



ORIGINAL ARTICLE

Qualitative study of how women define and use information about breast symptoms and diagnostic tests

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Summary Unstructured interviews were conducted with 14 women with recent experience of diagnostic testing to explore the definition and role of information in women's experiences of undergoing diagnostic breast tests.

Analysis showed that women see information as more than what they are told by healthcare professionals. Information also comes from significant others, administration and reception staff, media, comparison with previous breast symptoms, silences, gestures and behavior of healthcare professionals and significant others, and the number of tests they undergo. Information is about more than understanding. It can provide support and control, reduce anxiety, facilitate question asking and promote women's trust and confidence in themselves and their healthcare professionals.

Healthcare professionals need to be aware that women define information more broadly than what they are told, and of the importance women attach to this other information. They also need to be aware that information serves more purposes than helping women understand the diagnostic testing process and their result.

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Introduction

Diagnostic breast tests include clinical breast examination, mammogram, ultrasound and biopsy. Far more women undergo diagnostic breast tests every year, than are actually diagnosed with breast cancer.^{1,2} Despite this, research in the area of women's breast health has mostly involved

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quantitative studies of women's information needs,³⁻⁶ quality of life,⁷⁻⁹ and psychosocial well being^{9,10} after a diagnosis of breast cancer. Such studies focus on the cancer experience and thus provide little, if any, information about women's experiences of diagnostic testing.

Research on the diagnostic testing period itself has focused on women's heightened distress,¹¹⁻¹⁴ which results from their fear of having breast cancer.^{12,15,16} Few studies have elicited women's experiences of diagnostic testing, or their preferences for information and support during this process. Existing studies have found that women use cues from healthcare providers and the testing environment to gauge the likelihood of cancer.¹⁷⁻²⁰ Some of these studies have included women with symptoms and screen-detected abnormalities in the same sample,¹⁷ without exploring the potential systematic differences between these groups, while others have included women with no personal experience of diagnostic breast tests.¹⁹ In addition, studies have generally used samples where every woman has undergone biopsy,^{17,18,20} even though most women who have diagnostic breast tests only have clinical breast examination and imaging. Thus the voices of the largest group of women undergoing diagnostic breast tests are missing from research to date. The aim of this study was to explore how women define and use information in the context of having any diagnostic tests to investigate a breast symptom.

Materials and methods

Participants

Women who were aged 18 years or older, had a current breast symptom (lump, lumpiness, change in the shape or feel of the nipple or breast, nipple discharge change or pain²¹), had been referred to the participating clinic, and did not require an interpreter.

Data collection and analysis

Due to the clinic's privacy policy and record structure, it was not possible to identify a purposive sample. Therefore a random sample of women derived from 89 participants in a larger quantitative study on information needs was invited to participate. This was achieved by assigning an ID number to each questionnaire and using randomization software²² to allocate ID numbers to the interview group. Women gave written consent

to be interviewed. They were telephoned one week after their appointment to arrange a telephone interview. Where women were not contactable or did not participate, the next consecutive woman was contacted. This continued until the women being interviewed provided no new information. In total 22 women were contacted, with 14 completing an interview, 2 declining, 1 being too ill, 3 being non-contactable, and 2 being unavailable during the study period. The small number of women needed to achieve information redundancy may in part be due to the clinic's set testing procedure.

HMD interviewed all women. Interviews were unstructured²³ and consisted of women telling their story from when the symptom was first noticed, with questions asked at the end to elicit further information or clarification. Interviews were conducted 7-27 days after appointments and lasted 30-90 min.

Tapes were transcribed verbatim by a professional transcription service and checked for accuracy. An interpretive approach to data analysis was employed, as appropriate for exploratory enquiry. This required an iterative approach to identifying emerging themes, initially based on women's own words. Following the analysis of three transcripts, the authors met to discuss emerging themes, with excellent agreement. Additional transcripts were read, analyzed and discussed, with a focus on identifying new themes and refining existing ones. Finally higher order themes encompassing several issues and illustrative quotes were identified.

The medical director of the participating clinic and The University of Sydney Human Research Ethics Committee approved the study.

Results

Participants

Participants' demographic, symptom, and test characteristics are summarized in [Table 1](#).

Themes

Information is more than what the doctor says

Verbal information

From women: Women generally gave limited information to significant others (partner, family, friends, and colleagues) about their symptom, tests and results. They gave healthcare professionals all potentially relevant health information.

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