

CoRIPS Research Award 95

Patsy Whelehan

Exploring women's experience of mammography: a qualitative study

Awarded £7,244

PRINCIPAL AIM

To understand women's experiences of mammography in the breast screening setting, through qualitative exploration of client and staff perceptions.

RESEARCH QUESTIONS

- What are women's thoughts and feelings about the experience of having a mammogram?
- What factors and circumstances do they think contribute to a good or bad experience?
- How do women make sense of their experiences?
- What reactions and responses do they have to the mammography staff?

- What do mammography staff think the experience of having a mammogram is like for clients?
- What factors and circumstances do mammography staff consider may affect women's perceptions of the examination?
- What are the thoughts and feelings of mammography staff about performing mammograms?
- What reactions and responses to the clients do they experience?

OUTCOMES

It is expected that this research will provide new insights into an area which has received little prior qualitative research attention and to date remains surprisingly poorly understood. As well as advancing knowledge per se, identifying the issues impacting on the quality of women's mammography experiences will form the basis of future quantitative research. This proposed qualitative study will contribute to item-generation for survey-based assessment of the mammography experience and the factors affecting it. The ultimate aim is to develop and test interventions to improve the experience of the mammography examination for women. The proposed project will be the first step in identifying key targets for such interventions, and will focus specifically on radiographic practice.

LITERATURE REVIEW; GAPS IN CURRENT KNOWLEDGE

Considerable attention has been paid in the literature to uptake rates in mammography screening and has focussed, for example, on psychological aspects(1) and socio-demographic and economic aspects(2). Repeat, or cumulative, participation has been studied less often but the client experience has been implicated in non-re-attendance(3).

The most frequently studied aspect of the mammography experience is pain. It is well-documented that pain or "discomfort" from mammography is experienced to varying degrees in a large proportion of women undergoing mammography(4). A recent systematic review has confirmed that this deters some women from re-attending for mammographic screening(5). However, pain is a complex phenomenon, and it is possible that when women say that pain was their reason for not re-attending, this could be masking more subtle and complex adverse perceptions.

While numerous publications on various aspects of perceptions of the mammography experience exist, there is a shortage of qualitative research focussing on this area. Rather, most authors on the subject have conducted quantitative, survey-based investigations using instruments which have not taken clients' own views as the starting point for the design(6, 7). The qualitative research which has been published concerning women's experiences of mammography has tended to take a very broad approach. In 2004, Poulos and Llewellyn published work aiming to understand mammography discomfort from a holistic perspective(8).

This work identified a number of themes which merit further attention. Aspects of poor experience relating to mammographic practice included staff not listening, and responding inadequately to concerns, but also included issues around trust and perceived competence. Similar themes were identified by Watson and Johnson in 2011(9), who conducted a qualitative study in the U.S.A. with women who had previously been adjacent to a screening

qualitative study in the U.S.A. with women who had previously been adherent to screening guidelines but whose attendance had lapsed. This study also highlighted women's concerns about the mammography procedure in terms of efficacy, radiation risk and risk of causing spread of any cancer present. A recent focus-group study from the U.S.A.(10) set out to examine concerns specific to women of certain ethnicities and showed that modesty and embarrassment seemed of greater concern among Hispanic women. The study also identified communication as a major theme. Quantitative work too has demonstrated the importance of radiographer communication skills on client experience, with particular reference to pain. For example, Van Goethem et al showed that if women felt that they had had a conversation with the radiographer, and if the radiographer had made it clear that the woman could speak out to limit the compression level, reported pain levels were lower(11).

Mathers et al have recently published qualitative research investigating experiences of breast imaging and interventional procedures among those diagnosed with breast cancer(12). With reference to mammography examinations, women's perceptions of the radiographer were again shown to be important. In addition, women talked about having to be a "contortionist" during mammography positioning, which also has potential implications for radiographic practice.

None of the qualitative studies focussing specifically on screening mammography has been conducted in the UK, so their findings cannot be assumed to represent the experience for UK women. Although the recent study by Mathers et al(12) was set in the UK, it did not focus primarily on mammography but on experiences of the diagnostic journey in the breast imaging department more broadly.

The proposed work aims to focus specifically and in greater depth than previous authors on the screening mammography examination itself, in order to understand more clearly where key potential targets for future intervention may lie. The context, and the attitudes, feelings and prior experience that women bring to the episode will remain important as these undoubtedly have an influence on the mammography encounter itself. In addition, the proposed study will explore the thoughts, feelings and perspectives of mammography staff in order to identify new insights into how the interaction between client and practitioner may play into clients' experiences.

METHODOLOGY

A qualitative design is suitable for this research because it aims to arrive at an understanding of mammography from the perspective of those experiencing it. The broad philosophy behind qualitative investigation, consisting of "person centeredness", and an open-minded starting point(13), suits the aims of this study. The study aims to identify new perspectives rather than relying on pre-supposition or previous quantitative research findings which generally have not taken the client's perspective as the starting-point for designing measurement instruments.

METHODS

The study will be set within the Scottish NHS Breast Screening Programme. Qualitative semi-structured interviews will be undertaken with clients and staff of the Programme. Semi-structured interviews are preferred over in-depth interviews for this study because of the need to focus on a relatively narrow topic and to avoid an unmanageable amount of data being produced. With the semi-structured interview method, questions are asked but respondents are also given freedom to talk about the topic and give their views in their own time and their own words. The interview schedules will be informed by literature, hypothesis and expert opinion but will also leave room to elicit completely new concepts/themes from the participants.

In the case of clients, a purposive sample will be drawn to achieve maximum diversity concerning socio-demographic factors, screening history, and interval between the last mammogram and the research interview. To achieve a reasonable degree of saturation across primary and secondary sampling criteria, 29 participants will be required.

The screening service will send study invitation letters and information sheets to batches of women with a range of screening histories. It is estimated that 2-3 women will need to be contacted to obtain one response(10) but the ethics application will seek approval to write to a greater number in case this projected recruitment rate should prove over-optimistic. Women will be asked to return a pre-paid reply slip providing their telephone number if they are willing to be contacted by the research radiographer.

The research radiographer will telephone respondents to answer any questions about the study, to obtain information to allocate women to cells in the purposive sampling grid, and, if the woman fits the grid and chooses to take part, to arrange an interview appointment. The interview will take place either in the woman's home, at the Clinical Research Centre on the hospital site, or elsewhere by mutual agreement. Written informed consent will be obtained in

person, immediately prior to the interview.

In the case of mammography staff, the interviews will be conducted away from the research radiographer's own site, as it is expected that greater participant candour is likely if the researcher is not personally known to the participants. A purposive sample will be drawn to reflect the diversity of the staff population in terms of age, years of experience, whether practitioner, assistant practitioner or advanced practitioner, and whether the mammographer has had a mammogram herself. The local superintendent radiographer will ask all staff whether they are willing to take part and will then fill the sampling grid with eligible participants until there is reasonable saturation across the required categories. It is expected that this will require a sample size of 24. The inclusion of additional centres will be considered if a full complement cannot be obtained from a single centre. Extensive consideration has taken place concerning the inclusion of a range of ethnicities among the staff sample. The consensus on the research team is that, although not essential, this is desirable and additional centres may need to be asked to participate in order to achieve diversity on this factor.

Data will be analysed using Thematic Analysis, largely because of the importance of context in this work and the need to uncover subtle nuances from the data(13). The approach will draw on phenomenological theory, because of the need to understand women's experiences and perceptions from their own perspectives. Data analysis will aim to be inductive and will be interpretive because the actual words used are considered less important than the meaning attached to the words by the participants. Quantification of content and themes will not be attempted. The measure of importance of the emergent themes will be how strongly the participants express them, rather than how frequently they are expressed.

In qualitative research, credibility comes from detailed and transparent reporting of the methods used in data collection and analysis. Researcher reflexivity will be thoroughly considered. The influence of the researcher is expected to be a particular issue in this study because of her high level of expertise within the field and low level of experience of conducting qualitative research. In addition, the interpretive approach to data analysis needs to be undertaken with due regard to the potential for researcher influence.

One of the main ethical considerations in this study is information governance in the identification of women suitable for participation in this study and in deciding how to approach them. This has been addressed by designing the recruitment process such that women are initially approached by the screening service, which already has a relationship with them. A further consideration is how to ensure that participants' identities are not revealed when verbatim data are reported. Each participant will be given a unique identifier which does not contain and is not derived from her name. If women express serious dissatisfaction with the service they have received, the interviewer will ask whether they wish this to be fed back to the superintendent radiographer or not, and whether they wish their anonymity to be maintained in any feedback. In general, it will be made clear that the interviews are conducted independently of the service and that all data will be anonymised.

The study has been designed with the involvement of members of the screening service – radiography, management and administrative staff – which has helped to ensure the feasibility of the project within the service. A member of the public – a woman of breast screening age - has also contributed to the design, particularly regarding the methods for identifying, approaching and recruiting participants.

POTENTIAL IMPACT

This study is expected to have an impact in its own right, by advancing understanding among radiography staff and the screening community about how women experience mammography and how radiography staff might impact on the experience. In addition, it will form the basis for future quantitative work to measure the importance of individual factors affecting the quality of women's experiences of mammography. This in turn will lead to work to develop radiography-based interventions to improve the experience. Despite over 20 years of organised breast screening in the UK and around the world, there is a documented lack of effective interventions to reduce pain in mammography(14). This may be because research has been inconclusive on the most promising ways to target this but it may also be because researchers have not been sufficiently persistent in pursuing effective interventions. We do not believe that pain should be considered in isolation as it is only part of the story of poor experience. We do believe that poor experience, including pain, can lead to decisions to drop out of screening. It is increasingly being recognised that cumulative participation in screening is an important performance factor, as distinct from average or overall participation rates(15). This proposed project is the first step in a concerted effort to help address cumulative participation in breast screening. Early detection of cancer is currently a strategic priority for the UK governments as they strive to improve cancer survival rates. While this study focusses on screening mammography, it is expected that much of the learning

will also be applicable to the diagnostic setting.

DISSEMINATION STRATEGY

We aim to present this work at Symposium Mammographicum 2014. It will also be disseminated through the NHSBSP radiographers' group, through local networks which include public dissemination, and written up for publication. While the PI would favour Radiography as the most appropriate journal, there may be an imperative to take Impact Factor into account, and if so, The Breast or the Journal of Medical Screening may be deemed appropriate. We would be happy to take the committee's input on this, should this application be successful.

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