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The challenge of being diagnosed and treated for ductal carcinoma in situ (DCIS)

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Abstract

Following the introduction of the National Health Service Breast Screening Programme (NHSBSP) in the UK increasing numbers of women are diagnosed with ductal carcinoma in situ (DCIS). In DCIS, the cancer cells are confined to the ducts of the breast but considerable uncertainty surrounds the condition. Patients are often reassured that it is non-invasive and not life-threatening but they are recommended similar treatments to patients with invasive breast cancer. Little research has investigated the psychosocial impact of DCIS; therefore the aim of this qualitative study was to explore women's experiences of the condition. Semi-structured interviews were conducted with a purposive sample of 16 women previously diagnosed and treated for DCIS. Thematic analysis identified six key themes: 1) Invisibility of DCIS, 2) Uncertainty, 3) Perceptions of DCIS, 4) Acceptance of Treatment, 5) Social Support and 6) Moving On. The results highlight the substantial challenges faced by women diagnosed with DCIS. These findings have clear significance for healthcare professionals, especially specialist nurses, who work closely with DCIS patients.

Keywords: Ductal carcinoma in situ; DCIS; Illness perception; Support; Qualitative

Introduction

Since the NHS Breast Screening Programme was established the rates of diagnosis of ductal carcinoma in situ (DCIS) have increased dramatically and now represent 20% of screen-detected cancers in the UK (NHSBSP, 2006). DCIS is a non-invasive breast condition where cancer cells are confined to the ducts of the breast (Leonard and Swain, 2004). Following treatment most patients have an excellent prognosis and few will ultimately die of breast cancer (Ernster et al. 2000).

However, although a diagnosis of DCIS is not indicative of a life-threatening condition, this does not necessarily imply that patients endure less psychological distress. Instead, 'different' psychosocial problems may occur (Wellisch, 1997) which may be due to a number of issues. Firstly, as DCIS is commonly detected asymptomatically it is often unanticipated (Hamilton, 1992) and the majority of women are unaware that the condition exists (Schwartz et al., 2000; Prinjha et al., 2006). The natural history of DCIS remains poorly understood because most patients receive surgery (Erbas et al., 2006); currently therefore it is difficult to accurately predict the risk of developing invasive breast cancer with or without treatment. Treatment options for DCIS are also controversial but involve surgery, possibly radiotherapy and hormone therapy. Therefore, ironically patients may be reassured that the condition is non-invasive and not life-threatening yet the treatment offered is similar to invasive breast cancer (Webb and Koch, 1997).

In contrast to invasive breast cancer, there is scarce psychosocial research specifically focusing on DCIS (Carrera and Payne, 1999). Anecdotal reports propose that the favourable prognosis should result in lower levels of psychosocial concerns

(Hoffman, 1997). However, Rakovitch et al. (2003) found that despite the generally positive outlook, DCIS patients expressed serious concerns and similar psychological morbidity to patients with invasive breast cancer. Research also suggests that women are confused about DCIS (De Morgan et al., 2002), have deficient knowledge about the condition and worry about their future cancer risk (Bluman et al., 2001).

Aim

The small number of previous studies highlights the limited understanding of the psychosocial impact of DCIS. Therefore, a qualitative exploratory study with patients previously diagnosed with DCIS was designed, with the aim of investigating women's experiences of the condition, in order to inform the provision of appropriate support and future research.

Methods

Design

A qualitative approach was employed because of the exploratory nature of the study and the lack of existing research in the area. The use of a qualitative approach is endorsed by Carrera and Payne (1999) who recognise its value and appropriateness in enabling a detailed understanding of DCIS. Qualitative interviews are also encouraged when researching sensitive areas such as this, because they allow participants to describe and validate their experience (Mathieson, 1999). The key objective of the study was to gain

an in-depth account of women's experiences of DCIS, thus exploring their 'lived experiences' of the condition and following a phenomenological approach which maintains that each person has a unique view which is meaningful and valid (Streubert and Carpenter, 1995). Furthermore, this approach was considered important prior to embarking on more detailed studies (see conclusion section for further details).

Recruitment

Women who had previously been diagnosed with DCIS were recruited through various media, including adverts on the websites and newsletters of relevant support organisations (Breast Cancer Campaign and Breast Cancer Care). Interested volunteers contacted the researcher (first author) for further information. The inclusion criterion was women who reported a diagnosis of DCIS in the UK within the last 10 years but were at least 6 months post-diagnosis. Non-UK patients and those diagnosed over 10 years previously were excluded because clinical policies and treatment protocols may differ (between countries and over time). As the study was exploratory and retrospective, to have included women less than 6 months post-diagnosis may have reduced their ability to reflect on the whole experience. Furthermore, the final selection of interviewees were selected using purposive sampling to reflect the diversity of detection and treatment experiences within DCIS, thus aspires to the qualitative paradigm (Barbour, 2001).

Participants

16 women participated in the study. The majority were married (n = 11) and ranged between 39 and 74 years of age (average age 52.5 years). Average time since diagnosis

was 41 months (ranging from 8 to 108 months). Seven participants were diagnosed asymptomatically by routine screening, seven found a lump or symptom (e.g. pain) and for two it was an incidental finding during clinical investigation of the contra-lateral breast. Participants had been treated in a number of hospitals across the UK. Several had undergone multiple procedures, but the final treatments were mastectomy (n = 4), mastectomy with reconstruction (n = 6; 5 immediate, 1 delayed) and wide local excision (WLE) or lumpectomy (n = 6; 2 with radiotherapy).

Interviews

Semi-structured interviews were conducted in participants' homes by the first author who had previous experience of conducting qualitative interviews with oncology patients. The interviews lasted an average of 50 minutes. An interview schedule developed from previous research (De Morgan et al., 2002; Carrera, 2000; Mathieson and Stam, 1995) guided the interviews. The acceptability and suitability of the schedule was established by two key informants who had previously been treated for DCIS. The areas explored included the experience of diagnosis, treatment, decision-making, information and care. Topics were deliberately kept broad to allow women to tell their own stories. Further detail of the schedule is available from the first author.

Ethics

Ethical approval for this study was achieved from the university ethics committee. Participation in the study was voluntarily and a written informed consent was obtained from participants prior to the interview, and their right to withdraw from the study, at any time, was highlighted.

Rigor

To enhance the validity of the study findings a number of techniques were used (Barbour, 2001). Analysis was primarily carried out by the lead author, however, a random selection of the transcripts were additionally coded (by three independent researchers and the second author) in order to verify the analysis. This revealed similar codes and themes. A summary of the study themes was also sent to participants for member checking.

Data analysis

The data was transcribed verbatim and analysed with inductive thematic analysis using the guidelines specified by Braun and Clarke (2006). This method uses a systematic and transparent process to identify, analyse and report patterns within the data (Boyatzis, 1998; Braun and Clarke, 2006). This involved reading and rereading the transcripts, noting and formulating codes into emergent major themes. This technique was suitable due to the lack of existing research and enabled a rich account of the experience of DCIS.

Findings

Six key themes were identified in the analysis: 1) Invisibility of DCIS, 2) Uncertainty, 3) Perceptions of DCIS, 4) Acceptance of treatment, 5) Social support, and 6) Moving on. These will be discussed using exemplars from the interviews. To maintain anonymity all identifying features have been removed and pseudonyms are used throughout.

Invisibility of DCIS

Reactions to the diagnosis primarily entailed shock and distress. This was shared by all the women, but appeared especially prominent in asymptomatic patients:

> if you find a lump…in the days or weeks between finding the lump and getting in front of a surgeon you've had all sorts of things going through your head and you're vaguely prepared ('Sue', aged 46)

Most women initially expressed indifference when they were recalled for further tests or at the first sign of a problem. Therefore most were ill-prepared, the diagnosis was unexpected and the shock was enhanced by the invisibility of DCIS and because they felt fit and healthy, not ill. Several women were shown the area of concern on the mammogram and some requested a copy of their pathology report, which helped them to visualise the DCIS:

> I did ask about getting pathology reports…it's almost like a physical thing to look at, to take in what's been invisible ('Lisa', aged 49)

Some women described being ignorant about the possible outcomes of screening and others claimed that the information supplied before breast screening should mention the possibility of DCIS being discovered. Thus, the invisibility of DCIS extends beyond the lack of physical symptoms and relates to a lack of awareness both individually and universally of the condition, especially within the screening service:

> breast screening literature really ought to make it clear; women…don't know about DCIS…we need to know before that so that we're prepared ('Denise', aged 55)

The majority of women had never heard of the condition prior to their diagnosis - only one participant had been aware of it. Even among those who had symptoms, the diagnosis of DCIS was still foreign to them. It is possible that the invisibility of DCIS intensified the shock and distress experienced.

Uncertainty

Uncertainty resonates throughout the women's accounts of condition itself and the information available.

The terms used to depict the condition varied considerably but included 'breast cancer', 'early cancer', 'in situ', 'pre-malignant', 'ductal carcinoma in situ', 'DCIS',

‘abnormal cells’, ‘non-invasive’ and ‘pre-cancer(ous)’. This reveals the diverse language used by different healthcare professionals and in the information literature. One woman who had several second opinions said:

> I’ve found that each hospital does have…different terms for it (‘Nicola’, aged 41)

This contributed to confusion, uncertainty and difficulty understanding the diagnosis:

> I was having serious trouble, as I was discovering more about DCIS, about what it meant, whether it was really cancer…why I had to…loose my whole breast (‘Mary’, aged 74)

Women also recognised the uncertainty that their diagnosis was ‘only’ DCIS since there was still a possibility of invasive cancer being identified:

> relieved that they don't think it's invasive, but it might be. They won't know actually until they do the surgery, so that sword is still hanging over your head (‘Mary’, aged 74)

Unfortunately the information provided did not alleviate this uncertainty. Although most women reported receiving basic information about DCIS, this was often limited to the first consultation or one leaflet amongst others that focused primarily on invasive

breast cancer. Most women emphasised that information was absent, limited or contradictory, thus leaving them with further ambiguity:

> something in the literature that you read is…'women are confused about DCIS' and that makes me terribly angry, we're not confused…we're given confusing information…the information isn't there or seems contradictory ('Denise', aged 55)

Some women acknowledged the lack of scientific evidence, especially about the invasive potential of DCIS, which was a great concern. Uncertainty was also evident in reports of discrepant treatment advice from different professionals:

> having thought I needed radiotherapy all the way through, to then having this blip where I thought maybe I didn't ('Lisa', aged 49)

This inconsistent and often scarce information fuelled the women's confusion and desire to undertake independent research into the condition. Most expressed this need, the majority in response to the unfamiliarity and uncertainty surrounding DCIS. Women searched extensively for information from experts, the internet, journals and books. This process was described as empowering, and was seen as essential to make informed decisions and understand the necessity of the treatment. However, even following this research a number of women acknowledged that the answers to some of their questions remained unknown:

> the question that somebody diagnosed with DCIS wants to know…what are the risks of this, for me, turning into invasive cancer? And we've got no information to give them, why, because as soon as anybody's diagnosed with this it's cut away ('Mary', aged 74)

However, women also acknowledged the difficulty in providing the right balance of information to meet individual needs. Suggestions were made about giving basic details and directing patients towards approved websites, books or articles. Above all, receiving honest information about DCIS was emphasised, including recognition of the current uncertainties.

Perceptions of DCIS – 'Breast cancer or not?'

Several perceptions of DCIS emerged across the interviews, specifically whether women viewed the condition as breast cancer or not. This related to attitudes towards treatment, decision-making and support. The theme also extends to the reactions and attitudes of those surrounding the patient, thus where relevant, the women's comments about others' views of DCIS are included in this theme.

Breast cancer

A number of women described how they simply saw their diagnosis as *'breast cancer'*, but perhaps emphasised that it was a different or lesser type of the disease:

> as far as I was concerned it was just a different sort of breast cancer ('Carol', aged 50)

Given that many of the women were given little specific information about DCIS and it was often included alongside general breast cancer literature it is not surprising that they expressed this view of their diagnosis. These women frequently felt relieved that their condition was detected at an early stage. Some participants indicated the importance of breast screening and others were thankful that they had followed their instincts about their symptoms. These appraisals indicate further their view of the condition as breast cancer, and most of these women readily accepted the treatment offered.

DCIS was generally viewed by family and friends as 'breast cancer', as they tended to focus on the treatment offered. This may reflect the lack of awareness and the complexity of DCIS for others:

> There's very little information in the public domain…we need our own Kylie, to have a DCIS, to say I've had DCIS so people become more aware ('Kate', aged 50)

Not 'real' breast cancer

Other women maintained that DCIS was '*not real breast cancer'*, rather it was:

> this mismatch…you fall between normal and cancer ('Kate', aged 50)

These women often acknowledged the possibility that the DCIS could develop into 'real' breast cancer in the future and they considered this risk to be a strong reason to undergo treatment, almost as a preventative action. However, this perception sometimes impacted on the women's feelings towards their diagnosis. Two women described the conflict within themselves in their reaction to something that was not 'real' cancer:

> one of the things I felt was guilt…because I was reacting emotionally in a way that I thought was disproportional to something that was nothing ('Kate', aged 50)

Women openly compared themselves to patients with invasive breast cancer, in that they had endured similar surgery and expressed how they also needed support. However, despite this, some felt that they, unlike those with invasive disease, were not entitled to use resources or request staff time because they didn't have 'real' cancer:

> I wasn't…ill enough to be using the hospice resources…one of the women had had exactly the same treatment as me but she'd had invasive cancer ('Lisa', aged 49)

Furthermore, one participant reported her worry of how to describe the condition to others:

> whether you say you've had breast cancer or not, because technically I haven't… because it wasn't invasive…it's daft to say 'well I haven't had breast cancer but I've had a mastectomy anyway' ('Denise', aged 55)

Pre-cancer

Finally, three participants emphatically conveyed that:

> it isn't cancer, its pre-cancer ('Jacky', aged 45)

This view often reflected what they had read about DCIS or the description they had been given by health professionals. These women often stressed the uncertainty about the risk in an optimistic way, for example that it may never develop into invasive cancer:

> I latched on to it in a 'yeah but it might not way' rather than, another woman might think 'what do you mean it could…bloody hell I'll get rid of this now'...my mind just went the other way ('Nicola', aged 41)

However, this perception created specific difficulties when a mastectomy was advised:

> we saw a doctor who said 'you don't have breast cancer'…'but we're going to offer you a mastectomy'. And that really seemed a paradox ('Denise', aged 55)

This links to the women's belief that treatment is paradoxical (see next theme: "Acceptance of Treatment"):

Contrasting perceptions

Participants reported considerable variation in how health professionals viewed and described the condition, but one of the strongest feelings that emerged was that, at times, the medical staff treated their diagnosis as inferior:

> it's not exactly that you're a second class citizen but…I don't think you're afforded the same concern ('Sue', aged 46)

An underlying feeling expressed by several women was that because they 'only' had DCIS, they were 'lucky'. However, some challenged this because, like those with invasive disease, they had undergone extensive treatment:

> a lot of us are told when we are diagnosed with DCIS…that we are lucky. We're very fortunate…when you are feeling absolutely depressed like you've been hit with a sledgehammer…you should feel lucky, when you don't ('Mary', aged 74)

This trivialisation was generally described as unfair and unhelpful. Most women accepted that DCIS was not as serious as invasive breast cancer but, to them, it was still a difficult, uncertain time and they needed sensitivity and support from the healthcare professionals:

> alright it's not full blown stage four breast cancer, but to every woman who hears a diagnosis like that it might as well be…we all need them ('Kathy', aged 50)

One participant described that this made it difficult for her to seek much needed support:

> might be only DCIS but look what you've done to me…it made it difficult…to seek after the right support because you kind of felt that women with 'real' breast cancer should get that…was difficult, you kind of just shut up and got on ('Sue', aged 46)

However, equally distressing for two women were the medics who curtly regarded their DCIS as 'breast cancer'. Interestingly this contradicted the women's own perception that it was pre-cancer, and this conflict may have prompted their dissatisfaction:

> I can't see why if this isn't breast cancer…, I need a mastectomy…she [nurse] was very brusque 'you just see it as a tumour…it has to go' ('Denise', aged 55)

Therefore, it appears that difficulties arose when a mismatch was present between the women's perception of the condition and how others, particularly health professionals, viewed DCIS and interacted with them.

Acceptance of Treatment

Acceptance of treatment appeared to be strongly linked to the women's perception of DCIS and the uncertainty surrounding the condition. This can be conceptualised along a continuum; at one extreme some were reluctant to undergo surgery and stressed the paradox this presented; whereas others readily accepted the treatment.

Paradox

The conflict between the favourable prognosis of DCIS and the recommended surgery was highlighted. This paradox was predominantly upheld by those who perceived it as a pre-cancer (links with previous theme "Perceptions of DCIS") and were offered a mastectomy:

> I very probably only had…pre-cancer and yet they want to treat it more surgically, more radically than, it just doesn't seem to make sense to me ('Nicola', aged 41)

A few women further emphasised this irony when comparing themselves to patients with invasive disease who sometimes had less extensive surgery. Accusations of overtreatment were expressed by some alongside emphasis of the medical uncertainty. This conveyed a strong sense of distrust in the health professionals and medical world:

> they've got a technology which identifies changes in cells which might be something and therefore they have to give you the worst of the treatment…because they don't know what else to do ('Mary', aged 74)

One woman described that she still finds herself questioning the mastectomy she underwent (now almost 2.5 years post-treatment):

> I can't reconcile the two things, I am grateful not to have breast cancer…but somewhere deep inside I don't understand why I had to have that operation ('Denise', aged 55)

Interestingly, four participants delayed their treatment while they researched the condition. All of these women emphasised the paradox, three strongly argued that DCIS is pre-cancer and that they were willing to take the risk. After much deliberation, and often turmoil, most accepted the treatment. One developed an invasive cancer and others realised they could not live with any continued uncertainty. However, these women often felt "railroaded" into the system and expressed that the initial urgency to undergo treatment was unnecessary due to the early stage of DCIS.

Acceptance

In contrast, some women readily accepted the treatment. The perceived risk was often the main focus for these women:

> 'if there is anything there, I don't want it there...get rid of it ('Ellie', aged 39)

Furthermore, unlike the previous group, although uncertainty was prominent it was viewed more pessimistically. Some recognised the possibility that an invasive cancer might be detected during the surgery to remove the DCIS and most could not accept the implications of declining treatment:

> If I didn't have any treatment…I was going to live with the uncertainty ('Emma', aged 59)

Most women pursued and trusted the surgeon's advice, although two participants chose a mastectomy which was not initially suggested. Other decisions reflected fears concerning the toxicity of radiotherapy and the availability of reconstruction after mastectomy.

Social Support

Many women described positive care and support received from health professionals:

> I was treated with enormous compassion and respect at every point…I felt I was very much part of the process ('Emma', aged 59)

However, some had mixed experiences and a few endured difficulties with at least one member of their medical team. Some felt that the professionals were solely focused on medical issues which left them feeling unsupported in relation to emotional needs:

> The minute I shed a tear he [surgeon] was out of the door…he was very detached from the emotional side (‘Carol’, aged 50)

As previously discussed many indicated they felt their diagnosis was treated trivially, and this prompted some to feel excluded from the support services:

> I didn’t feel like I…was entitled to have that breast care nurse really, although she was assigned to me (‘Lisa’, aged 49)

Women frequently described the shock and distress of the diagnosis for their family, which was often linked to others viewing DCIS as breast cancer and therefore support was given accordingly:

> everyone else was afraid then that I was going to die of cancer…because nobody knew what the DCIS was (‘Jane’, aged 52)

This social support helped most to cope; however a few described the negative implication of others viewing their diagnosis as breast cancer. Some found it difficult to talk about their diagnosis, and one woman recounted that the kind support she had received from others made her feel guilty:

> a fraud…people know you’ve got this breast cancer diagnosis and they are all concerned as they would be if you had ‘real’ breast cancer (‘Mary’, aged 74)

Many participants felt that peer support could have been improved; especially contact with other DCIS patients:

> I never, never saw face-to-face anybody who'd ever had DCIS, which was a disaster because that was who I needed to talk to ('Mary', aged 74)

This was portrayed as being in contrast to the availability of breast cancer networks. 'Mary' was later involved in encouraging the inclusion of DCIS in various support websites (Breast Cancer Care; DIPEx). These recent developments of DCIS specific support were acknowledged favourably by other participants:

> get on the website…it was my bible going on there…anytime of the day or night and someone's always there to give you…push you along ('Ellie', aged 39)

A few women found it helpful to speak with patients with invasive cancer or attend breast cancer support groups. However, others felt the issues were very different and reported the difficulty of discussing DCIS with patients with invasive disease:

> I've contacted a number of DCIS patients who, like me, find it really quite difficult to discuss breast cancer with women who've had other breast cancer diagnoses and not DCIS ('Mary', aged 74)

This highlights that the women viewed themselves as different to patients with invasive disease and most emphatically agreed that being able to share their feelings in DCIS specific support groups would have helped reduce the isolation of this diagnosis.

'Moving on' following DCIS

Although some participants appeared to have adjusted well, others expressed concern relating to the ongoing implications of their DCIS diagnosis. These concerns are categorised as psychological, physical and attitudes towards breast screening.

Psychological

Women talked vividly about the initial period of shock being a surreal time and some experienced feelings of denial at this stage. Many stressed it was not easy to forget, some were prescribed anti-depressants or counselling and most spent a considerable time afterwards reflecting and trying to move on.

Likewise, anxiety about recurrence was frequent and continued long after the treatment had ended:

> it never leaves you…four years on I still think oh god…is that something ('Ellie', aged 39)

Changes in identity, both positive and negative, were also evident. Some spoke avidly about positive changes in attitude, increased empathy and personal strength; however others disclosed lingering feelings of self-doubt and reduced self-confidence:

> I'm a more anxious person now, so I think somewhere in the whole process I have changed. Part of it might just be that it pricked my little bubble of invulnerability ('Denise', aged 55)

Finally, some expressed that the diagnosis had forced them into a medical category that subsequently informed health choices and affected interactions with medical staff.

Physical

Appearance concerns were evident for several women across surgical categories. Although some were pleased with the end result; others were very conscious about their appearance:

> I can't wear the sort of the bras I used to wear and that's something I do feel quite sad about because…my body doesn't feel quite the same now ('Lisa', aged 49)

Physical problems were also described, primarily among mastectomy patients, including difficulties with prostheses, stiffness, pain and discomfort:

> the repercussions of that diagnosis have been immense on my life because I feel… physically disabled in a lot of ways, there are a lot of things I can't do now ('Jacky', aged 45)

Attitudes towards breast screening

For some women the experience had undoubtedly influenced their feelings towards breast screening. Some endorsed the importance of screening because it detects abnormalities early. However, scepticism and negativity were also evident. One woman described how the disillusionment has prompted her to decline any future appointments, she explains:

> I've taken a shot in the dark…why do I want to go to be told that I've got white spots on my breast, when all I know about these white spots…it's so uncertain and making you ill when you're probably not ill, that I don't want to put myself through that again ('Mary', aged 74)

Discussion and implications for nursing

The six themes in this study primarily suggest that DCIS is a challenging diagnosis. In spite of the relatively good prognosis, women's accounts reveal that for some, the experience is distressing and the implications are long-term, resulting in personal difficulties 'moving on' from the experience. The findings support the growing evidence that DCIS patients do not face 'less' distress (Rakovitch et al., 2003) but encounter different stress and emotions compared with those diagnosed with invasive breast cancer (Wellisch, 1997). This study identified a number of key issues which should be recognised and could inform future care and support in order to help DCIS patients adjust following the diagnosis and treatment.

Many of the difficulties reported reflect the considerable uncertainty surrounding the condition. In addition to the absence of prior awareness of DCIS, the uncertainty and lack of specific information created much confusion and distress. Similar findings have been reported by De Morgan et al. (2002) and Bluman et al. (2001). Therefore it seems justified, and in line with previous commentary (Thornton, 1997), that raising awareness of DCIS in general and particularly before screening should be carefully considered so that women are more prepared and aware of the condition.

It is widely accepted that most women with invasive breast cancer require adequate information to help them accept and adjust to the diagnosis (Graydon et al., 1997) and this can enhance psychological well-being (Okamura et al., 2003). This study suggests that DCIS patients have similar needs, requiring accurate and sufficient information to facilitate adjustment, but importantly in the case of DCIS, information is needed particularly to achieve an understanding of an unfamiliar and complex condition. The lack of clear information prompted many women to search independently; hence there is a need to determine the best way to provide reliable and adequate information to patients in light of the current ambiguities. In Australia, the National Breast Cancer Centre (NBCC) has produced a comprehensive publication specifically about DCIS (NBCC, 2004) and similar possibilities in the UK and elsewhere in Europe should be explored.

Women in the study held diverse perceptions about the condition (De Morgan et al., 2002) that appeared to have an impact on their adjustment; especially feelings towards treatment, interactions with health professionals, information and support. The findings imply that perceptions of DCIS could influence acceptance, and previous

research suggests that inaccurate perceptions can increase psychosocial distress (Buick, 1997; Cameron and Moss Morris, 2004). Leventhal et al. (1980) proposed that illness perceptions develop from a variety of sources, such as the treatment, communication, information and past illness experiences. Their views seem very relevant to DCIS.

In the context of clinical practice it may be beneficial for health professionals to explore how patients perceive DCIS. This could help to identify those individuals who require more support and resources could be tailored accordingly. For example, a patient who views DCIS as 'not breast cancer' may require more time and guidance to understand the condition and treatment options. It is also imperative that caution is exercised in how DCIS is described and that the terminology used by different sources (e.g. health professionals, clinic and wider literature) is consistent to help reduce some of the confusion that can accompany the diagnosis (Fallowfield, 2007).

The significance of appropriate support and sensitivity from the healthcare staff involved with DCIS patients is crucial. This is especially important due to the unfamiliarity and uncertainty of DCIS and patients may require more assistance in order to understand and accept the condition. Reassurance and positivity is beneficial because patients should recognise that the outlook for DCIS is favourable (Hoffman, 1997; Brown et al., 2000) but the women in this study emphasised that they still needed support and this should be recognised. It is evident that any mismatch between the patient and health professional views is undesirable. This was also highlighted by Bluman et al. (2001) and previous research indicates that this may be detrimental to doctor-patient relationships and a barrier to effective communication (Buick, 1997; Heijmans et al., 2001). The present findings suggest that these sorts of conflict were a source of considerable distress for some women.

Finally, the value of peer support is emphasised by this study. Some women found contact with patients with invasive disease was beneficial (Brown et al., 2000); whereas others noted that support from other DCIS patients would be more valuable (alike De Morgan et al., 2002). It cannot be assumed that the similarities in treatment will bond these two groups and this study indicates that DCIS patients can be conscious of the differences. In terms of clinical practice, specifically tailoring support resources for DCIS may be favourable and would be readily accepted by those affected.

Limitations

While the current study provides some important insights into the experience of being diagnosed with DCIS, several limitations are evident. Firstly, all the women self-selected and self-reported a previous DCIS diagnosis, thus volunteer bias may be present and the participants may differ to non-responders. Although participants were carefully selected on the basis of the medical details they disclosed, without accessing the women's medical records the diagnosis of DCIS cannot be definitively verified. It is therefore acknowledged that the results may not be representative of all DCIS patients.

Conclusions

DCIS presents an unfamiliar and uncertain condition that can be a challenging diagnosis for those affected. The areas explored in this paper highlight a number of key issues and emphasise the need for further research to explore the psychosocial impact of DCIS.

In particular, future research should involve prospective, longitudinal studies following DCIS patients from the time of diagnosis (which is currently being undertaken and further details are available from the first author), in order to more fully inform future patient care and support services.

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