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Health literacy and the perception of risk in a breast cancer family history clinic☆,☆☆

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ABSTRACT

Background: Informed consent is an essential component of medical practice, and especially so in procedural based specialties which entail varying degrees of risk. Breast cancer is one of the most common cancers in women, and as such is the focus of extensive research and significant media attention. Despite this, considerable misperception exists regarding the risk of developing breast cancer.

Aims: This study aims to examine the accuracy of risk perception of women attending a breast cancer family history clinic, and to explore the relationship between risk perception accuracy and health literacy.

Methods: A cross-sectional study of women attending a breast cancer family history clinic ($n = 86$) was carried out, consisting of a patient survey and a validated health literacy assessment. Patients' perception of personal and population breast cancer risk was compared to actual risk as calculated by a validated risk assessment tool.

Results: Significant discordance between real and perceived risks was observed. The majority (83.7%) of women overestimated their personal lifetime risk of developing breast cancer, as well as that of other women of the same age (89.5%). Health literacy was considered potentially inadequate in 37.2% of patients; there was a correlation between low health literacy and increased risk perception inaccuracy across both personal ten-year ($r_s = 0.224$, $p = 0.039$) and general ten-year population estimations. ($r_s = 0.267$, $p = 0.013$).

Conclusion: Inaccuracy in risk perception is highly prevalent in women attending a breast cancer family history clinic. Health literacy inadequacy is significantly associated with this inaccuracy.

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Introduction and literature review

Maximising patient understanding and the timely delivery of informed consent are both critical factors in modern medical practice. However, patients may over or under-estimate disease risk, with implications for compliance, consent and public health initiatives.[1–3] As the medical profession moves from a paternalistic model of practice to an increasingly patient-led model, an appreciation of factors underlying patient comprehension is increasingly important. Understanding patient perception of risk may enable healthcare professionals of all disciplines to optimize perception accuracy and gain truly informed consent within a clinical setting where time and resources are finite.

This concept is illustrated here in the field of breast surgery for a number of reasons, although it may be extrapolated to other surgical specialties. The incidence of breast cancer amongst our ageing population is significant, with one in eight women living to old age developing breast cancer, and one in thirty-six women dying of breast cancer.[4]

In addition, the concept of risk-reducing surgery for high-risk patients has gained considerable traction in the field, with high profile cases in recent years capturing public attention.[5] A similar case may be made in the case of elective colorectal surgeries for both hereditary conditions (Lynch syndrome, Familial Adenomatous Polyposis) and chronic inflammation (Ulcerative Colitis). Given the significant morbidity and potential mortality that can be associated with these procedures the perception of disease risk must be accurate in order to empower patients and facilitate informed consent.

Furthermore, an overestimation of risk carries implications for mental health and psychological well being. It has previously been demonstrated that a perception of high risk of breast cancer correlates strongly with breast cancer associated worry.[6] Metcalfe[7] assessed 205 women who had a sister newly diagnosed with breast cancer. Using the Impact of Events Scale, cancer related distress and perception of risk were recorded. Half of the women scored in the moderate or severe distress range; the most significant predictor of cancer-related distress was perceived lifetime breast cancer risk.

Finally, there exists a finite amount of medical resources. The overestimation of risk may potentially lead to excessive screening behaviour and unnecessary engagement with specialist services, a concept which may be readily appreciated in any healthcare setting. Haber et al.[8] found that patients who had a family history in a first degree relative had an increased personal risk perception. This study was conducted in a large cohort, none of whom had a personal history of cancer. It also used screening behaviour as a marker; showing that having a maternal history of breast cancer increased mammography by 0.5 mammograms over 6 years in comparison with women who did not have a maternal history of breast cancer. Conversely, underestimation may reduce engagement with primary preventative measures.[9]

Having recognized the importance of accurate risk perception above, it becomes necessary to examine the factors that may affect this perception. Health literacy is defined by the United States Centres for Disease Control and Prevention as "*the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions*".[10] The World Health Organization defines health literacy as "*the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health*"[11]; health literacy is a key component of the WHO initiative on Global Health Promotion. Health literacy is an issue that spans both developing and developed health systems. Evidently challenges to healthcare systems vary enormously depending on context; but the concept of health literacy is broadly applicable, from engagement with infectious disease control measures to primary prevention of chronic non infectious disease in more developed healthcare systems. Indeed the WHO has also identified health literacy as a key area in health policy across the EU.[12] A 2012 study noted either inadequate or problematic levels of health literacy in 47% of the population in eight EU states including Ireland.[13] As such, health literacy is a topic relevant to all healthcare professionals, particularly as patient engagement, empowerment, and integration into clinical decision-making becomes increasingly important.

This importance has also been extensively documented in cancer care. Health literacy has an obvious role in an individual's perception of their own cancer risk, as demonstrated by Brewer et al.,[14] in which health literacy was assessed utilising the Rapid Estimate of Adult Literacy in Medicine (REALM) tool. Respondents were breast cancer survivors deemed to have either "high" or "low" levels of health literacy, and their risk perception of cancer recurrence was subsequently assessed. Risk perception was less accurate in the "low literacy" group, although the use of a dichotomous measure of literacy poses some methodological issues. In a wider context, a 2011 meta-analysis found that low health literacy was associated with poorer health outcomes and suboptimal utilisation of healthcare resources.[15]

Several other factors may influence a patient's view of risk. It can be easily understood that a positive family history could skew a patient's perception of risk, as was evident in a US cohort[16] in which 92% percent of women with a close friend or family member with breast cancer (vs 77% of those without) felt women should continue to undergo annual mammography in their forties, in contravention of the established US guidelines. Thus, we see that risk perception is formed in a socio-cultural and personal context. Furthermore, this miscalculation can lead to excessive screening behaviours and demand for specialist services. Not only is this practice suboptimal for patients, but it can be a considerable drain on resources for health systems.

As part of the same study[16] the power of media in patient risk perception was demonstrated. Attitudes to screening and risk perception were examined by asking one group of patients to read a "pro-screening" article and the other a "less screening" article. Of those who read the "pro-screening article" 93% felt that women in their 40s should have an annual mammogram; amongst those who were randomized to the "less screening" article this figure was 83%. This demonstrates that media influences may shape patient attitudes to risk; conversely however it also illustrates the potential of

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