

Original article

Can an educational application increase risk perception accuracy amongst patients attending a high-risk breast cancer clinic?



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ABSTRACT

Objectives: To design, develop and test the effect of an educational initiative to improve risk perception amongst patients attending a high-risk breast cancer clinic. This was achieved through three objectives – 1. identifying an optimal method of presenting risk data, 2. designing and building a risk application, and 3. testing the ability of the application to successfully modify patients perceived risk of cancer.

Materials and methods: A mobile application was developed for this project using best practice methods for displaying risk information. Patients (n = 84) were randomly allocated into two groups – ‘Control’ or ‘Treatment’. Both groups underwent standard risk counseling while the application was employed in the ‘Treatment’ group. The patients were surveyed before their session, immediately after and six weeks later.

Results: Increases in accuracy were seen in both groups with larger increases demonstrated in the ‘Treatment’ group with ‘Personal 10 Year Risk’ statistically significant (‘Control’ group increase from 21% to 48% vs the ‘Treatment’ group increase from 33% to 71% - p = 0.003).

Conclusion: This project demonstrated trends towards improved risk perception, however mixed logistic regression was unable to show a 30% difference between groups. Numerical literacy and understanding of risk were identified as issues amongst the general population. Overestimating risk remains high amongst attendees.

Using mobile applications to convey risk information to patients is a new and evolving area with a corresponding paucity of data. We have demonstrated its potential and emphasised the importance of designing how this information is communicated to patients in order to make it understandable and meaningful.

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1. Introduction

Cancer will affect at least one in three people in their lifetime [1]. Breast Cancer is the most common cancer diagnosed in women annually comprising 30.2% of all new female cancer diagnoses in 2012 in Ireland [2]. Approximately one in eight women will develop breast cancer over the course of their lifetime [3]. Breast cancer has featured prominently among recent discussions in conventional and social media. The “Angelina Jolie effect” is thought to have contributed to the current high awareness of breast cancer amongst the general population [4], and their overestimation of the risk of

being a BRCA gene carrier [5]. There is a surfeit of research done across multiple areas of the BRCA genes – from knowledge of the gene, to genetic counseling for family members of confirmed carriers, to links with other types of cancers and availability of treatment options. Of relevance to this study is research in areas related to the general public’s perception of prevalence of the BRCA genes in the population and individual risk of being a carrier. A study carried out by MacHew et al. [6] demonstrated that participants overestimated the general risk of someone being a BRCA gene carrier. However recent work from our centre has shown that women are over-estimating their risk of developing breast cancer, particularly when they have a family member diagnosed with breast cancer [7].

An increased perception of the risk of developing breast cancer increases patient anxiety and stress [8,9]. Furthermore the

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improved education of patients regarding their actual risk may potentially help reduce the burden of unnecessary referrals [7].

Currently there exists a paucity of published research available on the use of technology such as smartphones as a means to communicate health information and modify patient's risk perception. Previously published data from our group has highlighted the fact that most patients attending the high risk clinic are smartphones users [10].

There was minimal published research available on the use of smartphones (or smartphone applications) to communicate health and risk information to patients – the only research found relating smartphones and their ability to change user's perception of risk and behaviours related to sun exposure and produced negligible results [11]. However, it is expected that there will be an increase in publications focused on smartphones in the near future. General technology usage points inferred from Chen [12] are that patients should have permanent access to the technology and that the technology should be free. This makes the case for a mobile application more compelling.

This study aimed to develop a mobile application, displaying easy-to-understand graphical risk data, and to evaluate it's effect on improving patient understanding of their risk of developing breast cancer.

2. Methods

2.1. Current standard care

In Ireland, patients currently attend a high-risk family history breast clinic via a General Practitioner (GP) referral. This is either GP or patient initiated, and is usually preceded by a family member being diagnosed with breast cancer. The patient attends an appointment with a specialist at a dedicated clinic where a detailed history is acquired, allowing the specialist to calculate the patient's actual risk information using the Tyrer-Cuzick model ("IBIS Breast Cancer Risk Evaluation" tool which was developed by the Wolfson Institute of Preventative Medicine in the UK). The specialist reviews the risk figures generated and counsels the patient accordingly.

2.2. Study design

A randomised control trial where participants were randomly allocated into one of two arms – a control group and an intervention group. The control group were managed in the standard care pathway as described. The intervention group completed an identical pathway in addition to being provided with the newly developed application after their specialist counseling session.

2.3. Application

In order to develop this application, a literature review was conducted into methods of presenting data to the end user. The findings indicated that there was no overall "one best method" of displaying data. Therefore a variety of data display methods were used in a paper-based pilot study. The graphs and corresponding text was reviewed and modified by the National Adult Literacy Agency (NALA) to ensure clarity. Content and face validity assessment was then completed using a panel of five patients and five nominated experts, following which, recommended edits were made. The authors produced a requirements document and an application developer was engaged to produce the final application that was used in the project. The application was developed in standard HTML/JavaScript and is available for free to download on the Apple Store.

2.4. Participants

Patients were recruited to the study in a consecutive manner based on their attendance at the high-risk family history breast clinic at Cork University Hospital between the period of July to September 2015. A follow up copy of the survey was sent out to participants from the week commencing August 2015 to the week commencing October 2015. Patients were randomised through the use of unmarked envelopes. Patients were deemed eligible if they met the inclusion criteria of having a positive family history of breast cancer, being asymptomatic and consenting to participate.

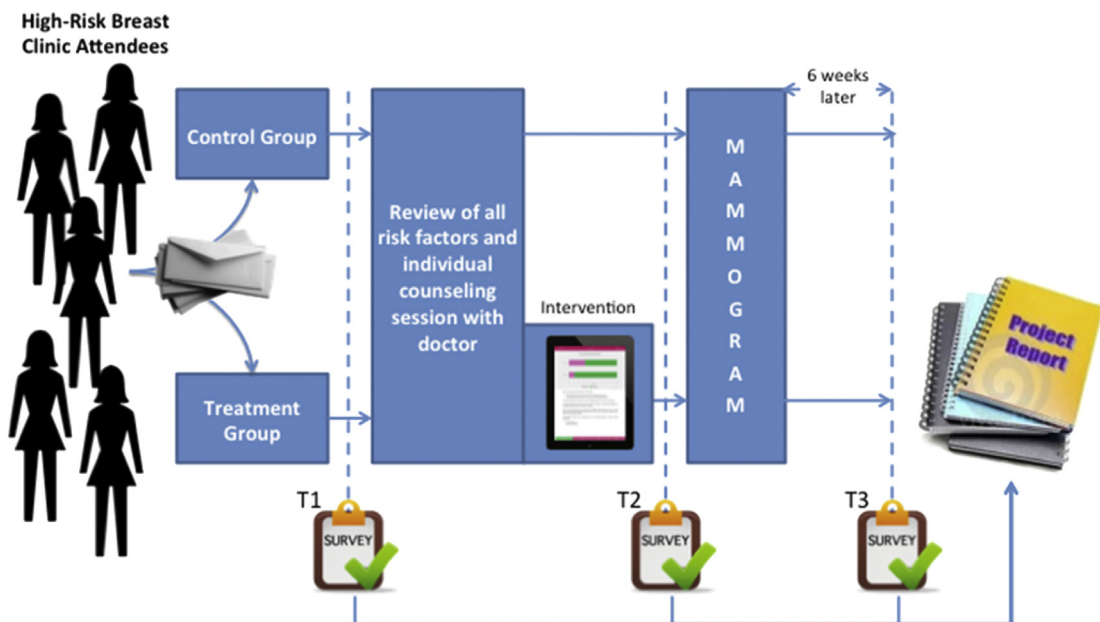


Fig. 1. Diagrammatic representation of data collection methodology.

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