



Patient Perception, Preference and Participation

Knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women diagnosed with ductal carcinoma in situ (DCIS)[☆]Simone De Morgan^{a,*}, Sally Redman^b, Catherine D'Este^c, Kris Rogers^b^a Faculty of Behavioural Science in Relation to Medicine, University of Newcastle, Newcastle, Australia^b The Sax Institute, Sydney, Australia^c Centre for Clinical Epidemiology and Biostatistics School of Medicine and Public Health, University of Newcastle, Newcastle, Australia

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ABSTRACT

Objective: To assess knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women diagnosed with ductal carcinoma in situ (DCIS) and to explore the factors associated with less knowledge and greater confusion about DCIS.

Methods: A cross-sectional survey of women diagnosed with DCIS in Australia ($N = 144$).

Results: This study found misunderstanding and confusion amongst women diagnosed with DCIS and a desire for more information about their breast disease. Approximately half of participants worried about their breast disease metastasizing; approximately half expressed high decisional conflict; 12% were anxious and 2% were depressed. Logistic regression analysis demonstrated that worry about dying from the breast disease was significantly associated with not knowing that DCIS could not metastasize (OR 3.9; 95% CI 1.03–14.25); and confusion about whether DCIS could metastasize was significantly associated with dissatisfaction with information (OR 12.5; 95% CI 3.8–40.2).

Conclusion: Good communication about how DCIS differs from invasive breast cancer is essential to alleviating the confusion and worry amongst women with DCIS.

Practice implications: Recommendations about how best to communicate a diagnosis of DCIS, including the uncertainties, are needed to guide health professionals to promote better understanding about DCIS and increase the well-being of women with DCIS.

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1. Introduction

The incidence of ductal carcinoma in situ has increased with the commencement and escalation of screening mammography worldwide [1,2]. Unlike invasive breast cancer, DCIS cannot metastasize and a woman cannot die from DCIS unless it develops into invasive breast cancer [3]. Some but not all DCIS will develop into invasive breast cancer if left untreated. The best estimates are that 14–53% of untreated DCIS may progress to invasive breast cancer over a period of 10 years or more [4]. However, the natural history of DCIS is not well understood and it is currently not possible to accurately predict which women with DCIS will go on to develop invasive breast cancer [5,6]. This uncertainty complicates treatment decision making for patients and doctors [4,6,7].

Studies suggest that women with DCIS may not fully understand their diagnosis and its implications [7–12]. A lack of

knowledge about DCIS may result in an unnecessary psychological burden on women and indeed women with DCIS have been found to experience similar levels of psychological distress to women with invasive breast cancer [10,11]. Research about the information needs of women with DCIS highlights that many are dissatisfied with the information about their diagnosis [7,8,13–15]. Any confusion about DCIS and its implications is likely to make decisions about treatment more difficult for women.

Previous research, using qualitative methodology, has explored women's understanding of their DCIS diagnosis, and their satisfaction with information and treatment decision making [7,11,13–15]. Quantitative studies have assessed knowledge, risk perceptions, psychological morbidity, and quality of life amongst women with DCIS. Women's satisfaction with information has been assessed in two quantitative studies in terms of satisfaction with 'information from doctors' and 'information related to future health problems'; [8] and satisfaction with 'information about the disease', 'information about surgery', and 'information about radiotherapy' [16], but there has been no research on satisfaction with information about the various aspects of the diagnosis and treatment in women with DCIS. While cancer-specific worry has been assessed in two quantitative studies in terms of the level of 'worry about getting breast cancer'; [8] and the level of 'intrusive or

[☆] I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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avoidant thoughts' in response to the diagnosis [8,12] no previous studies have investigated the frequency of worry about the various breast cancer-related events specific to DCIS. In addition, there is a lack of information about confusion relating to the diagnosis; or decisional conflict in women with DCIS.

We undertook a study to assess knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women diagnosed with DCIS. We were particularly interested in women who did not know that DCIS cannot metastasize or were confused about whether DCIS can metastasize as this has emerged as a central concern in previous qualitative work [7]. We therefore tested the hypotheses that (a) not knowing that DCIS cannot metastasize and (b) being confused about whether DCIS can metastasize, is associated with not receiving or not being satisfied with information about this aspect of the diagnosis; worry about dying from the breast disease or other breast cancer-related events; increased anxiety, depression, or decisional conflict; choosing a mastectomy; and a range of demographic factors (older age, residing in rural or remote area, lower education levels, not being employed, or having a non-English speaking background). We also collected qualitative data to improve understanding of the meaning of the quantitative results.

2. Methods

2.1. Study population

Women who were eligible to participate in the study were diagnosed with ductal carcinoma in situ (DCIS) in NSW, Australia, and were notified to the NSW Central Cancer Registry (cancer registry) over a 1 year period. Notification of cancer to the cancer registry is legally required of all pathology laboratories, hospitals and radiotherapy facilities in NSW. Women were excluded if they had a previous or simultaneous diagnosis of invasive breast cancer, or micro-invasive disease which the cancer registry codes as invasive breast cancer. In addition, women were excluded if they were deemed by their doctor to be too ill or unable to speak English adequately for the self-completed survey. Women were recruited to the study 6–12 months after their diagnosis.

2.2. Sampling and participation

Confirmation of the woman's eligibility for the study was sought from doctors who notified women to the cancer registry. Of the 290 women who were identified by the cancer registry, 234 were deemed eligible by their doctor to participate in the study. Eligible women were informed about the study and asked for their consent to having their contact details forwarded from the cancer registry to the study investigators. Consenting women ($n = 159$) were sent an information package and the survey. Non-responding clinicians and women were followed-up by a letter and two telephone calls. The number of returned completed surveys was 144. The overall response rate was 62%. There were no significant differences between participants and eligible non-participants according to age, area of residence, or country of birth. Ethics approval to conduct the study was granted by the NSW Cancer Council Ethics Committee.

2.3. Measures

2.3.1. Measures developed by the authors

The authors developed specific items about knowledge, confusion, satisfaction with information, worry about the DCIS diagnosis, and psycho-social support from the authors' previous study with women with DCIS [7] and an exhaustive literature review. The developed items were reviewed by a multidisciplinary

team that included surgeons, a radiation oncologist, a psychiatrist, a breast nurse, senior academic health researchers, and seven women diagnosed with DCIS including one woman who was actively involved in breast cancer support networks. The individual items were not intended to be combined into summary scores or scales. The kappa statistic was used to assess the test–retest reliability of the survey with 34 participants (24% of the sample) who were amongst the first 40 participants to return the initial survey. Seventy percent of the developed items scored above 0.50 in Kappa analysis [17].

Knowledge items were developed to assess whether women comprehended the nature of their diagnosis. Twelve knowledge items were included with response options: *true*, *false* and *don't know*; one of the items assessed knowledge about whether DCIS could metastasize and was selected a priori for inclusion in the logistic regression analyses. Confusion items were developed to assess the level and content of women's 'bewilderment' about aspects of their diagnosis. Confusion is distinct from knowledge and has been described as one of the dimensions of emotional distress [18,19]. Seven confusion items were included with response options: *very confused*, *a little confused* and *did not feel confused*; one of the items assessed confusion about whether DCIS could metastasize and was selected a priori for inclusion in the logistic regression analyses. Cancer-specific worry has been shown to be distinct from risk perception [20,21] and anxiety and depression [22,23]. Worry items were developed to assess the frequency of worry about breast cancer-related events specific to the DCIS diagnosis. Four worry items were included with response options: *rarely or never*, *sometimes or occasionally*, *often*, and *most of the time*. Information items were developed to assess participants' satisfaction with information. Eleven information items were included with response options: *I would have liked more information*, *I received as much information as I needed*, *I received too much information*, *I didn't want any information* and *I would have liked information*. Three psycho-social support items were developed to assess whether participants had the opportunity to consult with a counsellor, breast nurse, psychologist or psychiatrist and included *yes* and *no* response options. Open questions in most sections of the survey enabled participants to make additional comments.

2.3.2. Decisional conflict

Decisional conflict was measured using the Decisional Conflict Scale (DCS) [24]. The DCS is a 16 item Likert scale that has demonstrated validity and reliability in a variety of population groups. The scale has five subscales: certainty; informed; values; social support; and perceived effective decision. The overall scores and subscores range from 0 (no decisional conflict) to 100 (extremely high decisional conflict). Scores exceeding 37.5 are associated with delayed decision making and decision reject [25].

2.3.3. Anxiety and depression

Anxiety and depression were assessed using the 14 item Hospitalized Anxiety and Depression Scale (HADS), with scores of 11 or greater on the HADS anxiety and depression subscales considered indicative of substantial anxiety or depression, respectively, based on the validation of this measure [26]; and scores of 8 or greater (scores that included cases and doubtful cases) as they have been shown to improve the sensitivity of the HADS scale, particularly the HADS Anxiety Scale [27,28] and have identified patients with prolonged psychological distress [29].

2.3.4. Participant characteristics

Date of diagnosis; age; residence; first language; Aboriginal or Torres Strait Islander origin; education; relationship status; employment status; usual occupation; whether any close family

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