to breast and ovarian cancers: updates and extensions. Br J Cancer. 2008;98:1457–66.
7. Chen S, Parmigiani G. Meta-analysis of BRCA1 and BRCA2 penetrance. J Clin Oncol. 2007;25:1329–33.
8. Claus E, Risch N, Thompson W. Autosomal-dominant inheritance of early-onset breast cancer—implications for risk protection. Cancer. 1994;73:643–51.
9. Constantino JP, Gail MH, Pee D, Anderson S, Redmond CK, Benichou J, et al. Validation studies for models projecting the risk of invasive and total breast cancer incidence. J Natl Cancer Inst. 1999;91:1541–8.
10. Gail MH, Mai PL. Comparing breast cancer risk assessment models. J Natl Cancer Inst. 2010;102:665–8.
11. Gail M, Brinton L, Byar D, Corle D, Green S, Schairer C, et al. Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. J Natl Cancer Inst. 1989;81:1879–86.
12. Tyrer J, Duffy S, Cuzick J. A breast cancer prediction model incorporating familial and personal risk factors. Stat Med. 2004;23:1111–30.
13. Daly MB, Pilarski R, Berry M, Buys SS, Farmer M, Friedman S, et al. NCCN Guidelines Insights: genetic/familial high-risk assessment: breast and ovarian, version 2.2017. Fort Washington: National Comprehensive Cancer Network; 2016.
14. Kurian AW. BRCA1 and BRCA2 mutations across race and ethnicity: distribution and clinical implications. Curr Opin Obstet Gynecol. 2010;22:72–8.
15. John EM, Miron A, Gong G, Phipps AI, Felberg A, Li FP, et al. Prevalence of pathogenic BRCA1 mutation carriers in 5 US racial/ethnic groups. JAMA. 2007;298:2869–76.
16. King M-C, Levy-Lahad E, Lahad A. Population-based screening for BRCA1 and BRCA2. J Am Med Assoc. 2014;312:1091–2.
17. Manchanda R, Legood R, Burnell M, McGuire A, Raikou M, Loggenberg K, et al. Cost-effectiveness of population screening for BRCA mutations in Ashkenazi jewish women compared with family history-based testing. J Natl Cancer Inst. 2015;107:380.
18. Southey MC, Goldgar DE, Winqvist R, Pylkäs K, Couch F, Tischkowitz M, et al. PALB2, CHEK2 and ATM rare variants and cancer risk: data from COGS. J Med Genet. 2016;53(12):800–11.
19. Blazer KR, Slavin T, Weitzel JN. Increased reach of genetic cancer risk assessment as a tool for precision management of hereditary breast cancer. JAMA Oncol. 2016;2:723–4.
20. Rosenberg SM, Ruddy KJ, Tamimi RM, Gelber S, Schapira L, Come S, et al. BRCA1 and BRCA2 mutation testing in young women with breast cancer. JAMA Oncol. 2016;2:730–6.
21. Bevers TB, Ward JH, Arun, BK, Colditz GA, Cowan KH, Daly MB, et al. Breast cancer risk reduction: NCCN evidence blocks, version 1.2017. 2016. https://www.nccn.org/professionals/physician_gls/pdf/breast_risk_blocks.pdf. Accessed 21 Mar 2017.
22. US Preventive Services Task Force. Final recommendation statement: BRCA-related cancer: risk assessment, genetic counseling, and genetic testing - US Preventive Services Task Force. 2013. https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/brca-related-cancer-risk-assessment-genetic-counseling-and-genetic-testing. Accessed 23 Jan 2017.
23. Bevers TB, Armstrong DK, Arun B, Carlson RW, Cowan KH, Daly MB, et al. Breast cancer risk reduction. NCCN. 2010;8:1112–46.
24. Hartmann LC, Schaid DJ, Woods JE, Crotty TP, Myers JL, Arnold PG, et al. Efficacy of bilateral prophylactic mastectomy in women with a family history of breast cancer. N Engl J Med. 1999;340:77–84.
25. Jatoi I, Benson JR, Liau SS, Chen Y, Cisco RM, Norton JA, Moley JF, Khalifeh KW, Choti MA. The role of surgery in cancer prevention. Curr Probl Surg. 2010;47:750–830.
26. Lostumbo L, Carbine NE, Wallace J. Prophylactic mastectomy for the prevention of breast cancer (review). Cochrane Collab. 2010;1–91.
27. Nathanson KL, Domchek SM. Therapeutic approaches for women predisposed to breast cancer. Annu Rev Med. 2011;62:295–306.
28. Razzaboni E, Tazzioli G, Andreotti A, De Matteis E, Cortesi L, Federico M. Prophylactic surgery to reduce the risk of developing breast cancer: Issues and clinical implications. Curr Women's Health Rev. 2012;8:94–103 (10).
29. Rebbeck TR, Friebel T, Lynch HT, Neuhausen SL, van 't Veer L, Garber JE, et al. Bilateral prophylactic mastectomy reduces breast cancer risk in BRCA1 and BRCA2 mutation carriers: the PROSE study group. J Clin Oncol. 2004;24:1055–62.
30. Swisher EM, Calhoun KE. Management of women with inherited BRCA1 and BRCA2 mutations, the role of genetics in breast and reproductive cancers. New York: Springer-Verlag; 2010. p. 21–45.
31. Zakaria S, Degnim AC. Prophylactic mastectomy. Surg Clin N Am. 2007;87:317–31.
32. Barry M, Sacchini V. When is contralateral mastectomy warranted in unilateral breast cancer? Expert Rev. 2011;11:1209–14.
33. Bedrosian I, Hu C-Y, Chang GJ. Population-based study on contralateral prophylactic mastectomy and survival outcomes of breast cancer patients. J Natl Cancer Inst. 2010;102:401–9.
34. Hawley ST, Jagsi R, Morrow M, Janz NK, Hamilton A, Graff JJ, et al. Social and clinical determinants of contralateral prophylactic mastectomy. JAMA Surg. 2014;149:582–9.
35. Leff DR, Ho C, Thomas H, Daniels R, Side L, Lambert F, et al. A multidisciplinary team approach minimises prophylactic mastectomy rates. Eur J Surg Oncol. 2015;41:1005–12.
36. Metcalfe KA, Kim-Sing C, Ghadirian P, Sun P, Narod SA. Health care provider recommendations for reducing cancer risks among women with a BRCA1 or BRCA2 mutation. Clin Genet. 2014;85:21–30.
37. Society of Surgical Oncology. position statement on prophylactic mastectomy. 2010. http://www.surgonc.org/resources/consensus-statements/position-statement-on-prophylactic-mastectomy. Accessed 21 Mar 2017.
38. Tung N. Management of women with BRCA mutations: a 41-year-old woman with a BRCA mutation and a recent history of breast cancer. JAMA. 2011;305:2211–20.
39. Finch APM, Lubinski J, Moller P, Singer CF, Kalran B, Senter L, et al. Impact of oophorectomy on cancer incidence and mortality in women with a BRCA1 or BRCA2 mutation. J Clin Oncol. 2014;32:1547–53.
40. Boughey JC, Hoskin TL, Degnim AC, Sellers TA, Johnson JL, Kasner MJ, et al. Contralateral prophylactic mastectomy is associated with a survival advantage in high-risk women with a personal history of breast cancer. Ann Surg Oncol. 2010;17:2702–9.
41. Tuttle TM. Incorporating genetic testing for guided prevention of contralateral breast cancer. Gastric Breast Cancer. 2008;7:9–12.
42. Tuttle TM, Abbott A, Arrington A, Rueth N. The increasing use of prophylactic mastectomy in the prevention of breast cancer. Curr Oncol Rep. 2010;12:16–21.

43. Yi M, Hunt KK, Arun BK, Bedrosian I, Barrera AG, Do K-A, et al. Factors affecting the decision of breast cancer patients to undergo contralateral prophylactic mastectomy. Cancer Prev Res. 2010;3:1026–34.
44. Heemskerk-Gerritsen BAM, Rookus MA, Aalfs CM, Ausems MGEM, Collee JM, Jansen L, et al. Improved overall survival after contralateral risk-reducing mastectomy in BRCA1/2 mutation carriers with a history of unilateral breast cancer: a prospective analysis. Int J Cancer. 2015;136:668–77.
45. Stan DL, Shuster LT, Wick MJ, Swanson CL, Pruthi S, Bakkum-Gamez JN. Challenging and complex decisions in the management of the BRCA mutation carrier. J Womens Health (Larchmt). 2013;22:825–34.
46. Chlebowski RT. IBIS-I tamoxifen update: maturity brings questions. Lancet. 2015;16:7–8.
47. Cuzick J, Forbes JF, Sestak I, Cawthorn S, Hamed H, Holli K, et al. Long-term results of tamoxifen prophylaxis for breast cancer: 96-month follow-up of the randomized IBIS-I trial. J Natl Cancer Inst. 2007;99:272–82.
48. Cuzick J, Sestak I, Bonanni B, Costantino JP, Cummings S, DeCensi A, et al. Selective oestrogen receptor modulators in prevention of breast cancer: an updated meta-analysis of individual participant data. Lancet. 2013;381:1827–34.
49. Cuzick J, Sestak I, Cawthorn S, Hamed H, Holli K, Howell A, et al. 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.
50. Fisher B, Dignam J, Wolmark N, Wickerham DL, Fisher ER, Mamounas E, et al. Tamoxifen in treatment of intraductal breast cancer: National Surgical Adjuvant Breast and Bowel Project B-24 randomised controlled trial. Lancet. 1999;353:1993–2000.
51. Freedman AN, Graubard BI, Rao SR, McCaskill-Stevens W, Ballard-Barbash R, Gail MH. Estimates of the number of U.S. women who could benefit from tamoxifen for breast cancer chemoprevention. J Natl Cancer Inst. 2003;95:526–32.
52. Freedman A, Yu B, Gail M, Costantino J, Graubard B, Vogel V, et al. Benefit/risk assessment for breast cancer chemoprevention with raloxifene or tamoxifen for women age 50 years or older. J Clin Oncol. 2011;29:2327–33.
53. Metcalfe KA. Prophylactic bilateral mastectomy for breast cancer prevention. J Women's Health. 2004;13:822–9.
54. Vogel VG, Costantino JP, Wickerham DL, Cronin WM, Cecchini RS, Atkins JN, et al. Effects of tamoxifen vs raloxifene on the risk of developing invasive breast cancer and other disease outcomes: the NSABP Study of Tamoxifen and Raloxifene (STAR) P-2 trial. JAMA. 2006;295:2727–41.
55. Vogel VG, Constantino JP, Wickerham DL, Cronin WM, Cecchini RS, Atkins JN, et al. Update of the National Surgical Adjuvant Breast and Bowel Project Study of Tamoxifen and Raloxifene (STAR) P-2 Trial: preventing breast cancer. Cancer Prev Res. 2010;3:696–706.
56. Howell A, Anderson AS, Clarke RB, Duffy SW, Evans DG, Garcia-Closas M, et al. Risk determination and prevention of breast cancer. Breast Cancer Res. 2014;16:1–19.
57. Lambrechts S, Decloedt J, Neven P. Breast cancer prevention: lifestyle changes and chemoprevention. Acta Clin Belg. 2011;66:283–92.
58. Pruthi S, Heisey RE, Bevers TB. Chemoprevention for breast cancer. Ann Surg Oncol. 2015;22:3230–5.
59. Mallick S, Benson R, Julka PK. Breast cancer prevention with anti-estrogens: review of the current evidence and future directions. Breast Cancer. 2016;23:170–7.
60. Saslow D, Boetes C, Burke W, Harms S, Leach MO, Lehman CD, et al. American Cancer Society guidelines for breast screening with MRI as an adjunct to mammography. CA Cancer J Clin. 2007;57:75–89.
61. Hoogerbrugge N, Kamm YJL, Bult P, Landsbergen KM, Bongers EMHF, Brunner HG, et al. The impact of a false-positive MRI on the choice for mastectomy in BRCA mutation carriers is limited. Ann Oncol. 2008;19:655–9.
62. Kuhl C, Weigel S, Schrading S, Arand B, Bieling H, Konig R, et al. Prospective multicenter cohort study to refine management recommendations for women at elevated familial risk of breast cancer: the EVA Trial. J Clin Oncol. 2010;28:1450–7.
63. Lerman C, Hughes C, Croyle RT, Main D, Durham C, Snyder C, et al. Prophylactic surgery decisions and surveillance practices one year following BRCA 1/2 testing. Prev Med. 2000;31:75–80.
64. Toss A, Sebastiani F, Elisabetta R, De Matteis E, Marchi I, Proietto M, et al. Chemoprevention strategies for high risk women. Curr Women's Health Rev. 2012;8:86–93.
65. Warner E, Hill K, Causer P, Plewes D, Jong R, Yaffe M, et al. Prospective study of breast cancer incidence in women with a BRCA1 or BRCA2 mutation under surveillance with and without magnetic resonance imaging. J Clin Oncol. 2011;29:1664–9.
66. Saadatmand S, Tilanus-Linthorst MMA, Rutgers EJT, Hoogerbrugge N, Oosterwijk JC, Tollenaar RAEM, et al. Cost-effectiveness of screening women with familial risk for breast cancer with magnetic resonance imaging. J Natl Cancer Inst. 2013;105:1314–21.
67. Ozanne E, Esserman L. Decision making in breast cancer prevention. Psicooncologia. 2010;7:299–311.
68. McTiernan A, Porter P, Potter JD. Breast cancer prevention in countries with diverse resources. Cancer. 2008;113:2325–30.
69. Sakorafas GH. The management of women at high risk for the development of breast cancer: risk estimation and preventative strategies. Cancer Treat Rev. 2003;29:79–89.
70. Schwartz MD, Isaacs C, Graves KD, Poggi E, Peshkin BN, Gell C, et al. Long-term outcomes of BRCA1/BRCA2 testing: risk reduction and surveillance. Cancer. 2012;118:510–7.
71. Willsher P, Ali A, Jackson L. Laparoscopic oophorectomy in the management of breast disease. ANZ J Surg. 2008;78:670–2.
72. Roukos DH, Briasoulis E. Individualized preventive and therapeutic management of hereditary breast ovarian cancer syndrome. Nat Rev Clin Oncol. 2007;4:578–85.
73. Shah P, Rosen M, Stopfer J, Siegfried J, Kaltman R, Mason B, et al. Prospective study of breast MRI in BRCA1 and BRCA2 mutation carriers: effect of mutation status on cancer incidence. Breast Cancer Res Treat. 2009;118:539–46.
74. Grann VR, Patel PR, Jacobson JS, Warner E, Heitjan DF, Ashby-Thompson M, et al. Comparative effectiveness of screening and prevention strategies among BRCA1/2-affected mutation carriers. Breast Cancer Res Treat. 2011;125:837–47.
75. Abdollahian M, Das TK. A MDP model for breast and ovarian cancer intervention strategies for BRCA1/2 mutation carriers. IEEE J Biomed Health Inform. 2015;19:720–7.
76. Tambor ES, Bernhardt BA, Geller G, Helzlsouer KJ, Doksum T, Holtzman NA. Should women at increased risk for breast and ovarian cancer be randomized to prophylactic surgery? An ethical and empirical assessment. J Women's Health Gend Based Med. 2000;9:223–33.
77. Metcalfe KA, Foulkes WD, Kim-Sing C, Ainsworth P, Rosen B, Armel S, et al. Family histoy as a predictor of uptake of cancer preventive procedures by women with a BRCA1 or BRCA2 mutation. Clin Genet. 2008;73:474–9.
78. Metcalfe KA, Mian N, Enmore M, Poll A, Llacuachaqui M, Nanda S, et al. Long-term follow-up of Jewish women with a BRCA1 and BRCA2 mutation who underwent population genetic screening. Breast Cancer Res Treat. 2012;133:735–40.
79. Morgan D, Sylvester H, Lucas FL, Miesfeldt S. Cancer prevention and screening practices among women at risk for heredity breast and ovarian cancer after genetic counseling in the community. Familial Cancer. 2009;8:277–87.
80. Schover LR. A lesser evil: Prophylactic mastectomy for women at high risk for breast cancer. J Clin Oncol. 2008;26:3918–9.
81. Skytte AB, Gerdes AM, Anderson MK, Sunde L, Brondum-Nielsen K, Waldstrom M, et al. Risk-reducing mastectomy and salpingo-oophorectomy in unaffected BRCA mutation carriers: uptake and timing. Clin Genet. 2010;77:342–9.
82. McLaughlin CC, Lillquist PP, Edge SB. Surveillance of prophylactic mastectomy. Cancer. 2009;115:5404–12.
83. Meiser B, Butow P, Price M, Bennett B, Berry G, Tucker K, et al. Attitudes to prophylactic surgery and chemoprevention in Australian women at increased risk for breast cancer. J Women's Health. 2003;12:769–78.
84. Printz C. New data on BRCA mutations and prophylactic surgeries. Cancer. 2011;117:657–9.
85. Gahm J, Wickman M, Brandberg Y. Bilateral prophylactic mastectomy in women with inherited risk of breast cancer—prevalence of pain and discomfort, impact on sexuality, quality of life and feelings of regret two years after surgery. Breast. 2010;19:462–9.
86. Baker SK, Mayer DK, Esposito N. The contralateral prophylactic mastectomy decision-making process. Plast Surg Nurs. 2013;33:11–21. 23.
87. Howard-McNatt M, Schroll RW, Hurt GJ, Levine EA. Contralateral prophylactic mastectomy in breast cancer patients who test negative for BRCA mutations. Am J Surg. 2011;202:298–302.
88. Tuttle TM, Habermann EB, Grund EH, Morris TJ, Virnig BA. Increasing use of contralateral prophylactic mastectomy for breast cancer patients: a trend toward more aggressive surgical treatment. J Clin Oncol. 2007;25:5203–9.
89. Mamtani A, Morrow M. Why are there so many mastectomies in the United States? Annu Rev Med. 2016;68:229–41.
90. Port ER, Montgomery LL, Heerdt AS, Borgen PI. Patient reluctance toward tamoxifen use for breast cancer primary prevention. Ann Surg Oncol. 2001;8:580–5.
91. Ropka ME, Keim J, Philbrick JT. Patient decisions about breast cancer chemoprevention: a systematic review and meta-analysis. J Clin Oncol. 2010;28:3090–5.

92. Smith SG, Sestak I, Forster A, Partridge A, Side L, Wolf MS, et al. Factors affecting uptake and adherence to breast cancer chemoprevention: a systematic review and meta-analysis. Ann Oncol. 2015;27:575–90.
93. Ralph AF, Ager B, Bell ML, Collins IM, Andrews L, Tucker K, et al. Women's preferences for selective estrogen reuptake modulators: an investigation using protection motivation theory. Patient Educ Couns. 2014;96:106–12.
94. Nichols HB, DeRoo LA, Scharf DR, Sandler DP. Risk-benefit profiles of women using tamoxifen for chemoprevention. J Natl Cancer Inst. 2015;107:354.
95. Bober SL, Hoke LA, Duda RB, Regan MM, Tung NM. Decision-making about tamoxifen in women at high risk for breast cancer: clinical and psychological factors. J Clin Oncol. 2004;22:4951–7.
96. Fallowfield L, Fleissig A, Edwards R, West A, Powles TJ, Howell A, et al. Tamoxifen for the prevention of breast cancer: psychosocial impact on women participating in two randomized controlled trials. J Clin Oncol. 2001; 19:1885–92.
97. Hoerger M, Scherer LD, Fagerlin A. Affective forecasting and medication decision making in breast-cancer prevention. Health Psychol. 2016;35(6): 594–603.
98. Hum S, Wu M, Pruthi S, Heisey R. Physician and patient barriers to breast cancer preventive therapy. Curr Breast Cancer Rep. 2016;8:158–64.
99. Crew KD. Addressing barriers to uptake of breast cancer chemoprevention for patients and providers. Am Soc Clin Oncol Educ Book. 2015;e50-58.
100. Reimers L, Crew KD. Tamoxifen vs raloxifene vs exemestane for chemoprevention. Curr Breast Cancer Rep. 2012;4:207–15.
101. Stubert J, Dieterich M, Gerber B. Medical prevention of breast cancer. Breast Care (Basel). 2014;9:391–6.
102. Stout NK, Nekhlyudov L, Li L, Malin ES, Ross-Degnan D, Buist DSM, et al. Rapid increase in breast magnetic resonance imaging use: trends from 2000 to 2011. JAMA Intern Med. 2014;174:114–21.
103. American Cancer Society. California cancer facts and figures 2009. Oakland: American Cancer Society, California Division; 2008.
104. Gerry AA. Breast cancer screening disparities among ethnically diverse women in California: a latent profile analysis. PhD Dissertation. San Diego: University of California San Diego; 2011.
105. Gomez SL, Tan S, Keegan TH, Clarke CA. Disparities in mammographic screening for Asian women in California: a cross-sectional analysis to identify meaningful groups for targeted intervention. BMC Cancer. 2007;7:12.
106. Vadaparampil ST, Miree CA, Wilson C, Jacobsen PB. Psychosocial and behavioral impact of genetic counseling and testing. Breast Disease. 2006;27:97–108.
107. Hartmann LC, Lindor NM. The role of risk-reducing surgery in hereditary breast and ovarian cancer. N Engl J Med. 2016;374:454–68.
108. Haroun I, Graham T, Poll A, Sun P, Hill K, Weitzner E, et al. Reasons for risk-reducing mastectomy versus MRI-screening in a cohort of women at high hereditary risk of breast cancer. Breast. 2011;20:254–8.
109. Litton JK, Westin SN, Ready K, Sun CC, Peterson SK, Meric-Bernstam F, et al. Perception of screening and risk reduction surgeries in patients tested for a BRCA deleterious mutation. Cancer. 2009;115:1598–604.
110. Madalinska JB, van Beurden M, Bleiker EMA, Valdimarsdottir HB, Lubsen-Brandsma L, Massuger LF, et al. Predictors of prophylactic bilateral salpingo-oophorectomy compared with gynecologic screening use in BRCA 1/2 mutation carriers. J Clin Oncol. 2007;25:301–07.
111. Metcalfe KA. Oophorectomy for breast cancer prevention in women with BRCA1 or BRCA2 mutations. Women's Health. 2009;5:63–8.
112. Stuckey A, Dizon D, Wilbur JS, Kent J, Tejada-Berges T, Gass J, et al. Clinical characteristics and choices regarding risk-reducing surgery in BRCA mutation carriers. Gynecol Obstet Invest. 2010;69:270–3.
113. Yao K, Stewart AK, Winchester DJ, Winchester DP. Trends in contralateral prophylactic mastectomy for unilateral cancer: a report from the National Cancer Database, 1998–2007. Ann Surg Oncol. 2010;17:2554–62.
114. Maeland MK, Eriksen EO, Synnes O. The loss of a mother and dealing with genetic cancer risk: women who have undergone prophylactic removal of the ovaries. Eur J Oncol Nurs. 2014;18:521–6.
115. Singh K, Lester J, Karlan B, Bresee C, Geva T, Gordon O. Impact of family history on choosing risk-reducing surgery among BRCA mutation carriers. Am J Obstet Gynecol. 2013;208:329. e1–6.
116. De Leeuw J, van Vliet M, Ausems M. Predictors of choosing life-long screening or prophylactic surgery in women at high and moderate risk for breast and ovarian cancer. Familial Cancer. 2008;7:347–59.
117. Beesley H, Holcombe C, Brown SL, Salmon P. Risk, worry and cosmesis in decision-making for contralateral risk-reducing mastectomy: analysis of 60 consecutive cases in a specialist breast unit. Breast. 2013;22:179–84.
118. Brewster AM, Parker PA. Current knowledge on contralateral prophylactic mastectomy among women with sporadic breast cancer. Oncologist. 2011; 16:935–41.
119. Graves KD, Peshkin BN, Halbert CH, DeMarco TA, Isaacs C, Schwartz MD. Predictors and outcomes on contralateral prophylactic mastectomy among breast cancer survivors. Breast Cancer Res Treat. 2007;104:321–9.
120. Katz SJ, Morrow M. Contralateral prophylactic mastectomy for breast cancer: addressing peace of mind. JAMA. 2013;310:793–4.
121. Kwong A, Chu ATW. What made her give up her breasts: a qualitative study on decisional considerations for contralateral prophylactic mastectomy among breast cancer survivors undergoing BRCA1/2 genetic testing. Asian Pac J Cancer Prev. 2012;13:2241–7.
122. Soran A, Ibrahim A, Kanbour M, McGuire K, Balci FL, Polat AK, et al. Decision making and factors influencing long-term satisfaction with prophylactic mastectomy in women with breast cancer. Am J Clin Oncol. 2015;38:179–83.
123. American Cancer Society. Breast cancer facts & figures 2007–2008. Atlanta: American Cancer Society, Inc.; 2007.
124. Centers for Disease Control and Prevention. Breast cancer rates by race and ethnicity. breast cancer. 2013. http://www.cdc.gov/cancer/breast/statistics/race.htm. Accessed 21 Mar 2017.
125. Hall MJ, Olopade OI. Disparities in genetic testing: thinking outside the BRCA box. JCO. 2006;24:2197–203.
126. Hughes C, Fasaye G-A, LaSalle VH, Finch C. Sociocultural influences on participation in genetic risk assessment and testing among African American women. Patient Educ Couns. 2003;51:107–14.
127. Lannin DR, Mathews HF, Mitchell J, Swanson MS. Impacting cultural attitudes in African-American women to decrease breast cancer mortality. Am J Surg. 2002;184:418–23.
128. Rauscher GH, Allgood KL, Whitman S, Conant E. Disparities in screening mammography services by race/ethnicity and health insurance. J Womens Health (Larchmt). 2012;21:154–60.
129. Sherman KA, Miller SM, Shaw L-K, Cavanagh K, Sheinfeld GS. Psychosocial approaches to participation in BRCA1/2 genetic risk assessment among African American women: a systematic review. J Community Genet. 2014;5:89–98.
130. Haas JS, Hill DA, Wellman RD, Hubbard RA, Lee CI, Wernli KJ, et al. Disparities in the use of screening magnetic resonance imaging of the breast in community practice by race, ethnicity, and socioeconomic status. Cancer. 2016;122:611–7.
131. Facing Our Risk of Cancer Empowered (FORCE). FORCE Website: fighting hereditary breast and ovarian cancer. https://www.facingourrisk.org/. Accessed 21 Mar 2017.
132. Hoskins LM, Greene MH. Anticipatory loss and early mastectomy for young female BRCA1/2 mutation carriers. Qual Health Res. 2012;22:1633–46.
133. Julian-Reynier C, Bouhnik A-D, Mouret-Fourme E, Gauthier-Villars M, Berthet P, Lasset C, et al. Time to prophylactic surgery in BRCA1/2 carriers depends on psychological and other characteristics. Gend Med. 2010;12: 801–7.
134. Hamilton R, Hurley KE. Conditions and consequences of a BRCA mutation in young, single women of childbearing age. Oncol Nurs Forum. 2010;37:627–34.
135. Hoskins LM, Werner-Lin A, Greene MH. In their own words: treating very young BRCA1/2 mutation-positive women with care and caution. PLoS One. 2014;9:e87696.
136. Werner-Lin A, Rubin LR, Doyle M, Stern R, Savin K, Hurley K, et al. "My funky genetics": BRCA1/2 mutation carriers' understanding of genetic inheritance and reproductive merger in the context of new reprogenetic technologies. Fam Syst Health. 2012;30:166–80.
137. Donnelly LS, Watson M, Moynihan C, Bancroft E, Evans DGR, Eeles R, et al. Reproductive decision-making in young female carriers of a BRCA mutation. Hum Reprod. 2013;28:1006–12.
138. Julian-Reynier C, Eisinger F, Evans G, Foulkes W, Sobol H. Variation in prophylactic surgery decisions. Lancet. 2000;356:1687.
139. Kinney AY, Richards C, Vernon SW, Vogel VG. The effect of physician recommendation on enrollment in the Breast Cancer Chemoprevention Trial. Prev Med. 1998;27(5 Pt 1):713–9.
140. Schaefer KM, Ladd E, Gergits MA, Gyauch L. Backing and forthing: the process of decision making by women considering participation in a breast cancer prevention trial. Oncol Nurs Forum. 2001;28:703–9.
141. Brownlee S, Wennberg J, Barry M, Fisher E, Bynum J, Goodman D. Improving patient decision-making in health care: a 2012 Dartmouth Atlas Report highlighting the Pacific States. Lebanon: The Dartmouth Institute for Health Policy & Clinical Practice; 2012.

142. Edwards AGK, Naik G, Ahmed H, Elwyn GJ, Pickles T, Hood K, et al. Personalised risk communication for informed decision making about taking screening tests. Cochrane Database Syst Rev. 2013;2:CD001865.
143. Elwyn G, Scholl I, Titbohl C, Mann M, Edwards AGK, Clay C, et al. "Many miles to go…": a systematic review of the implementation of patient decision support interventions into routine clinical practice. BMC Med Inf Decis Making. 2013;13(Supplement 2):S15.
144. Gunn CM, Soley-Bori M, Battaglia TA, Cabral H, Kazis L. Shared decision making and the use of screening mammography in women younger than 50 years of age. J Health Commun. 2015;20:1060–6.
145. Holmberg C. Decision making in the context of breast cancer chemoprevention: patient perceptions and the meaning of risk. Am Soc Clin Oncol Educ Book. 2015; e59–64.
146. Lovegrove E, Rumsey N, Harcourt D, Cawthorn SJ. Factors implicated in the decision whether or not to join the tamoxifen trial in women at high familial risk of breast cancer. Psychooncology. 2000;9:193–202.
147. Scherer LD, Ubel PA, McClure J, Greene SM, Alford SH, Holtzman L, et al. Belief in numbers: when and why women disbelieve tailored breast cancer risk statistics. Patient Educ Couns. 2013;92:253–9.
148. Klitzman R, Chung W. The process of deciding about prophylactic surgery for breast and ovarian cancer: patient questions, uncertainties, and communication. Am J Med Genet Part A. 2010;152A:52–66.
149. Leonarczyk TJ, Mawn BE. Cancer risk management decision making for BRCA+ women. West J Nurs Res. 2015;37:66–84.
150. Glassey R, Ives A, Saunders C, Musiello T. Decision making, psychological wellbeing and psychosocial outcomes for high risk women who choose to undergo bilateral prophylactic mastectomy—a review of the literature. Breast. 2016;28:130–5.
151. Kinnersley P, Edwards A, Hood K, Cadbury N, Ryan R, Prout H, et al. Interventions before consultations for helping patients address their information needs (review). Cochrane Collab. 2010. p. 1-84.
152. Connors LM, Voian N, Shi Y, Lally RM, Edge S. Decision making after BRCA genetic testing. Down the road of transition. Clin J Oncol Nurs. 2014;18: E58–63.
153. Bouchard L, Blancquaert I, Eisinger F, Foulkes WD, Evans G, Sobol H, et al. Prevention and genetic testing for breast cancer: variations in medical decisions. Soc Sci Med. 2004;58:1085–96.
154. Pal T, Lee J-H, Besharat A, Thompson Z, Monteiro ANA, Phelan C, et al. Modes of delivery of genetic testing services and the uptake of cancer risk management strategies in BRCA1 and BRCA2 carriers. Clin Genet. 2014;85: 49–53.
155. Landsbergen KM, Brunner HG, Manders P, Hoogerbrugge N, Prins JB. Educational-support groups for BRCA mutation carriers satisfy need for information but do not affect emotional distress. Genet Couns. 2010;21:423–37.
156. 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. Hered Cancer Clin Pract. 2011;9:7.
157. 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;6:256–82.
158. Howard AF, Bottorff JL, Balneaves LG, Kim-Sing C. Women's constructions of the "right time" to consider decisions about risk-reducing mastectomy and risk-reducing oophorectomy. BMC Womens Health. 2010;10:24.
159. Hallowell N, Jacobs I, Richards M, Mackay J, Gore M. Surveillance or surgery? A description of the factors that influence high risk premenopausal women's decisions about prophylactic oophorectomy. J Med Genet. 2001;38:683–91.
160. Landsbergen KM, Prins JB, Kamm YJL, Brunner HG, Hoogerbrugge N. Female BRCA mutation carriers with a preference for prophylactic mastectomy are more likely to participate in an educational-support group and to proceed with the preferred intervention within 2 years. Fam Cancer. 2010;9:213–20.
161. Hesse-Biber S. The genetic testing experience of BRCA-positive women: deciding between surveillance and surgery. Qual Health Res. 2014;24:773–89.
162. Mcquirter M, Castiglia LL, Loiselle CG, Wong N. Decision-making process of women carrying BRCA1 or BRCA2 mutation who have chosen prophylactic mastectomy. Oncol Nurs Forum. 2010;37:313–20.
163. Salant T, Ganschow PS, Olopade OI, Lauderdale DS. "Why take it if you don't have anything?" breast cancer risk perceptions and prevention choices at a public hospital. J Gen Intern Med. 2006;21:779–85.
164. Heiniger L, Butow PN, Charles M, Price MA. Intuition versus cognition: a qualitative exploration of how women understand and manage their increased breast cancer risk. J Behav Med. 2015;38:727–39.
165. Hesse-Biber S, An C. Genetic testing and post-testing decision making among BRCA-positive mutation women: a psychosocial approach. J Genet Couns. 2016;25(5):978–92.
166. Howard AF, Balneaves LG, Bottorff JL, Rodney P. Preserving the self: the process of decision making about hereditary breast cancer and ovarian cancer risk reduction. Qual Health Res. 2011;21:502–19.
167. Jeffers L, Morrison PJ, McCaughan E, Fitzsimons D. Maximising survival: the main concern of women with hereditary breast and ovarian cancer who undergo genetic testing for BRCA1/2. Eur J Oncol Nurs. 2014;18:411–8.
168. Donnelly LS, Evans DG, Wiseman J, Fox J, Greenhalgh R, Affen J, et al. Uptake of tamoxifen in consecutive premenopausal women under surveillance in a high-risk breast cancer clinic. Br J Cancer. 2014;110:1681–7.
169. Brandberg Y, Arver B, Johansson H, Wickman M, Sandelin K, Liljegren A. Less correspondence between expectations before and cosmetic results after risk-reducing mastectomy in women who are mutation carriers: a prospective study. ESJO. 2012;38:38–43.
170. Samson A, DiMillo J, Theriault A, Lowry S, Corsini L, Verma S, et al. Living with the BRCA1 and BRCA2 genetic mutation: learning how to adapt to a virtual chronic illness. Psychol Health Med. 2014;19:103–14.
171. DiMillo J, Samson A, Thériault A, Lowry S, Corsini L, Verma S, et al. Living with the BRCA genetic mutation: an uncertain conclusion to an unending process. Psychol Health Med. 2013;18:125–34.
172. Dillard AJ, Scherer L, Ubel PA, Smith DM, Zikmund-Fisher BJ, McClure JB, et al. Breast cancer anxiety's associations with responses to a chemoprevention decision aid. Soc Sci Med. 2013;77:13–9.
173. Frost MH, Schaid DJ, Sellers TA, Slezak JM, Arnold PG, Woods JE, et al. Long-term satisfaction and psychological and social function following bilateral prophylactic mastectomy. JAMA. 2000;284:319–24.
174. Fuller S, Anderson RC. Adjustment issues related to bilateral prophylactic mastectomy in women at elevated risk of developing breast cancer. Plast Surg Nurs. 2006;26:60–5.
175. Spear SL, Schwarz KA, Venturi ML, Barbosa T, Al-Attar A. Prophylactic mastectomy and reconstruction: clinical outcomes and patient satisfaction. Plast Reconstr Surg. 2008;122:1–9.
176. 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; 14:517–34.
177. Lerman C, Daly M, Sands C, Balshem A, Lustbader E, Heggan T, et al. Mammography adherence and psychological distress among women at risk for breast cancer. J Natl Cancer Inst. 1993;85:1074–80.
178. Miller SJ, O'Hea EL, Lerner JB, Moon S, Foran-Tuller KA. The relationship between breast cancer anxiety and mammography: experiential avoidance as a moderator. Behav Med. 2011;37:113–8.
179. van Driel CMG, Oosterwijk JC, Meijers-Heijboer EJ, van Asperen CJ, van Emmichoven IAZ, de Vries J, et al. Psychological factors associated with the intention to choose for risk-reducing mastectomy in family cancer clinic attendees. Breast. 2016;30:66–72.
180. Jolie A. My medical choice. The New York Times. 2013;162. p. A25.
181. Gomez SL, France A-M, Lee MM. Socioeconomic status, immigration/ acculturation, and ethnic variations in breast conserving surgery, San Francisco Bay area. Ethnicity and disease. 2004;14. http://w.ishib.org/ED/ journal/ethn-14-01-134.pdf. Accessed 21 Mar 2017.
182. Kerner JF. Breast cancer prevention and control among the medically underserved. Breast Cancer Res Treat. 1996;40:1–9.
183. Fagerlin A, Zikmund-Fisher BJ, Nair V, Derry HA, McClure JB, Greene S, et al. Women's decisions regarding tamoxifen for breast cancer prevention: responses to a tailored decision aid. Breast Cancer Res Treat. 2010;119:613–20.
184. Feldman-Stewart D, O'Brien MA, Clayman ML, Davison BJ, Jimbo M, Labrecque M, et al. Providing information about options in patient decision aids. BMC Med Inform Decis Mak. 2013;13(Supplement 2):S4.
185. Korfage IJ, Fuhrel-Forbis A, Ubel PA, Zikmund-Fisher BJ, Greene SM, McClure JB, et al. Informed choice about breast cancer prevention: randomized controlled trial of an online decision aid intervention. Breast Cancer Res. 2013;15:R74.
186. Kukafka R, Yi H, Xiao T, Thomas P, Aguirre A, Smalletz C, et al. Why breast cancer risk by the numbers is not enough: evaluation of a decision aid in multi-ethnic, low-numerate women. J Med Internet Res. 2015;17:e165.
187. Metcalfe KA, Poll A, O'Connor A, Gershman S, Armel S, Finch A, et al. Development and testing of a decision aid for breast cancer prevention for women with a BRCA1 or BRCA2 mutation. Clin Genet. 2007;72:208–17.

188. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. In: Cochrane Database of Systematic Reviews. The Cochrane Collaboration, Stacey D, editors. Chichester, UK: John Wiley & Sons, Ltd; 2011. http://www.cochrane.org/CD001431/COMMUN_decision-aids-to-help-people-who-are-facing-health-treatment-or-screening-decisions. Accessed 12 Feb 2013.
189. Metcalfe KA, Dennis C-L, Poll A, Armel S, Demsky R, Carlsson L, et al. Effect of decision aid for breast cancer prevention on decisional conflict in women with a BRCA1 or BRCA2 mutation: a multisite, randomized, controlled trial. Genet Med. 2016;19:330–36.
190. Banegas MP, McClure JB, Barlow WE, Ubel PA, Smith DM, Zikmund-Fisher BJ, et al. Results from a randomized trial of a web-based, tailored decision aid for women at high risk for breast cancer. Patient Educ Couns. 2013;91:364–71.
191. Fagerlin A, Dillard AJ, Smith DM, Zikmund-Fisher BJ, Pitsch R, McClure JB, et al. Women's interest in taking tamoxifen and raloxifene for breast cancer prevention: response to a tailored decision aid. Breast Cancer Res Treat. 2011; 127:681–8.
192. Juraskova I, Bonner C. Decision aids for breast cancer chemoprevention. Breast Cancer Res. 2013;15:106.
193. Kurian AW, Munoz DF, Rust P, Schackmann EA, Smith M, Clarke L, et al. Online tool to guide decisions for BRCA1/2 mutation carriers. J Clin Oncol. 2012;30:497–506.
194. Ozanne EM, Annis C, Adduci K, Showstack J, Esserman L. Pilot trial of a computerized decision aid for breast cancer prevention. Breast J. 2007;13: 147–54.
195. Ozanne EM, Howe R, Omer Z, Esserman LJ. Development of a personalized decision aid for breast cancer risk reduction and management. BMC Med Inform Decis Mak. 2014;14:4.
196. Schwartz M, Valdimarsdottir H, DeMarco T, Peshkin B, Lawrence W, Rispoli J, et al. Randomized trial of a decision aid for BRCA1/BRCA2 mutation carriers: impact on measures of decision making and satisfaction. Health Psychol. 2009;28:11–9.
197. Tiller K, Meiser B, Gaff C, Kirk J, Dudding T, Phillips K, et al. A randomized controlled trial of a decision aid for women at increased risk of ovarian cancer. Med Decis Mak. 2006;26:360–72.
198. Trikalinos TA, Wieland LS, Adam GP, Zgodic A, Ntzani EE. Decision aids for cancer screening and treatment. Rockville: Agency for Healthcare Research & Quality; 2014.
199. van Roosmalen M, Stalmeier P, Verhoef L, Hoekstra-Weebers J, Oosterwijk J, Hoogerbrugge N, et al. Randomized trial of a shared decision-making intervention consisting of trade-offs and individualized treatment information for BRCA1/2 mutation carriers. J Clin Oncol. 2004;22:3293–301.
200. Collins IM, Bickerstaffe A, Ranaweera T, Maddumarachchi S, Keogh L, Emery J, et al. iPrevent®: a tailored, web-based, decision support tool for breast cancer risk assessment and management. Breast Cancer Res Treat. 2016;156:171–82.