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The shifting nature of women's experiences and perceptions of ductal carcinoma in situ

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ABSTRACT

Aim: This paper is a report of a descriptive qualitative study of the evolution of women's perceptions and experiences of ductal carcinoma in situ from the period near to diagnosis to one year later.

Background: Ductal carcinoma in situ is a non-invasive breast condition where cancer cells are detected but confined to the ducts of the breast. With treatment, the condition has a positive prognosis but ironically patients undergo treatment similar to that for invasive breast cancer. There is a lack of longitudinal qualitative research studying women's experiences of ductal carcinoma in situ, especially amongst newly diagnosed patients and how experiences change over time.

Methods: Forty-five women took part in an initial interview following a diagnosis of ductal carcinoma in situ and twenty-seven took part in a follow-up interview 9-13 months later. Data were collected between January 2007 and October 2008. Transcripts were analysed using a hybrid approach to thematic analysis.

Findings: Women's early perceptions of ductal carcinoma in situ merged and sometimes conflicted with their lay beliefs of breast cancer. Perceptions and experiences of the condition shifted over time. These overriding aspects were evident within four themes identified across the interviews: 1) perceptions of DCIS versus breast cancer, 2) from paradox to acceptance, 3) personal impact, and 4) support and interactions with others.

Conclusion: This study represents one of the few longitudinal qualitative studies with newly diagnosed patients, capturing women's initial and shifting experiences and perceptions of the condition. The issues identified need to be recognised in clinical practice and supported appropriately.

Keywords: ductal carcinoma in situ (DCIS); breast cancer; illness perceptions; breast care nurses; communication; information; support

SUMMARY STATEMENT

What is already known about this topic

- Ductal carcinoma in situ is a complex condition – patients are reassured it is non-invasive and is not life-threatening, but they are often offered extensive treatment similar to that used to treat invasive breast cancer
- Mixed results have been reported in the small amount of psychosocial research exploring women's experiences, but this work has often been retrospective and conducted post-treatment
- Little in-depth qualitative longitudinal research has been conducted in the period near to diagnosis

What this paper adds

- Women's perceptions of ductal carcinoma in situ are diverse, merge and sometimes conflict with their lay beliefs of breast cancer, which can lead to difficult feelings and experiences
- Women's perceptions and experiences of ductal carcinoma in situ shift and develop over time during the diagnosis, treatment and post-treatment period as they interpret various cues encountered in their experience
- Four key issues were identified relating to women's perceptions of the condition, their feelings about treatment, the personal impact of the diagnosis and treatment, and interacting with others

Implications for practice and/or policy

- Clinicians should carefully consider the language they use to describe the ductal carcinoma in situ. Further work should explore the potential for the development of clear, coherent and flexible communication guidelines for clinicians
- There is a need for the provision of appropriate and tailored help, support and information in clinical practice to meet the specific and evolving needs of women diagnosed with ductal carcinoma in situ
- Further research should continue to determine the most appropriate care, support and information for this group of patients

INTRODUCTION

Since the introduction of routine breast screening, ductal carcinoma in situ (DCIS) has been increasingly detected in the UK and elsewhere (Houghton et al. 2003), and now represents around 20% of screen-detected breast cancers (National Health Service Breast Screening Programme (NHSBSP) 2008, NHSBSP 2006). DCIS is a non-invasive condition where cancer cells are contained in the ducts of the breast (Leonard & Swain 2004), but uncertainty surrounds its natural history, particularly whether it would progress into invasive breast cancer (IBC) if untreated (Erbas et al. 2005).

This has created two factions within the medical community (Graff, 2010). Some view DCIS as a carcinoma in situ, emphasising that the majority of cases have a high risk of progression (Evans et al. 2001) and require detection and treatment to reduce the incidence of IBC (Cady, 1998). However, because DCIS has not invaded into the surrounding breast tissue, others view DCIS as a pre-cancerous condition (Dell, 1997). Some argue that the rise of DCIS detection constitutes an overdiagnosis (Baum, 1995) and that many cases would never develop into clinically life-threatening IBC during the patient's lifetime (Mittra et al. 2000).

With treatment most DCIS patients have an excellent prognosis (Ernster et al. 2000), but treatment is controversial because it is similar to that offered for IBC (including mastectomy, and possibly radiotherapy and hormone treatment). Therefore, paradoxically patients are reassured that the condition is contained and not life-threatening, whilst recommended to undergo extensive, invasive treatment (Webb & Koch 1997).

BACKGROUND

Although research investigating the psychosocial impact of DCIS has emerged in Europe, Australia, Canada and the United States, it has received much less attention than IBC (Carrera & Payne 1999; Ganz, 2010). Some studies suggest that DCIS patients recover and adjust relatively easily (Webb & Koch 1997, Nekhlyudov et al. 2006), possibly owing to the positive nature of the condition and reassurance received from health professionals. However, several quantitative studies in the US and Canada indicate that DCIS patients can experience similar levels of distress to IBC patients (Lauzier et al. 2009, Rakovitch et al. 2003, Janz et al. 2005) and overestimate the risk of DCIS (Rakovitch et al. 2003, Partridge

et al. 2008a). This suggests that DCIS patients may not appreciate their better prognosis (Morrow, 2004). Qualitative work in Australia and the UK has emphasised that women can be confused about the treatment (De Morgan et al. 2002) and have specific information needs (Prinjha et al. 2006).

Qualitative studies have also indicated that women previously diagnosed with DCIS hold diverse perceptions about the condition (ranging from it being breast cancer to it being a non-invasive condition or pre-cancer (De Morgan et al. 2002, Kennedy et al. 2008, Wong et al. 2008, Farmer 2000)), which are integrally linked to their experiences. Inaccurate illness perceptions can negatively impact on patients' experiences of any health condition (Buick, 1997; Cameron & Moss-Morris, 2004). The Common Sense Model of Illness Representations (CSM) (Leventhal, Meyer & Nerenz, 1980) suggests that illness perceptions develop from a variety of sources, including lay knowledge of the illness, the external environment and significant others (e.g. advice of clinicians), and current or previous experience with illness. The CSM focuses on the patient, in how their implicit illness beliefs shape their coping and adjustment. Ward (1993) highlights how this mirrors the focal point in nursing and recommends the CSM as a framework to guide knowledge development and nursing research. Therefore, the CSM may provide a useful way for researchers and clinicians (including specialist nurses) to conceptualise patients' perceptions of DCIS. Two studies highlight how health professionals in the US and UK hold similarly diverse views of DCIS, and use different terminology when communicating about it with their patients (Partridge et al. 2008b, Kennedy, et al. 2009). Illness perceptions therefore have important implications for patient's experiences and provision of care, but further research is needed to explore perceptions of DCIS and identify the factors that inform their development from the point of diagnosis onwards.

Much of the aforementioned research to date has been retrospective and conducted post-treatment, thus obscuring women's early experiences (Kennedy et al 2008). Exceptionally, in a longitudinal quantitative study, Partridge et al. (2008a) recruited women within 3 months post-treatment. However, in-depth qualitative research of women's early perceptions and experiences of DCIS is rare. An unpublished thesis (Carrera, 2001) is unique in qualitatively exploring 13 women's experiences at 6 weeks and 6 months post-diagnosis, but did not explore whether perceptions changed over time. Furthermore, most participants underwent conservative surgery, were treated by one surgeon, and the study was conducted in 1999, all of which limit the generalisability of the findings.

The current study was conducted as part of a mixed methodology longitudinal project aiming to address these gaps in the literature by exploring the psychosocial impact of DCIS (Kennedy, 2009). Fifty women with newly diagnosed DCIS completed a series of quantitative measures over the first year post-diagnosis (see Kennedy et al. 2010; Kennedy, 2009) and were invited to participate in interviews near to diagnosis and again 9-13 months later, which are the focus of this paper.

THE STUDY

Aim

This aim of this study was to describe the evolution of women's perceptions and experiences of ductal carcinoma in situ from the period near to diagnosis to one year later.

Design

All participants in the overall longitudinal mixed methods project (Kennedy, 2009) were invited to complete interviews and/or questionnaires over the first year post-diagnosis. The current paper focuses on the qualitative interviews, which have not been published elsewhere. Given the paucity of previous research (Carrera & Payne 1999), a detailed qualitative insight was essential. This embraces a phenomenological approach whereby each person's unique view is considered meaningful and valid, and is particularly useful in under-researched areas (Streubert & Carpenter 1995).

Participants

Women recently diagnosed with DCIS (with no evidence of invasion, and not a recurrence) in 9 UK breast clinics were approached by their breast care nurse (BCN), who provided the study information sheet and, if they were interested in participating, passed their contact details to the researcher. Nine months after diagnosis, all participants were invited to take part in a follow-up interview. Although this meant that saturation was likely to be exceeded (Teddlie & Yu, 2007), this was considered more appropriate and ethical than purposefully choosing individuals to re-interview, or only interviewing until saturation. Due to the study methods and lack of translating facilities, participants needed a fluent comprehension of English.

Data collection

Semi-structured interviews were conducted by the first author who had experience in this area. Interviews were guided by a schedule developed from previous research (De Morgan

et al. 2002; Carrera 2001) (Figure 1) and were conducted at a time and place convenient for the participant (typically their home).

Initial interviews were conducted between January 2007 and February 2008, on average 38 days post-diagnosis. In order not to overburden women, the interviews were designed to be brief, although the researcher encouraged women to talk as much or as little as they wished (range 10-84 minutes, average 33). Follow-up interviews took place between October 2007 and October 2008, at 9-13 months post-diagnosis, and lasted between 31 and 107 minutes (average 69).

Ethical considerations

All necessary NHS Ethics and Research and Development approvals were obtained. All participants received an information sheet, gave written consent prior to each interview, and were reminded of their right to withdraw at any time. Given the potential for distress, participants were reminded of the availability of their BCN and other sources of support.

Data analysis

Data was transcribed verbatim and analysed using thematic analysis (Braun & Clarke 2006). In recognition of the lead researcher's prior experience of exploring women's experiences of DCIS (Kennedy et al. 2008), a hybrid of inductive and deductive thematic analysis was undertaken (Fereday & Muir-Cochrane 2006).

The initial interview data were comprehensively coded line-by-line using an inductive approach, aiming to provide a rich description, whilst also deductively referring and comparing to the findings in Kennedy et al. (2008). Analysis of follow-up interviews focused on the changes in women's experiences over time by incorporating with and comparing to the earlier interviews. This comparative analysis was undertaken broadly by drawing on the whole sample, whilst also exploring several participants' individual experiences (Smith, 2003). During this analysis any new aspects were noted. Saturation in the follow-up analysis was reached after 18 interviews (Flick 2002), but the remaining 9 were reviewed for novel aspects.

Rigour

The first author carried out the analysis. Two independent researchers coded several transcripts to verify the coding and the analysis was regularly discussed with the research team. A reflective diary was kept throughout the project, which recorded any evolving ideas

during data collection and analysis. Participants were sent a summary of the themes for member checking, to ensure that the findings 'ring true' (Ziebland & McPherson, 2006).

FINDINGS

Forty-five women participated in the initial interviews (25 were post-surgery and 20 pre-surgery at this point in time). They ranged between 34 and 84 years old (mean 58.8) and most were in a relationship (n=34). Twenty-seven also participated in the follow-up interviews. Compared to those who declined to be re-interviewed, follow-up interviewees were more likely to have been awaiting surgery at the time of the first interview and had reported higher illness coherence/understanding scores on the quantitative measures completed at 9 months (see Kennedy 2009). Therefore, these women may have felt they had much to share at follow-up (e.g. experiences since surgery) and had a clear understanding of their diagnosis.

At the time of follow-up, all women had completed their treatment (surgery and/or radiotherapy) and 5 had been diagnosed with multifocal DCIS or IBC during the surgery. These women were not excluded from the sample, but demonstrate the potential complexity of DCIS cases. Treatment details and participant codes are presented in Table 1.

The following sections explore four themes that emerged across the two interviews. Broadly, the initial interviews identified an overarching theme emphasising how women's DCIS experiences merged and sometimes conflicted with their lay beliefs of IBC, and the follow-up interviews highlighted the shifting nature of women's perceptions and experiences.

Perceptions of DCIS versus breast cancer

Participants' main response to their diagnosis was a feeling of relief, especially given DCIS' early, contained state and positive prognosis. However, some equated it with their lay beliefs of breast cancer (often centred on having a lump and that a mastectomy indicated a more serious diagnosis). This evoked feelings of fear, due to the term 'carcinoma' within DCIS and notions about treatment and prognosis. This might reflect their lack of awareness of DCIS, prompting them to associate it with a condition about which they were more knowledgeable.

Paradoxically, many women had been asymptomatic but were advised to have a mastectomy, which led some to adjust their perception of breast cancer:

when you get told that you have breast cancer all you can think of is what is my prognosis and am I going to live and will I lose my breast. It doesn't dawn on you that actually there is a more detailed picture (p25)

Initial perceptions of DCIS were informed by the terminology used by health professionals. Often these were 'pre-cancer(ous)' or 'DCIS', but other explanations included 'early stages of breast cancer', which contradicted with others being told 'it wasn't cancer':

the first word that was said to me was cancer, not DCIS, so as far as I'm concerned DCIS is cancer (p15)

they say DCIS...it's not cancer cause they haven't labeled it as that (p23)

Noticeably, several women were confused about whether DCIS was cancer or not:

sometimes they refer to it as breast cancer and then when I went to oncology last week he said 'it's not breast cancer, it's pre-cancer', so it's a little bit confusing as to whether it is or whether it isn't (p41)

This confusion was enhanced by conflicting information between what they were verbally told and the written information they were given, which was often primarily designed for women with IBC.

During follow-up interviews, women's perceptions of DCIS were still diverse, but for some these had clearly shifted over time as they had gathered more information about the condition. Several women now expressed dissatisfaction and resentment with the term 'pre-cancer(ous)':

pre-cancer to my mind...lessens it and poo poo's it...it is cancer and it should be treated as cancer (Follow-up interview (FU) p9)

we've found out more from [internet/charities] because the consultant at the [hospital], all he would say was 'no, no it's not cancer...' yet the information that you actually find out is that it is (FU p1)

The treatment they had received earlier also influenced women's current perceptions. For some, the need for treatment in addition to surgery had indicated severity and "cancer", whilst not requiring further treatment prompted a less serious and worrying view:

if it was breast cancer I know I would have to go through treatment (FU p12)

The consequences of the diagnosis and treatment also impacted on women's perceptions. Some recovered fairly swiftly, had no long-term physical or emotional after effects and thus viewed it as relatively insignificant, whereas others described substantial changes to their lives, which they considered to be identical to those experienced by IBC patients:

if you're going to go through the treatment and the discrimination from the insurance companies and the time off work, and lose your career...then it almost begs to be recognised as cancer. (FU p25)

Overall, women initially fluctuated between feelings of relief and uncertainty, where they were aware of the positive nature of the diagnosis, and fear of the risks they still faced. Confusion and conflict between these different perceptions created difficulty for some. Women's perceptions were dynamic and evolved as they interpreted various cues and negotiated their way through the diagnosis, treatment and its consequences.

From paradox to acceptance

As in previous research (Kennedy et al. 2008) women appeared to fall somewhere on a continuum from treatment paradox to acceptance, and their position on this continuum was related to their perceptions of DCIS. In each surgical group, some women reflected on the contradiction inherent in the invasive and extensive treatment advised (e.g. mastectomy, radiotherapy) for what was described, and they perceived, as a pre-cancer or non-cancerous condition. Less extensive surgery seemed easier to accept, suggesting that WLE and lumpectomy are more in-keeping with beliefs about what is appropriate treatment for a non-invasive condition:

I was a bit surprised that he said and 'we'll do a mastectomy' cause I thought well it'll just be a tiny bit (p7)

Women dealt with any dissonant feelings about their diagnosis and treatment in a variety of ways: some emphasised the uncertainty and risk of DCIS, whereas others shifted their view of the condition to be more concordant with the necessity for treatment:

[surgeon said] 'I don't know why you're worried, you haven't got cancer'. Ok well if I haven't got cancer why am I having radiotherapy and why have you taken a 9cm by 6cm by 3cm chunk out of my breast...? (p25)

Views about treatment shifted over time. Some women continued to emphasise the treatment paradox, but there was a greater sense of justifying the necessity of the treatment. However, as some women learned about the condition (and their perception of it shifted), their views about treatment also changed:

as it was, it was DCIS and it's only a little lump, and it's only pre-. And 'oh a lumpectomy's fine thank you, I don't need anything more...', but I may have felt differently had I known. (FU p23)

Most still reflected on risk and uncertainty in order to justify the necessity of treatment, particularly those who were found to have IBC or multifocal DCIS. Some women's experiences had positively exceeded their expectations of the physical and emotional consequences of surgery, which helped them defend the treatment, whereas others reported unexpected side effects, disappointment with the aesthetic outcome, ambiguity about future treatment and recovery, and a degree of regret about undergoing surgery:

if they could have categorically told me no it wasn't going to spread I wouldn't have had it...a little bit of me really regrets having it done...its taken my confidence (FU p42)

In summary, women continued to justify the necessity of their treatment, but feelings about it were linked to their perceptions of DCIS and their experiences over time.

Personal impact

Some women felt they had not been greatly affected, and reported 'sailing through' the treatment. However, others described physical difficulties (e.g. fatigue, discomfort), which some, particularly those who underwent more extensive surgery, were still enduring at the time of the follow-up interview.

At the initial interviews some women were not overly concerned since they had a positive view of DCIS. Those awaiting a WLE (rather than a mastectomy) seemed less shocked and distressed. However, others described how anxiety, disbelief and intrusive thoughts had impacted on their lives:

I'm lying there in bed thinking I'm riddled with it...they must have gone through the milk ducts to get to the calcifications so has the cancer leaked out (p6)

Women who were initially interviewed shortly after surgery reported mixed emotions including relief, anger, frustration, disbelief and guilt:

at worst I feel mutilated and angry and upset...At best I feel relieved that it was nothing more (p39)

I honestly feel really ashamed of myself for being so low about it all when really there's no need...I'm really very, very lucky (p20)

One of the most enduring emotions was the feeling of ongoing risk, which ranged from fleeting concerns to significant intrusive thoughts. Persistent concerns were voiced about the possibility of recurrence or development of IBC, and some felt they were living in a cloud of vulnerability and uncertainty about the future.

This concern continued in the follow-up interviews and led women to constantly seek reassurance. At the time of the follow-up interviews, their first mammogram post-diagnosis (usually at 1 year) was imminent, which women saw as a major milestone and opportunity for reassurance that would enable them to move on.

Some women described concern over the impact of the surgery on their appearance and body image and how this had left them feeling disappointed, vulnerable and self-conscious:

I lacked the confidence when I went back [to work]...they were just looking at me and because I felt that I wasn't perfect in that area...I felt very exposed (FU p6)

These concerns were particularly evident in those who had undergone immediate reconstruction and were still in the midst of an ongoing reconstructive process. For some, appearance concerns had impacted on their intimate relationships and confidence:

Even though I've had reconstruction surgery I don't feel normal whatsoever, and I don't know how I can go into a relationship, and that makes me angry (FU p42)

Others felt positive or impartial about their appearance post-surgery; reflecting that they had little scarring or had already accepted their altered appearance.

Overall, DCIS had a profound impact on some women, but this was juxtaposed with relief that their disease was caught early.

Support and interactions with others

Women's own lack of awareness and confusion about DCIS made telling others challenging. Some women used the terminology used by their clinicians, but several were concerned that this would lead others to perceive the diagnosis as serious and assume it was breast cancer. Some specifically tried to reduce their family's concern by using the term 'pre-cancer(ous)' to minimise its significance:

if I said I've got breast cancer she [mum] would have been hysterical, so I was very much '... a really, really, really tiny area of pre-cancerous cells' (p24)

In essence, women's disclosure patterns fluctuated between a DCIS/less serious and breast cancer/more serious view. In contrast, at the follow-up interviews, several emphasised not fully explaining DCIS and preferred instead to say it was early breast cancer in order to validate their treatment:

I wanted them to know that there was a cancer in the title...you need to justify why you're having such major surgery. (FU p24)

Whilst most women felt they had received appropriate support from others, some reported how the diagnosis did not generate huge reactions:

I feel as though everyone's going 'well that's alright then' and it's not as though I want ...loads of sympathy but a little bit of validation wouldn't go amiss (p25)

Just as women themselves held diverse perceptions of DCIS, their family, friends and health professionals' views also varied which sometimes conflicted with the women's own feelings:

[daughter] 'oh well that's great, it's not cancer'...I couldn't be truthful about how I was feeling. I shouldn't be upset because it was pre-cancerous (p32)

One year post-diagnosis, most participants felt they no longer needed health professionals' support, but were grateful if it was still available. BCNs were highlighted as providing invaluable support in most, but not all, cases:

I was given a leaflet by [BCN]...then she whipped it out of my hand, she said 'oh you've only got DCIS haven't you, you can't have the massage' (FU p8)

Thus, some women sensed an air of 'only DCIS' and a lack of support towards them. They recognised that they were fortunate compared to IBC patients, but the diagnosis was still of major significance to them and they felt they had needed support.

Most women tried to put the experience behind them and were happy that their family and friends did not dwell upon the episode. However, some still needed support and received this from their peers who had undergone similar experiences, for example via the internet or buddy schemes. However, some shied away from meeting women with IBC:

I would feel like a fraud [attending a breast cancer group]...having not required chemotherapy or radiotherapy and having a very good prognosis (FU p24)

There were mixed feelings about the value of DCIS-specific peer support. Some felt it would have helped them to make sense of DCIS, but others were concerned about meeting women with different views of the condition or who had undergone different treatment since they thought this could cause concern rather than be beneficial.

Overall, participants' interactions with others highlight both the similarities and differences between DCIS and IBC. Many tried to portray DCIS positively but some needed validation of their experience and ongoing support.

DISCUSSION

Given the potentially vulnerable time in women's lives at which these interviews took place, a flexible and sensitive approach to recruitment and data collection was essential. This

entailed relying on BCNs to routinely identify and approach eligible patients, and also meant that the initial interview was conducted at a time best suited to each participant rather than at a specific, consistent number of days post-diagnosis. The findings are also limited to the experiences of DCIS among a small number of White women treated in England, 27 of whom chose to participate in the follow-up interviews. Therefore, we recognise the caveats of the sample and we do not claim that the findings are representative of all DCIS patients.

Despite these limitations, the current findings make a valuable, novel contribution to the literature by identifying how women's perceptions of DCIS, the treatment, and their emotions, can shift and evolve over time. These findings have important implications for those providing care for DCIS patients, including specialist nurses.

Previous retrospective research has indicated that perceptions of DCIS vary amongst patients (De Morgan et al. 2002, Kennedy et al. 2008), but the current study has shown this diversity is present from diagnosis onwards and that perceptions can shift over time. The findings endorse the Common Sense Model of Illness Representations (CSM) (Leventhal et al. 1980) in emphasising how illness perceptions are dynamic (Leventhal et al. 1998) and develop from various sources, including previous illness experience, terminology used by clinicians, treatment received (e.g. 'if I need a mastectomy, then it is cancer') and consequences of the experience. As highlighted by Ward (1993), the CSM embraces the need for health professionals to recognise patients' perceptions of their illness. It has particular relevance for advanced nursing practice to help nurses understand patients' perspectives in order to provide patient-focused individualised support and care.

The key issue of whether or not DCIS is considered cancer resonated throughout participants' accounts and concords with previous research (De Morgan et al. 2002, Napoles-Springer et al. 2007). Women fluctuated between viewing themselves as having cancer and having a non-cancerous condition, and these conflicting views were a cause of distress for some. Other research has suggested that women newly diagnosed with screen-detected breast cancer can hold a positive conceptual model of their disease (i.e. it is caught early and treatable), yet at times the same women resorted to a traditional view involving fear and risk (Farmer, 2000). Farmer explained the struggle between these views as due to the cognitive conflict when 'early' 'minor cancer' requires major treatment. The current study found views of DCIS that were akin to those identified by Farmer and that these views were influenced by the treatment advised/received. Specialist BCNs therefore need to elicit patients' views of their diagnosis and treatment in order to provide support and information to help reconcile any perceived conflict.

The way in which health professionals describe DCIS strongly influenced women's early perceptions of their diagnosis. As noted previously in research with patients (Kennedy et al. 2008) and clinicians (Partridge et al. 2008b, Kennedy et al. 2009), a variety of terms were used. Fallowfield (1997) argues that avoiding the word cancer or using euphemisms can cause distress and prevent successful adjustment. This is interesting in the context of DCIS where the situation is compounded by medical ambiguity about whether it meets the criterion for cancer (Graff, 2010).

Overall, the term 'pre-cancer(ous)' seemed counterproductive in helping some women understand and adjust to the diagnosis and treatment. This supports previous critics of this term (Kelly 2002) and a NHSBSP report highlighting the difficulties of terminology in DCIS (Goldsmith et al. 2007). Whilst Goldsmith et al. refer to written information, the current study indicates that verbal communication also requires consideration. From a patient-centred perspective, the language used across sources (e.g. clinicians, leaflets) should be non-ambiguous, coherent and understandable (Godby 2000, Prinjha et al. 2006). However, this is challenging given the variability of labels currently being used and the individual differences between patients, such that outright consistency of terminology may not be beneficial to individual patient needs. Clearly clinicians should carefully consider their communication methods, but further research is needed in this area. De Morgan et al. (2011) recently developed a communication aid to help clinicians in Australia explain DCIS to their patients. A small evaluation of this tool with clinicians and patients 12-18 months post-diagnosis suggests this may be a valuable resource but research is needed to explore its use in other health care systems and with newly diagnosed patients.

A lack of awareness about DCIS led women to struggle to understand the condition and explain it to others, whilst at the same time wanting to protect their loved ones. Some women minimised the diagnosis by using a less serious label ('pre-cancer') when telling others. Similar findings have been reported in research with other ambiguous conditions, including men's experiences of undergoing active surveillance for low-risk prostate cancer (Olliffe et al. 2009), whereby some men viewed the cancer as benign and downplayed the condition in order to live a normal life, but this stance reduced their ability to talk to others about their concerns. This could explain why some women changed their approach towards discussing DCIS, subsequently using the term 'cancer' in order to validate their experience and enable open discussions with others.

Previous authors (Farmer 2000, Partridge et al. 2008a) have speculated that DCIS patients may receive less time, information and support from others because the condition is viewed positively. This was evident in some women's accounts that their DCIS was trivialised (see also Kennedy et al. 2008). Overall, how the diagnosis of any condition is communicated is crucial in determining how patients and others perceive the condition and, in turn, potentially the support they receive and provide to others (Buick & Petrie, 2002; Buick, 1997).

The good prognosis associated with DCIS clearly contributed to the relief and adjustment evident amongst some women, supporting previous research (Webb & Koch 1997, Farmer, 2000). However, other women endured emotional and physical difficulties, including anxiety and appearance concerns, which mirror the quantitative work conducted alongside the current study (Kennedy et al. 2010) and the experience of IBC patients (Schmid-Buchi et al. 2008). Other concerns appear unique to DCIS, particularly how the complexities and uncertainty of the condition are perceived and understood (De Morgan et al. 2002, Kennedy et al. 2008). It is important that specialist BCNs, working with other members of their multidisciplinary teams, identify patients experiencing high levels of distress or misunderstandings about DCIS in order that appropriate support and care can be provided.

CONCLUSION

This study provides an important insight into women's initial perceptions and individual experiences of DCIS and how these evolve over time. Specialist BCNs have a key role in ensuring DCIS patients' support needs are met, including the provision of appropriate, up-to-date, tailored information to meet their needs throughout their journey. In order to achieve this further research is needed to determine appropriate and effective means of providing patient care, support and information. The CSM offers a relevant theoretical framework to guide both research and provision of care in this area.

REFERENCES

- Baum M. (1995). Screening for breast cancer, time to thank and stop? *Lancet*, **346**(8972), 436-7.
- Braun V. & Clarke V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, **3**, 77-101.

- Buick D. L. (1997). Illness representations and breast cancer: Coping with radiation and chemotherapy. In: Petrie K.J. & Weinman J.A. (eds.). *Perceptions of health and illness: Current research and applications*. Harwood Academic Publishers: Amsterdam, Netherlands, pp.379-409.
- Buick D.L., & Petrie K.J. (2002). "I know just how you feel": The validity of healthy women's perceptions of breast cancer patients receiving treatment. *Journal of Applied Social Psychology*, **32**(1), 110-123.
- Cady B (1998). How to prevent invasive breast cancer: Detect and excise duct carcinoma in situ. *Journal of Surgical Oncology*, **69**(2), 60-62.
- Cameron L.D., & Moss-Morris R. (2004). Illness-related cognition and behaviour. In A. Kaptein, & J. Weinman (Eds.), *Health psychology* (pp.84-110). Blackwell Publishing: Malden, US.
- Carrera C. (2001). *Ductal carcinoma in situ (DCIS) of the breast: Psychological issues surrounding its detection, diagnosis and treatment*. Unpublished doctoral thesis: University of Southampton, Southampton.
- Carrera C. & Payne S. (1999). Ductal carcinoma in situ (DCIS) of the breast: The need for psychosocial research. *Psycho-Oncology*, **8** (6), 538-545.
- De Morgan S., Butow P.N., Lobb E.A., Price M.A. & Nehill C. (In press). Development and pilot testing of a communication aid to assist clinicians to communicate with women diagnosed with ductal carcinoma in situ. *Supportive Care in Cancer*, DOI: 10.1007/s00520-010-1040-5.
- De Morgan S., Redman S., White K. J., Cakir B. & Boyages J. (2002). "Well, have I got cancer or haven't I?" the psycho-social issues for women diagnosed with ductal carcinoma in situ. *Health Expectations*, **5** (4), 310-318.
- Dell D.D (1997). Common questions about ductal carcinoma in situ. *American Journal of Nursing*, **97**(5), 61.
- Erbas B., Provenzano E., Armes J. & Gertig D. (2005). The natural history of ductal carcinoma in situ of the breast: A review. *Breast Cancer Research & Treatment*, **97** (2), 135-144.
- Ernster V. L., Barclay J., Kerlikowske K., Wilkie H. & Ballard-Barbash R. (2000). Mortality among women with ductal carcinoma in situ of the breast in the population-based surveillance, epidemiology and end results program. *Archives of Internal Medicine*, **160** (7), 953-958.
- Evans A.J., Pinder S.E., Ellis I.O. & Wilson A.R. (2001). Screen detected ductal carcinoma in situ (DCIS): Overdiagnosis or an obligate precursor of invasive disease? *Journal of Medical Screening*, **8**(3), 149-151.

- Fallowfield L.J. (1997). Truth sometimes hurts but deceit hurts more. *Annals of the New York Academy of Sciences*, **809**, 525-536.
- Farmer A. J. (2000). The minimization to clients of screen-detected breast cancer: A qualitative analysis. *Journal of Advanced Nursing*, **31** (2), 306-313.
- Fereday J. & Muir-Cochrane E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods* [online], **5** (1), Retrieved 15 May 2008 from http://www.ualberta.ca/~iiqm/backissues/5_1/pdf/fereday.pdf
- Flick U. (2002). *An introduction to qualitative research*. Sage Publications: London.
- Ganz P (2010). Quality of life issues in patients with ductal carcinoma in situ. *Journal of the National Cancer Institute Monographs*, **41**, 218-222.
- Godby C. J. (2000). Women's attitudes to false positive mammography results. A formerly clueless patient responds. *British Medical Journal*, **321** (7273), 1409-10.
- Goldsmith M., Bankhead C. & Austoker J. (2007). *Improving the quality of the written information sent to women about breast screening: Evidence-based criteria for the content of letters and leaflets*. **No. 64**, NHS Cancer Screening Programmes: Sheffield.
- Graff S (2010). Ductal carcinoma in situ: Should the name be changed? *Journal of the National Cancer Institute*, **102**(1), 6-8.
- Houghton J., George W.D., Cuzick J., Duggan C., Fentiman I.S., Spittle M., et al. (2003). Radiotherapy and tamoxifen in women with completed excised ductal carcinoma in situ of the breast in the UK, Australia and New Zealand: Randomised controlled trial. *Lancet*, **362** (9378), 95-102.
- Janz N.K., Mujahid M., Lantz P.M., Fagerlin A., Salem B., Morrow M., Deapen D. & Katz S.J. (2005). Population-based study of the relationship of treatment and sociodemographics on quality of life for early stage breast cancer. *Quality of Life Research*, **14** (6), 1467-1479.
- Kelly P. T. (2002). Explaining ductal carcinoma in situ to patients: The role of specific information and absolute risks. In: Silverstein M.J. (ed.). *Ductal carcinoma in situ of the breast*. 2nd ed. Lippincott Williams & Wilkins: Baltimore, pp. 572-575.
- Kennedy F. (2009). *The psychosocial impact and perception of ductal carcinoma in situ (DCIS)*. Unpublished doctoral thesis, University of the West of England: Bristol.
- Kennedy F., Harcourt D., Rumsey N. & White P. (2010). The psychosocial impact of ductal carcinoma in situ (DCIS): A longitudinal prospective study. *The Breast*, **19**, 382-387.
- Kennedy F., Harcourt D. & Rumsey N. (2008). The challenge of being diagnosed and treated for ductal carcinoma in situ (DCIS). *European Journal of Oncology Nursing*, **12** (2), 103-111.

- Kennedy F., Harcourt D. & Rumsey N. (2009). Perceptions of ductal carcinoma in situ (DCIS) among UK health professionals. *The Breast*, **18** (2), 89-93.
- Lauzier S., Maunsell E., Levesque P., Mondor M., Robert J., Robidoux A. & Provencher L. (2009). Psychological distress and physical health in the year after diagnosis of DCIS or invasive breast cancer. *Breast Cancer Research & Treatment*, **120**: 685-691.
- Leonard G.D. & Swain S.M. (2004). Ductal carcinoma in situ, complexities and challenges. *Journal of the National Cancer Institute*, **96** (12), 906-920.
- Leventhal H., Leventhal E. & Contrada R.J. (1998). Self-regulation, health, and behavior: A perceptual-cognitive approach. *Psychology & Health*, **13** , 717-733.
- Leventhal H., Meyer D. & Nerenz D. (1980). The common sense representation of illness danger. In: Rachman S. (ed.). *Medical psychology*. Vol 2, Pergamon: New York, pp. 7-30.
- Mittra I., Baum M., Thornton H. & Houghton J. (2000). Is clinical breast examination an acceptable alternative to mammographic screening? *British Medical Journal*, **321**(7268), 1071-1073.
- Morrow M. (2004). The certainties and the uncertainties of ductal carcinoma in situ. *Journal of the National Cancer Institute*, **96**(6), 424-425.
- Napoles-Springer A.M., Livaudais J.C., Bloom J., Hwang S. & Kaplan C.P. (2007). Information exchange and decision making in the treatment of Latina and White women with ductal carcinoma in situ. *Journal of Psychosocial Oncology*, **25** (4), 19-36.
- Nekhlyudov L., Kroenke C.H., Jung I., Holmes M.D. & Colditz G.A. (2006). Prospective changes in quality of life after ductal carcinoma-in-situ: Results from the nurses' health study. *Journal of Clinical Oncology*, **24** (18), 2822-2827.
- NHSBSP (2008). *NHS Breast Screening Programme Annual Review 2008*. NHS Cancer Screening Programmes: Sheffield.
- NHSBSP (2006). *Screening for breast cancer in England: Past and future*. **No. 61**, NHS Cancer Screening Programmes: Sheffield.
- Oliffe J.L., Davison B.J., Pickles T. & Mroz L. (2009). The self-management of uncertainty among men undertaking active surveillance for low-risk prostate cancer. *Qualitative Health Research*, **19** (4), 432-443.
- Partridge A., Adloff K., Blood E., Dees E.C., Kaelin C., Golshan M., Ligibel J., de Moor J.S., Weeks J., Emmons K. & Winer E. (2008a). Risk perceptions and psychosocial outcomes of women with ductal carcinoma in situ: Longitudinal results from a cohort study. *Journal of the National Cancer Institute*, **100** (4), 243-251.
- Partridge A., Winer J.P., Golshan M., Bellon J.R., Blood E., Dees E.C., Sampson E., Emmons K.M. & Winer E. (2008b). Perceptions and management approaches of physicians who care for women with ductal carcinoma in situ. *Clinical Breast Cancer*, **8** (3), 275-280.

- Prinjha S., Evans J. & McPherson A. (2006). Women's information needs about ductal carcinoma in situ before mammographic screening and after diagnosis: A qualitative study. *Journal of Medical Screening*, **13** (3), 110-114.
- Rakovitch E., Franssen E., Kim J., Ackerman I., Pignol J.P., Paszat L., Pritchard K.I., Ho C. & Redelmeier D.A. (2003). A comparison of risk perception and psychological morbidity in women with ductal carcinoma in situ and early invasive breast cancer. *Breast Cancer Research & Treatment*, **77** (3), 285-293.
- Schmid-Buchi S., Halfens R.J., Dassen T. & van den Borne B. (2008). A review of psychosocial needs of breast-cancer patients and their relatives. *Journal of Clinical Nursing*, **17** (21), 2895-2909.
- Smith N. (2003). Cross-sectional profiling and longitudinal analysis: research notes on analysis in the longitudinal qualitative study, 'Negotiating Transitions to Citizenship'. *International Journal of Social Research Methodology*, **6**(3), 273-277.
- Streubert H.J. & Carpenter D.R. (1995). *Qualitative research in nursing advancing the humanistic imperative*. J.B. Lippincott & Company: Pennsylvania.
- Teddlie C & Yu F. (2007). Mixed methods sampling: A typology with examples. *Journal of Mixed Methods Research*, **1** (1), 77-100.
- Ward S.E. (1993). The common sense model: an organizing framework for knowledge development in nursing. *Scholarly Inquiry for Nursing Practice: An International Journal*, **7**(2), 79-90.
- Webb C. & Koch T. (1997). Women's experiences of non-invasive breast cancer: Literature review and study report. *Journal of Advanced Nursing*, **25** (3), 514-525.
- Wong S.T., Chen W., Bottorff J.L. & Hislop T.G. (2008). Treatment decision making among Chinese women with DCIS. *Journal of Psychosocial Oncology*, **26** (4), 53-73.
- Ziebland S., & McPherson A. (2006). Making sense of qualitative data analysis: An introduction with illustrations from DIPEX (personal experiences of health and illness). *Medical Education*, **40**(5), 405-414.

Figure 1: Semi-structured interview questions

Initial interview

- Can you start by describing the time leading up to your diagnosis?
- In your own words, how do you understand your diagnosis?
- How did the doctor/nurse describe the condition? Any other terms?
- Had you previously heard of [use term individual used earlier] before?
- Has your doctor spoke to you about treatments yet?
- How do you feel about the diagnosis and treatment?

- Anything else you'd like to mention?

Follow-up interview

- Can you tell me what's happened since we last met?
- How did you feel after the treatment(s)? Have your feelings changed over the last year?
- Has the diagnosis/treatment changed the way you feel about your body/appearance?
- How do you view/feel about your diagnosis of DCIS now?
- How do you feel about the information you have received about DCIS?
- How do you feel about the support you've received during the past year?
- Are there any recommendations you would make for future care/support for DCIS patients?

Table 1 – Diagnosis and treatment details (Note: shaded rows indicate participants who took part in the initial interview only)

Participant	Timing of initial interview	Detection	Surgery Received	Radiotherapy	Hormone therapy	Any other details
1	Pre-op	Mammogram	WLE+RX	*		
2	Pre-op	Mammogram	WLE			
3	Pre-op	Mammogram	M+R			
4	Pre-op	Symptomatic	M+R	*	*	
5	Pre-op	Mammogram	WLE	*	*	IBC at surgery
6	Pre-op	Mammogram	M+R			
7	Pre-op	Mammogram	M			
8	Pre-op	Mammogram	WLE / M+R			Multi-focal DCIS
9	Pre-op	Mammogram	WLE / M+R			IBC at surgery
10	Pre-op	Mammogram	WLE	*	*	
11	Pre-op	Mammogram	BM+R			
12	Pre-op	Mammogram	WLE			
13	Pre-op	Symptomatic	M			
14	Pre-op	Symptomatic	M+R			
15	Pre-op	Mammogram	WLE			
16	Pre-op	Mammogram	WLE	*		

17	Pre-op	Mammogram	M	*	
18	Post 1 st op, pre- op 2 nd op	Mammogram	WLE+RX / M	*	Multi-focal DCIS
19	Post 1 st op, pre re-excision	Mammogram	WLE+RX	*	
20	Post 1 st op, pre re-excision	Mammogram	WLE+RX		
21	Post-op	Symptomatic	WLE+RX / M	*	
22	Post-op	Mammogram	WLE+RX		
23	Post-op	Symptomatic	WLE	*	IBC at surgery
24	Post-op	Symptomatic	M+R		
25	Post-op	Mammogram	WLE	*	
26	Post-op	Symptomatic	M	*	
27	Post-op	Mammogram	WLE		
28	Post-op	Symptomatic	WLE		
29	Post-op	Mammogram	WLE		
30	Post-op	Mammogram	WLE / M	*	
31	Post-op	Mammogram	WLE	*	
32	Post-op	Mammogram	WLE		
33	Post-op	Mammogram	WLE	*	*
34	Post-op	Mammogram	WLE		
35	Post-op	Mammogram	WLE		*
36	Post-op	Mammogram	WLE		*
37	Post-op	Mammogram	WLE	*	
38	Post-op	Symptomatic	M		
39	Post-op	Mammogram	M		
40	Post-op	Mammogram	WLE	*	
41	Post-op	Mammogram	WLE+RX	*	
42	Post-op	Symptomatic	Lumpectomy / M+R		
43	Post-op	Symptomatic	M	*	*
44	Post-op	Mammogram	WLE	*	
45	Post-op	Mammogram	WLE / M		

Key: M = mastectomy; +R = plus reconstruction; BM = bilateral mastectomy; WLE = wide local excision; +RX = re-excision

* indicates received treatment