Radiography 21 (2015) 308–314

Contents lists available at ScienceDirect

Radiography

journal homepage: www.elsevier.com/locate/radi

Preparing women for breast screening mammography: A feasibility study to determine the potential value of an on-line social network and information hub

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ARTICLE INFO

Article history:
Received 10 May 2015
Received in revised form
6 July 2015
Accepted 7 July 2015
Available online 30 July 2015

Keywords:
Mammogram
Qualitative
Socio-ecological
Social media
Digital support network

ABSTRACT

This feasibility study explored the attitudes of women towards social media for support about breast screening mammography. It sought their ideas about what a dedicated breast screening hub or Digital Support Network (DSN) might comprise; how they would network with other women on the DSN; what format information might take; and whether a health professional should be available on the DSN. Data comprised 94 survey questionnaires and two focus groups; one comprised women in the breast screening population age group, the other was a younger group. A socio-ecological framework was used to identify key influencers and potential barriers for the implementation of a mammography DSN. The study identified issues related to three intersecting concepts which influenced women's behaviour: on-line conversations about health in general; on-line conversations about breast screening mammography and the culture of privacy which makes conversing about intimate health (either face to face or on-line) difficult. Also, the transient nature of the mammography episode (three yearly), could mean an on-line breast screening digital network is challenging to sustain. super-users' may be needed to continue on-line conversations. The health professional was also seen as essential for moderating potential misinformation shared by women although the participants were also insistent that 'truth' be shared.

Introduction

As part of the UK NHS Breast Screening Programme (NHS BSP) women over the age of 50 are invited for screening every three years. Mammography, an X-ray examination of the breast, comprises four images during which the breast is compressed between two paddles. This examination is associated with high patient anxiety related to fear or expectations of pain, the possibility that a cancer could be discovered, false positive findings and the use of ionising radiation.[1] Good quality patient information and preparation can address some of these fears, leading to a more positive experience and ensuring that non-attendance is as a result of considered decision-making rather than fear of the unknown.[2]

However, Robinson et al.[1] found that women attending for breast screening said they were "*not well informed*". Although women in Robinson's study received NHS BSP patient leaflets (available at http://www.cancerscreening.nhs.uk/breastscreen/publications/ia-02.html) they said these were not memorable and preferred listening to the experiences of their friends and relatives in order to understand what breast screening entails. Others have found a similar preference for women to engage in family discussions about mammography.[3–5]

The advent of internet functionality which enables users to generate and co-create content and therefore be involved in an

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http://dx.doi.org/10.1016/j.radi.2015.07.004

active rather than passive manner might be a way of supporting this preference for word-of-mouth information. Women who want to talk about breast screening have an alternative space in which to network with others; furthermore, on-line communication can provide anonymity and 24-h access. This study therefore explored the feasibility of creating an on-line social space to provide information and also to enable women to share their lived experiences of breast-screening mammography with the purpose of informing and alleviating the potential anxieties of first time users.

Background literature

Patient-generated DSNs are prolific. Fox[6] reported that 23% of people with a chronic disease in the USA who have access to the internet turn to on-line communities for support, access to patient generated information and each other. On-line approaches are felt to be particularly relevant because they provide a non-judgemental, anonymous and safe environment for the discussion of sensitive health conditions and benefits include 24h availability and asynchronous communication which means patients can react or respond to others if and when they chose.[7]

However, some studies have found people may be reluctant to share information using DSNs. Cutrona[8] looked at adults' behaviours with regard to promoting health screening using electronic means of communication. Whilst 14.6% of (438) women had used email to share information about breast screening only 3.9% had used other forms of electronic communication such as DSNs. However, it is important to state that this study concerned screening examinations. Because of the different fiscal health model in the USA where screening must be paid for by the individual (or their insurer), motivation to attend for screening may vary compared to say the UK where health screening is free at the point of delivery. This could influence how individuals rate screening as a topic for discussion on-line.

Nevertheless, DSNs focussed towards the *symptomatic* population do exist in abundance. In a content analysis of Facebook groups, Bender et al.[9] found 620 sites related to breast cancer with more than 1 million members between them. Yet their study, which aimed to characterize the purpose, use, and originators of breast cancer-related Facebook groups found that these were created mainly for fundraising (44.7%). Only 7% were created for patient or care giver support. Interestingly, though, the support groups were associated with the greatest number of user-generated posts. In contrast to Cutrona's[8] study, this may suggest people who need support for symptomatic disease are more likely to create a sharing on-line network than people who just want information.

The difference between Cutrona's[8] and Bender et al.'s[9] studies may suggest that behaviour is dependent on the different motivations and needs which drive someone to visit or join on-line groups. Bender et al.[9] were concerned with breast cancer groups (i.e. symptomatic patients and their families/carers) whereas Cutrona[8] was concerned with the asymptomatic screening population. Thus the motivation to sustain long term support networks for an asymptomatic population may be limited.

Despite the proliferation of on-line support networks identified by Bender et al.,[9] there are few which focus specifically on breast screening. Yet, the authors suggest, the breast screening context is particularly suited to support through social media because the Office of National Statistics (ONS)[10] report that 68% of women in the UK, aged 35–44 and 54% aged 45–54 have a profile on sites such as Facebook or Twitter. This trend reflects the up-coming population of first-time attenders for mammography breast screening.

To address the assumptions posed by Cutrona's[8] and van Bender et al.[9] as to whether a screening social network is sustainable and useful for sharing information and having conversations about health a feasibility study was designed. The overarching question was:

Would women users of the UK NHS BSP find a dedicated DSN useful in preparing for their mammography screening?

The specific areas explored with participants in order to address this question were:

i) Were women already using social media to discuss health or breast screening?
ii) Would the use of a DSN for gaining information and support about breast screening be a good idea?
iii) In what format should *information* about breast screening be presented on the DSN?
iv) What method would they prefer for *networking* with other women about breast screening on the DSN?
v) Would the presence of a health practitioner on the DSN be important?

Methodology

A two stage, iterative approach was employed to both collect and analyse data[11] where information gained by surveying a large group of women was then used to explore attitudes and behaviours in more depth with an initial focus group and then, as a result of analysis, a purposively sampled second group.

Sample

1) Survey:

This comprised a convenience sample of women working at three large institutions (2 × National Health Service (NHS) Hospital Trusts and 1 × Higher Education Institution (HEI)) which employ women of the screening population age. All women aged 45–55 working in these institutions were invited to take part (the total number of this population is not known). The survey instrument comprised 14 questions structured around the key study questions detailed above (Fig. 1). The survey was piloted with a group of 10 female employees for comprehensibility.

2) Focus groups:

Two focus group interviews were held (identified as FG1 and FG2 respectively).

   i) FG1: 5 women who had agreed to be followed up after the survey and therefore fell within the breast screening population demographic. These were not selected, they were the only 5 women who agreed to follow up. Nevertheless, this smaller size of focus group is recommended for the discussion of sensitive issues.[12] Three were administrators and two were non-radiography lecturers (Occupational Therapy and Social Policy). Data collected at the focus group were iterative in that women were shown and asked to interpret the survey results.
   ii) FG2: a ‘younger’ sample of 5 women (18–45 years). The decision to interview a younger group of women emerged from FG1, where age was suggested as a potential influencer of health behaviours and the use of social media. These younger women comprised 3 university students, 1 recent graduate and 1 college leaver about to start university.