'Well, have I got cancer or haven't I?' The psycho-social issues for women diagnosed with ductal carcinoma *in situ*

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Abstract

Objectives To explore women's experience of being diagnosed with ductal carcinoma *in situ* (DCIS) in relation to the following: response to the diagnosis; understanding about the diagnosis; satisfaction with information; satisfaction with the level of involvement in treatment decision-making and satisfaction with support services.

Design An explorative descriptive qualitative design was used to facilitate an in-depth exploration of women's experiences.

Setting and participants Five focus group interviews were conducted in New South Wales (NSW), Australia, involving 26 women diagnosed with DCIS.

Results DCIS is a non-invasive breast disease, that in most cases will not recur if treated, and cannot of itself metastasize to other parts of the body. However, this study found that women were confused about whether or not they had cancer that could result in death. Women's confusion was compounded by the use of the term 'carcinoma' and by the recommendation of treatments such as mastectomy. Women's confusion was not alleviated by appropriate information, with most women reporting dissatisfaction with the information they received specifically about DCIS.

Conclusions This study identifies that a diagnosis of DCIS has a significant psychological impact on women. The communication challenges highlighted in this study are not only relevant to DCIS but to any other disease in which the natural history is uncertain and the evidence about treatment effectiveness is still emerging. Further research is needed in areas such as DCIS to explore the difficulties experienced in doctor–patient communication and their impact on patient outcomes, and how to optimize doctor–patient communication.

Introduction

In the last two decades, research has shown that good communication improves patient outcomes such as understanding,[1] satisfaction with care,[2] compliance,[3] physical health[4] and psychological adjustment.[5] Cancer patients place good communication high on their priorities of care.[6] Furthermore, the majority of malpractice allegations arise from a communication breakdown.[7] However, there is little research about doctor–patient communication in complex diseases such as ductal carcinoma *in situ* (DCIS) in which the evidence of benefit of treatment is limited and the natural history is uncertain.

DCIS is a proliferation of malignant duct epithelial cells without light microscopic evidence of invasion into the periductal stroma.[8] During the last decade as a result of screening mammography, the number of new cases of DCIS has increased substantiality. DCIS now represents approximately 12% of all breast cancer cases in Australia[9] and in the UK, DCIS represents 20–25% of malignancy detected at mammographic screening.[10]

DCIS represents a communication challenge for doctors for a number of reasons. First, the term 'carcinoma *in situ*' implies the progression of DCIS lesions to invasive breast cancer.[11] However, there is uncertainty about the natural history of DCIS.[9] DCIS is a complex disease that comprises a heterogeneous group of lesions with a diverse and not yet fully known malignant potential.[12] Indeed, some DCIS lesions, such as low grade DCIS lesions, may never progress to invasive breast cancer if left untreated. Limited historical data suggest that 20–35% of DCIS lesions will develop into invasive breast cancer.[13] Secondly, DCIS by itself cannot metastasize; although undetected areas of micro-invasion or disease recurring as invasive breast cancer *can* spread to other parts of the body. Thirdly, although DCIS is not an invasive breast cancer, women are often treated by mastectomy, especially if the DCIS lesion is widespread. Fourthly, although treatment for women diagnosed with DCIS now includes breast conserving surgery (lumpectomy) and radiotherapy, the evidence is still evolving about the effectiveness of different treatments for all types of DCIS lesions.[14,15] Uncertainty exists about which DCIS lesions may be left untreated, which DCIS lesions may be treated by breast conserving surgery, which DCIS lesions may need postoperative radiotherapy and which DCIS lesions may have such high recurrence rates that mastectomy is the preferred treatment. Therefore, it is not possible to fully inform a woman diagnosed with DCIS about her risk of developing invasive breast cancer with or without treatment.[16] Furthermore, most women who are diagnosed with DCIS do not know about DCIS prior to their diagnosis, particularly as they are not informed about the possibility of detecting the disease during screening programmes. A recent study reported that only 6% of women were aware that DCIS could be detected when deciding about screening.[17]

In addition, a diagnosis of DCIS may have a significant psycho-social impact on women given that research indicates that high levels of psychological distress occur after breast surgery and radiotherapy.[5,18] Research has also shown that women diagnosed with invasive breast cancer desire written and verbal information[19] and psycho-social support.[20] There is currently little research about the psycho-social issues for women diagnosed with DCIS[21–23] as highlighted in the literature.[24]

Given that there is little research about the communication and psycho-social issues for women diagnosed with DCIS, a qualitative methodology was considered most appropriate for this study in facilitating an in-depth exploration of the experiences of women diagnosed with DCIS.[25] This study explores women's experience of being diagnosed with DCIS in relation to the following: response to the diagnosis; understanding about the diagnosis; satisfaction with information; satisfaction with the level of involvement in treatment decision-making and satisfaction with support services.

Methods

Design

An explorative descriptive qualitative design was used to facilitate an in-depth exploration of women's experiences. Fifteen clinicians were invited to participate in the study because of their interest in breast cancer and their involvement in the treatment of women diagnosed with DCIS. Seven clinicians, including both surgeons and radiation oncologists, agreed to be involved in the study.

Clinicians sent an information letter and consent form to a consecutive sample of five women who had most recently been diagnosed with DCIS. Women were excluded from the study if they were diagnosed less than 6 months prior to the study, spoke poor English or were considered by their clinician to be too ill to participate. All correspondence with women contained the term 'breast disease' rather than 'DCIS' to prevent any confusion or alarm. Twenty-six women consented to participate in focus group interviews (Response rate = 74%). Five or six women attended each focus group.

Data collection

Five focus group interviews were conducted. Four of the focus groups were conducted in Sydney and one focus group was conducted in Orange, a rural town in mid-western New South Wales (NSW). All group interviews took place in July 1998. A discussion guide was developed for the focus group interviews by the authors, according to the aims of the study. The discussion guide was reviewed by a breast cancer consumer, who has extensive experience in providing information and support to women diagnosed with invasive breast cancer and DCIS, to ensure that questions were appropriate for this participant group. Questions were developed that might encourage the women to express their feelings in an uninhibited way and to facilitate the flow of discussion. All the focus group interviews were audio-taped. The metropolitan focus group interviews were facilitated by two authors (SDM, BC) to assure that all the issues in the discussion guide were discussed. The rural focus group interview was facilitated by one author (SDM). There was no evidence to suggest that the use of only one facilitator in the rural group affected the data collected.

Data analysis

The audio tapes from each group were transcribed verbatim. Content analysis of the data was then undertaken by the authors. Transcripts were read line-by-line and coded to capture the meaning of the data. The coding was then cross-checked to confirm that the same meaning was assigned to the codes. The codes were sorted, major and minor categories identified. These category descriptions were used to record women's perceptions of their diagnosis and their information and psychosocial support needs.

Results

Profile of participants

The study included a diverse group of women, as outlined in Table 1. Women were recruited from different socio-economic regions in Sydney. Due to the small numbers, the study does not attempt to represent the views of rural women ($n = 5$) or women from non-English speaking ($n = 1$) or Aboriginal and Torres Strait Islander ($n = 1$) backgrounds.

Findings

The findings of the study are described in five categories: response to the diagnosis; confusion about the nature of DCIS; lack of appropriate

Table 1 Demographic characteristics of participants in the focus group interviews ($n = 26$)

Demographic characteristics	%	*n*
Age		
<40 years	0	0
40–49 year	31	8
50–59 years	27	7
60–69 years	38	10
≥70 years	4	1
Education		
Secondary school (equivalent of <4 years secondary school)	15	4
Year 10/school certificate (equivalent of 4 years secondary school)	23	6
HSC/Leaving (equivalent of 6 years secondary school)	15	4
Technical colleges	15	4
University/colleges of advanced education	31	8
Marital status		
Married/*de facto*	92	24
Separated	4	1
Widowed	4	1
Work		
Employed/self-employed	46	12
Retired	15	4
Home duties	38	10
Time since diagnosis		
6 months	15	4
1 year	50	13
2 years	15	4
3 years	8	2
4 years	8	2
5 years	4	1

information; difficulty in treatment decision-making and lack of appropriate support services.

Response to the diagnosis

Most women reacted with shock to their diagnosis. Their response may have been compounded by DCIS being detected in largely asymptomatic women as part of a routine screening programme, as highlighted by one woman:

> I just couldn't believe it because I had never ever had a pain or ache or anything.

Confusion about the nature of DCIS

Although DCIS is a non-invasive breast disease that cannot of itself metastasize, women were confused about whether or not they had invasive breast cancer that could result in death:

> Well have I got cancer or haven't I?

The confusion surrounding a diagnosis of DCIS was influenced by the use of medical language such as the terms 'DCIS', 'ductal carcinoma *in situ*' and 'carcinoma'. Many women were confused by the terms 'DCIS' and 'ductal carcinoma *in situ*' and thought 'carcinoma' meant invasive cancer:

> They don't say cancer, do they? They say MISC or whatever it is. I don't even know what I had! They give it this initial and you think oh well that(s) alright, you know.
>
> But when they say the 'c' word you think, oooh.

Women's beliefs about the nature of their disease varied. Beliefs ranged from women thinking that they had an invasive breast cancer with a potential to metastasize, with one woman suggesting she should have scans of her whole body for metastases:

> My surgeon said 'The breast was riddled with cancer'.

to an early or a contained, non-invasive cancer or pre-cancer

> My surgeon said 'Yes, it's definitely cancer. It's in the milk ducts, which is all just contained'.

to a benign condition

> I was never told you had cancer or it could spread, or anything.

In this sample, women who thought they had invasive breast cancer described more distress associated with their diagnosis than women who thought they had a pre-cancer, a contained, non-invasive cancer, or a benign condition.

Lack of appropriate information

Most women in the focus group interviews expressed dissatisfaction with the amount of information, both written and verbal, they received about DCIS:

> They gave you plenty of stuff on breast cancer and radiotherapy and all those sorts of things but on the specifics of actual DCIS there wasn't a lot.

Some women were aware of the emerging nature of the evidence about DCIS:

> Because I think I'm at the cutting edge of research so not a lot of other information is available to say, well if you make this decision then this is likely to [happen], because we are creating that history, you know?

One woman's dissatisfaction about the lack of prognostic evidence affected her trust in her physician's competence:

> But you still feel at the end of the day it's inconclusive. Well I feel like I'm on some kind of see-saw of medical incompetence.

The lack of information provided about DCIS lead some women to seek information from various other sources such as the Internet, libraries and bookshops:

> I went to the feminist bookshop. I went anywhere I could think of that had stuff on women's health and particularly on DCIS. To find [information about] DCIS like I went through endless books.

Some women stressed the need for information to assist them in formulating questions to ask their clinician, particularly important for women wanting to participate in treatment decision-making:

> I think it is critical for women to get accurate, up-to-date information, whether its pamphlets or whatever… ...I've met some women who say 'I didn't think of any questions until after the operation or whatever. No one sat with me and explained a pamphlet or helped me formulate questions'.

Most women stressed the importance of thorough and clear verbal information provided by clinicians:

> I don't really think a pamphlet's the answer. I think somebody sitting down and talking to you one to one.

Although women were dissatisfied with the information about DCIS provided, the majority of women were very much satisfied with the psycho-social support they received from their primary clinician, such as their surgeon or radiation oncologist:

> She sits and talks to you as if you're her dearly beloved.
>
> He took time to get to know me and the family and he never stood over me.

Difficulty in decision-making about treatment

Some women experienced difficulty in treatment decision-making because of the uncertainty about the natural history of DCIS and the still emerging evidence about the effectiveness of various treatment options:

> The surgeon can't tell us a lot about what will be the long-term prognosis, its really hard for him to predict in 5 years time, or even in a years time.

The difficulty in treatment decision-making and the confusion about the nature of DCIS was compounded for some women by the use of mastectomy as a treatment option for DCIS. Mastectomy is a treatment used in invasive breast cancer and was considered by many of the women to indicate that their disease was an invasive condition. Some women were further confused by the promotion of breast conserving surgery (lumpectomy) to treat women with invasive breast cancer while they were recommended to have a mastectomy:

> I am having a mastectomy for this pre-cancerous condition. Am I really overreacting here or what's going on?

Lack of appropriate support services

Support services for women with invasive breast cancer in Australia usually include a volunteer service called the Breast Cancer Support Service (BCSS). The BCSS matches women previously diagnosed with invasive breast cancer or DCIS with newly diagnosed women to provide support and information on an individual basis. Currently, women are matched on the basis of age and type of treatment rather than the stage of the disease. Although most women's experiences of the support given by the BCSS were positive, some women in the focus group interviews felt that the BCSS was not appropriate for women diagnosed with DCIS:

> I saw a [breast cancer] volunteer here and she told me her story which was of no help to me at all because it was so different. Because what she had was a completely different cancer to me.

One woman was refused participation in a support group with women diagnosed with invasive breast cancer because of her diagnosis of DCIS:

> Well I rang [hospital] to see if I could join a support group and I was told I wasn't suitable because what I had was precancer.

Some women suggested that support groups specifically for women diagnosed with DCIS would be useful given the isolating experience of being diagnosed with DCIS. The experience of participating in the focus group interviews was expressed by all the women in the interviews as extremely rewarding in allowing them to share their stories and concerns, highlighting how valuable support groups may be in this population.

Discussion and conclusions

This small study used a convenience sample rather than a selected sample. Women were recruited by clinicians who were known to the National Breast Cancer Centre and had an interest in breast cancer. This group of women may have had greater access to information and support than is general among women diagnosed with DCIS. The interval from diagnosis for women participating in the study ranged from 6 months to 5 years. Although 65% of the women were interviewed 1 year or less since diagnosis, for some women, who were interviewed more than 1 year since diagnosis, their preferences for information and support may have changed over time as reported in the literature.[26]

Despite the limitations of this study outlined above, it is evident that a diagnosis of DCIS has a significant psychological impact on women. Most women in the focus group interviews were confused by the nature of their diagnosis. The confusion was compounded by the use of the term carcinoma *in situ* which for many women implied that they had an invasive breast cancer. Indeed, some pathologists have questioned the use of the term carcinoma *in situ* in a non-invasive disease with a diverse malignant potential.[11]

Given the confusion surrounding a diagnosis of DCIS, the complex nature of the disease and the difficulty in treatment decision-making, it is essential that women be given adequate information about DCIS, tailored to their particular situation. Research about women with invasive breast cancer has also shown that adequate information is related to increased psychological well-being[2] and that women who believe that they have been poorly informed were twice as likely to be depressed and/or anxious 12 months after diagnosis as those who thought they have been adequately informed.[5] Women diagnosed with invasive breast cancer have expressed a desire for written information about their diagnosis and treatment complemented by verbal information from their primary clinician.[27] Given the complexity of DCIS, women diagnosed with DCIS should receive written information about DCIS at the time of their diagnosis and clear verbal information that can be tailored to the needs of the particular woman and her type of DCIS lesion. Verbal information should be given in a manner that ensures ease of comprehension and clinicians should assess women's understanding during the consultation. Perhaps visual communication tools, which have been shown to be useful in other diseases including invasive breast cancer,[28] could be developed to assist clinicians to communicate a diagnosis of DCIS and help women decide about treatment.

The particular challenge for conditions such as DCIS is to communicate to patients the nature of the disease and information about available treatments while acknowledging the uncertainties and limited evidence about treatment effectiveness; this must be performed *without* increasing patients' anxiety, increasing their difficulty in treatment decision-making or decreasing their trust in their clinician's competence. Research has highlighted doctors' concern about the paucity of information about how best to communicate with patients where evidence is lacking[29] and the need for guidance about how to best communicate the implication of research findings to patients.[30] A programme recently developed in the UK to inform men about the uncertainties surrounding prostate specific antigen (PSA) testing for prostate cancer[31] may be beneficial for women diagnosed with DCIS and other diseases with uncertain natural history and limited evidence about treatment effectiveness.

Women's misconceptions about DCIS highlighted in this study may reflect the confusion even among health professionals about the nature of DCIS,[32] or the challenge in communicating complex information to patients or in patient recall of this information. Research is needed to investigate health professionals' understanding about the nature of DCIS; how best to communicate information to patients in conditions in which the natural history is uncertain and the evidence about treatment effectiveness is still being researched; and to develop methods to increase patient recall of complex information. An education programme for clinicians may also be needed to inform clinicians about current understanding and treatment recommendations for different types of DCIS lesions.

Women who are diagnosed with DCIS, in comparison with women who are diagnosed with invasive breast cancer, are more likely to be asymptomatic and therefore may be even less prepared for a diagnosis of a serious condition than women with invasive breast cancer. This may be further compounded by women not being informed about the possibility of detecting DCIS during a screening mammogram.[17] Some of the confusion about DCIS would also be prevented by educating health professionals and the healthy public about DCIS when offering screening programmes.

Psycho-social support can improve psychological well-being, social functioning and both treatment and disease-related symptoms.[20] Psycho-social support for women diagnosed with DCIS is important given the confusion surrounding a diagnosis of DCIS. As suggested in the findings of this study there is a need to develop information and support services specifically for women diagnosed with DCIS.

The communication challenges highlighted in this study are not only relevant to DCIS but to any other disease in which the natural history is uncertain and the evidence about treatment effectiveness is still emerging such as prostate cancer.[33] Further research is needed in conditions such as DCIS to explore the difficulties experienced in doctor–patient communication and their impact on patient outcomes, and how to optimize doctor–patient communication.

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