Risk communication and decision-making in the prevention of invasive breast cancer

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A B S T R A C T
Risk communication surrounding the prevention of invasive breast cancer entails not only understanding of the disease, risks and opportunities for intervention. But it also requires understanding and implementation of optimal strategies for communication with patients who are making these decisions. In this article, available evidence for the issues surrounding risk communication and decision making in the prevention of invasive breast cancer are reviewed and strategies for improvement are discussed.

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Breast cancer is the most commonly diagnosed cancer in women worldwide, with an increasing incidence in recent years in the developing world largely due to increased life expectancy and adoption of western lifestyles. In the primary prevention of invasive breast cancer, it is important to consider 3 general groups. There are women in the general population who are at “population risk” of getting breast cancer and for whom various models are used to predict an individual woman’s risk (e.g., Gail model, Tyrer-Cuzick model). Women with higher risk of disease should also be considered based either on a strong family history, including those with a known genetic predisposition, or based on their personal medical history. Women in this “high risk” group include individuals with a history of a prior risk lesion diagnosed in the breast such as atypical ductal/lobular hyperplasia (ADH/ALH) or lobular carcinoma in situ (LCIS) or prior history of therapeutic radiation to the chest. Finally, women with ductal carcinoma in situ (DCIS) represent a unique cohort to consider with regard to the prevention of invasive breast cancer given they have stage 0, noninvasive disease but are at very high risk of subsequently developing invasive disease. These groups have different risks of disease and correspondingly different though related options for prevention and management of risk. Options for population risk women include screening, lifestyle recommendations, and chemoprevention with tamoxifen, raloxifin or aromatase inhibitors, although the latter strategy is not FDA approved in the U.S.. Despite clear benefits from chemoprevention, patient uptake and adherence in the primary prevention setting has been limited [1]. For high risk women, addition of more sensitive screening for early detection (e.g., breast MRI) as well as risk-reducing salpingo-oophorectomy and/or prophylactic mastectomy are options. Here, there are increasing data for the benefits of these strategies with regard to disease free and overall survival for women with BRCA 1 or BRCA 2 mutations in particular, although barriers remain regarding counseling, testing and pursuit of intervention for many women [2].

The advent and growth of population-based screening mammography over the past several decades have led to a dramatic increase in the incidence of ductal carcinoma in situ (DCIS), proving substantial opportunities and challenges [3,4]. DCIS encompasses a heterogeneous group of lesions with a variable natural history and risk of progression to invasive breast cancer and treatment remains highly variable and controversial. Although DCIS itself does not metastasize and is rarely lethal, it may be a precursor of invasive breast cancer and is a clear marker of increased risk of invasive breast cancer. Thus, even though DCIS is fairly distinct from invasive disease, options for management of DCIS include most treatments offered for invasive disease except chemotherapy, including surgery with or without radiation to the affected breast, tamoxifen or aromatase inhibitor therapy, with recently launched studies evaluating the option of active surveillance for the management of lower risk DCIS [5].

In management of DCIS, Physicians note that decision-making about treatment for DCIS is very difficult for patients and DCIS patients over-estimate their risk of recurrence [6]. In one study, over 25% believed they have at least moderate likelihood of DCIS spreading to other places in their body [7]. In another, women with DCIS perceived similar risks as women with T1/T2 tumors [8]. Further, these inaccurate perceptions appear to persist over time,
This anxiety and inaccurate risk perceptions surrounding DCIS may be due in part because DCIS is not a disease with which most women are familiar, and among those diagnosed, there is a lack of understanding of the disease entity, particularly with regard to the non-invasive nature and whether or not it is “cancer” or could spread to other places in a woman’s body and become life-threatening. The common use of the term “breast cancer”, to refer to both DCIS as well as invasive disease, likely adds to the confusion given the different and much greater risks associated with invasive breast cancer compared to DCIS, Stage 0, or non-invasive breast cancer. Some have argued that consideration be given to removing the term “carcinoma” from DCIS, using cancer “occurrence” to mean the diagnosis of invasive cancer after DCIS instead of “recurrence,” shifting to a prophylactic paradigm of treatment after excision of DCIS [10]. One recent survey study revealed that when DCIS was framed as a high-risk condition rather than as cancer, a substantial proportion of women surveyed shifted their treatment preferences in theoretical scenarios from surgical to nonsurgical treatments suggesting that many women may prefer a less invasive, nonsurgical option if allowed to weigh each choice and its attendant risks [11]. Others have countered that changes in nomenclature would not likely result in different decisions being made by women given that ecologically valid options are the same as invasive cancer [3,12].

While decisions are usually less urgent in the primary prevention setting, there is also evidence that women at high risk of developing breast cancer have inaccurate risk perceptions which may hamper optimal decision-making. In a prospective interview and survey study at a high risk clinic including 146 high risk women and 4 physicians, women’s preferences for prevention interventions varied widely across women, although they were stable across time. Women overestimated their risk of disease, and physicians overestimated the decrease in perceived risk resulting from counseling (p < 0.001), and were not reliable able to predict their patients’ preferences with regard to risk reducing strategies [13].

Thus, there is great opportunity to improve risk communication and decision-making in the prevention of invasive breast cancer. Despite differences in risk and conventional options available for risk reduction between the different groups of women at risk, there are several generalizable concepts that apply each of these settings, as well as several other early breast cancer situations where decisions need be made, which may improve risk communication and associated decision making.

The main ingredients for a good decision include 1) communication of the risks of the disease, and clear disclosure of the potential risks and benefits of a given intervention for that individual; 2) Assessment and integration of patient values and preferences into decision; 3) Ability to implement a plan based on decisions made. Each step along the way, there are challenges when considering decision making surrounding the prevention of invasive breast cancer. The gold standard for optimal health decisions is shared decision making, which has been described as “the process of interacting with patients who wish to be involved in arriving at an informed, values-based choice among two or more medically reasonable alternatives.” [14] In the setting of certain health decisions, anxiety may be a strong driver of decisions, and optimal patient-centered communication therefore also requires attention and response to patient emotions, and help to manage uncertainty [1]. In the context of prevention of invasive breast cancer, decisions may be particularly complicated and emotional given the highly visible culture of breast cancer, both good and bad aspects, in the developed world. A woman’s prior experience with the disease is likely to impact on her emotional reaction to prevention of the disease and treatments. For example, if a woman’s mother or sister died of breast cancer, she may be more likely to be anxious when facing and making decisions about her own risk and risk reduction. Limitations of our general knowledge adds additional uncertainty about the risk of disease both on a population and individual level. In busy clinics, assessment and integration of patient values and preferences into decision-making is difficult and time may not allow for deliberation between patient and provider, and patients may perceive urgency to make a decision, particularly in the setting of DCIS given there are standard guidelines for treatment. Finally, the ability to implement any given decision is not universal and there remain issues of patient access, self-efficacy, and adherence that might thwart intervention efforts.

Despite these challenges, there is the potential for optimizing decision-making surrounding the prevention of invasive cancer for women at risk including those with DCIS to improve decision. The need for better risk predictors for an individual both in terms of risk of disease as well as risk of an adverse outcome from prevention intervention is the subject of much ongoing research [3]. Of course, more palatable options for the management of risk are always desired and clinical trials are underway to increase the number of choices available for women at risk or who have developed DCIS, including consideration of active surveillance for the latter in the LORIS randomised trials [3]. The LORIS trial, a phase III study in the U.K. comparing surgery to active surveillance for women with low risk DCIS has a patient oriented website with informative videos meant to educate women about their options...
Conflict of interest

Author declares no conflict of interest.

References