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The psychosocial impact of ductal carcinoma in situ (DCIS): a longitudinal prospective study

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Abstract

DCIS is a non-invasive breast cancer, increasingly detected through routine breast screening. Patients are reassured that the condition is early and not life-threatening but they undergo surgery similar to that used in the treatment of invasive breast cancer (IBC). Little research has explored the psychosocial impact of DCIS, especially in the UK. A longitudinal, prospective study was therefore conducted to address this gap. Fifty women newly diagnosed with DCIS were followed over the first year post-diagnosis. Anxiety and depression significantly reduced from baseline to 6 months. Body image distress was relatively stable, but extensive for some women. Those undergoing mastectomy with immediate reconstruction experienced significantly greater body image concerns. This study highlights that DCIS patients can experience psychosocial distress that is often transient but in some cases extensive and prolonged. Appropriate psychosocial support is needed to help DCIS patients adjust to the diagnosis, its treatment and long-term implications.

Keywords: Ductal carcinoma in situ (DCIS); psychosocial impact; anxiety; depression; body image distress.

Introduction

Ductal carcinoma in situ (DCIS) is a non-invasive breast condition which is increasingly detected by routine breast screening. In the UK 3,168 women were diagnosed with DCIS from 2006/07, which represents approximately 20% of UK screen-detected breast cancers. ^{1,2} DCIS cells are confined to the ducts of the breast ³ and although evidence suggests it can progress to invasive breast cancer (IBC), controversy surrounds its natural history.⁴ Some clinicians and researchers emphasise that because the majority of DCIS is high grade (which has a greater risk of progression), detection and treatment of DCIS is required, ⁵ which could also reduce the incidence of IBC.⁶ However, others are critical of breast screening and maintain that the rise in DCIS detection constitutes an overdiagnosis,⁷ that many cases would never develop into clinically life-threatening IBC during the patient's lifetime and that screening therefore causes patient harm rather than benefit.⁸ A further challenge for patients is that although they are typically reassured that their DCIS has been caught early and is not life-threatening, they are often offered the same treatment options (e.g. surgery, radiotherapy, hormone therapy) as those treated for IBC.⁹

These issues and debates have recently been intensified by a review of publicly organised screening programmes arguing that overdiagnosis is high ¹⁰ and that some women undergo unnecessary treatment. This work has generated numerous highly-charged contesting articles, letters and media reports about the benefits, or otherwise, of screening. Furthermore, Gøtzsche and others emphasise that the information given to women invited for screening requires improvement because it does not mention overdiagnosis or the

possibility of detecting DCIS.¹¹⁻¹³ Importantly, as these debates filter into the public domain, they may impact upon healthy women's concerns and decision making in relation to breast screening, as well as affecting those currently or previously diagnosed and treated for DCIS.

Therefore, against the backdrop of controversies and diverse opinions about DCIS, it is vital to understand the psychosocial impact of the condition in order to inform the provision of appropriate care, support and information. However, there is a paucity of research in this area.¹⁴ Some evidence suggests that patients adjust and recover relatively easily.^{15, 16} However, others indicate that, despite the relatively positive prognosis,¹⁷ DCIS patients can have levels of distress comparable to those diagnosed with IBC ¹⁸⁻²⁰ and hold inflated perceptions of the risk of the condition.^{19,21} Additionally, a few qualitative studies have highlighted the confusion and uncertainty about DCIS amongst previously diagnosed women.^{22, 23} However, the bulk of this previous research has been retrospective in nature conducted some months post-treatment. Early experiences following diagnosis have not been explored. One recent prospective study was conducted in the United States ²⁴ but to date no published UK research has prospectively examined the psychosocial impact of DCIS. Such research is important because treatment practices and views about DCIS differ across healthcare systems and health professionals in different countries.²⁵⁻²⁷ Finally, the DCIS literature has rarely explored the potential psychosocial impact of the surgery undergone by DCIS patients. The current study therefore aimed to address the gaps in the existing literature by prospectively exploring the psychosocial impact of DCIS amongst UK patients during the first year following diagnosis.

Materials and methods

Participants and recruitment

Ethical approval was obtained from Southmead Hospital NHS Ethics Committee (Bristol) and the R&D department in each NHS site. Nine breast clinics in the UK (primarily in the South-West) were involved in recruiting eligible patients. The study commenced at 5 sites in January 2007, whereas the latter clinics joined the study in September 2007. Recruitment continued until February 2008. Women were eligible if they had an initial biopsy diagnosis of DCIS (without evidence of invasion), had not yet completed surgical treatment or had undergone surgery within the previous 3 months, had no serious comorbidity, and a fluent comprehension of English (due to the study methods and a lack of translating facilities). Women with a recurrence of DCIS were excluded.

Eligible women were introduced to the study by their breast care nurse (BCN), who also obtained their agreement to release their contact details to the researcher (FK). Written informed consent was obtained from all women at each data collection point. Overall, 50 women participated in the study (80.6% participation rate of 62 women whose contact details were provided to the researcher). Unfortunately 7 women were diagnosed with IBC following surgery, and were excluded from the analysis in this paper, leaving 43 participants in this analysis. One woman was lost to follow-up at 9 months and was excluded from the longitudinal analyses. The 12 women who declined cited difficulty coping, no problems or a preference not to take part.

Questionnaires

Participants completed the following standardised questionnaires near to diagnosis, and at 6 and 9 months post-diagnosis:

- Hospital Anxiety and Depression Scale (HADS) ²⁸ a screening tool for anxiety and depression (7 items each). Scores of 8 10 are suggestive of 'borderline' problems, whilst equal or greater than 11 indicate substantial 'case' anxiety or depression which may benefit from psychological support.
- Body Image Scale (BIS) ²⁹- assesses cancer patients' body image distress. Scores range from 0 30, with a higher score indicating greater distress. Hopwood et al. ³⁰ suggest scores of 11 or more should be considered a priority for help.
- European Organisation for Research and Treatment of Cancer Quality of Life
 Questionnaire (EORTC QLQ-C30 version 3) ^{31, 32} assesses QoL in cancer patients.
 The global subscale was utilised to measure overall QoL, and a higher score
 represents healthy functioning.

Data Analysis Plan

An a priori power calculation using anxiety as the primary dependent variable was undertaken with the aim of having a sample size sufficiently large enough to detect a clinically meaningful medium effect with at least 80% power ($\alpha = 0.05$, $\beta \le 0.2$). For an analysis using a Bonferroni corrected pairwise application of the paired samples t-test to detect a longitudinal change in mean anxiety a sample size of n = 45 would be needed.

Data were analysed using SPSS (version 17). A series of separate one-way doublymultivariate repeated measures analysis of variance (ANOVA) ³³ were used to investigate changes in psychosocial measures (anxiety, depression, body image, QoL) over time and to assess potential systematic differences in these measures according to the between-subjects effects of type of surgery (wide local excision (WLE), mastectomy, mastectomy with reconstruction), method of detection (screen-detected, symptomatic), whether received radiotherapy or hormone treatment. Separate analysis of variances from a one-way repeated measures design was undertaken for each dependent variable, along with Bonferroni (or equivalent) corrected paired t-tests (two-tailed), to located precise differences whilst preventing the over capitalisation of Type I errors that may arise from the multiplicity of testing.

Prior to analysis a screening of the dependent variables using the Mahalanobis distance and an assessment of the residuals using Cook's distance indicated that there were no discrepant outlying or overly influential response profiles amongst respondents. An assessment of residuals using the Kolmogorov-Smirnov test indicated there were no gross departures from normality $p \ge 0.05$ in all cases. Mauchly's test of sphericity was used to determine whether the repeated measures analysis of variance should proceed using standard *F*-tests or the epsilon adjusted Greenhouse-Geisser *F*-tests.^{33, 34}

Results

Participant characteristics

The 43 women ranged between 34 and 87 years old (mean 60.2). Most were in a relationship (70%), diagnosed through routine screening (n = 33; 76.7%), and completed the baseline questionnaire approximately 44.7 days post-diagnosis (sd = 29, range 8 – 113). Table 1 presents the surgery details. Additionally, 12 underwent radiotherapy and 9 received hormone treatment.

Psychosocial impact over time

Table 2 presents the percentage of participants reporting HADS anxiety and depression scores above the cut-off scores. Overall, the incidence of anxiety 'caseness' reduced over time, but 2 women consistently remained at case or borderline level, 2 worsened, and 5 improved at 6 months but worsened at 9 months. Depression scores showed a similar pattern; one woman consistently reported a 'case' level of depressive symptoms, one worsened and one improved at 6 months but then reverted to 'case' level). Eight women (18.6%) reported no body image concerns at any point during the study. Using a cut-off score of 11, 30.2%, 20.9% and 19% of participants indicated considerable body image distress at baseline, 6 months and 9 months respectively.

Application of a one-way doubly multivariate repeated measures ANOVA revealed multivariate statistically significant changes over time in the linear combination of the four dependent variables: Pillai's trace = 0.43, Multivariate $F_{8, 32}$ = 3.04, p = 0.01. Bold type in Table 3 presents the values of each measure at each time point (n = 42, due to the attrition of 1 participant).

Follow-up one-way repeated measures ANOVAs for each variable found significant results for anxiety and depression: $F_{2, 78} = 14.88$, p < 0.001, and $F_{1.69, 66.05} = 8.55$, p = 0.001. Subsequent post-hoc paired samples t-test showed a significant reduction in anxiety (p < 0.001) and depression (p = 0.003) from baseline to 6 months, and baseline to 9 months (anxiety p < 0.001; depression p = 0.01), but no significant mean changes from 6 to 9 months. This indicates a reduction in anxiety and depression from baseline to 6 months, which is maintained at 9 months. Neither body image nor QoL differed significantly over time.

Psychosocial impact by type of surgery

Surgical group was entered as a between-subjects factor into the previous ANOVA (mastectomy, n = 10; mastectomy with reconstruction, n = 9; WLE, n = 23). No multivariate time-by-surgery interactions were found, but the multivariate surgery effect was significant: Pillai's trace = 0.41, Multivariate $F_{8, 74} = 2.39$, p = 0.02.

Follow-up between-subjects analysis showed no difference between the surgical groups in anxiety or QoL. The Games-Howell post-hoc test (which is more accurate when population variances differ ^{34, 35}), showed no difference in levels of depression, which indicates the

initial significant result for depression ($F_{2, 39} = 3.98$, p = 0.027) may be due to the uneven groups and population variances.

However, the surgical groups differed significantly in terms of body image distress: $F_{2, 39} =$ 7.37, p = 0.002. Women who underwent an immediate reconstruction reported significantly greater overall body image distress than WLE patients (p = 0.001) and marginally (p = 0.055) higher levels than those who underwent mastectomy without reconstruction (Table 3). The percentage reporting 'priority' levels of body image distress was also greatest amongst the immediate reconstruction group (Table 4).

Additional analyses

Similar separate ANOVAs were conducted with detection (screen-detected vs. symptom), radiotherapy and hormone treatment as between-subjects factors. No significant between-subject or multivariate interactions were found (Table 5), which indicates the method of detection and adjuvant treatment received were not overly influential factors on the psychosocial outcomes measured.

Discussion

This UK-based study provides a valuable insight into patterns of psychosocial distress during the first year post-diagnosis of DCIS. Overall, most patients reported positive adjustment (evidenced by the significant reduction in anxiety and depression) but some experienced prolonged distress. There was a clear effect of surgery on body image, in which women who underwent mastectomy with immediate reconstruction reported significantly higher levels of distress.

The early, prospective impact of DCIS has rarely been captured in previous research, especially in the UK. Participants were recruited from multiple breast care centres and there was very little attrition. However, the final sample was still relatively small and the use of Specialist BCNs to initially approach eligible participants may have incurred some selection bias. Most existing research in this field has been retrospective and conducted some time post-treatment, which may have obscured women's early experiences and the detail of changes over time. The current study makes a substantial contribution by capturing the psychosocial impact of the period around diagnosis. However, the complex nature of identifying and recruiting women with pure DCIS (e.g. no invasive disease) near to diagnosis meant that a pragmatic and sensitive approach was required. Seven women in the initial sample were found to have IBC at surgery, and due to the relatively small sample these women were removed from the current analysis. However, it is important that future research explores this subset of patients' psychosocial experiences in detail.

Despite the caveats previously mentioned, the results support a recent large study (n = 487) of newly diagnosed DCIS patients in the United States,²⁴ which reported a similar decrease in anxiety and depression over time. However, the current study found considerably higher levels of anxiety and depression at baseline. Although the US study by Partridge et al. ²⁴ might be considered more representative in terms of the large sample, the current study may more accurately reflect anxiety near to diagnosis (44.7 days post-diagnosis, sd = 29,

70% post-surgery, on average 4 weeks; versus 167.3 days post-diagnosis, sd = 60.8, and over 80% around 3 months post-surgery - Partridge, personal communication). Considerable levels of anxiety around the time of surgery have also been reported in patients diagnosed with IBC.^{36, 37} The high initial anxiety reported in the current study may relate to the more recent assimilation of the diagnosis and worries about either forthcoming treatment or post-surgical outcomes. Interestingly, and similar to previous research, there was no significant difference in psychosocial outcomes according to the method of detection ³⁸ or whether the women received radiotherapy or hormone treatment.³⁹ However, only a small number of outcomes were measured, and since this finding could be due to the sample size, future work needs to further investigate whether these variables are influential among women diagnosed with DCIS. For example, being offered adjuvant treatment could prompt a greater negative risk perception of DCIS, leading to psychosocial distress in the absence of appropriate support.

Partridge et al. ²⁴ reported a significant reduction in distress from baseline to 18 months. The 6 month assessment in the current study gives an earlier indication that the difficult emotions experienced near to diagnosis often reduce within the first year, as has also been reported in IBC research.^{37, 40, 41} Interestingly, 9 month anxiety levels increased slightly (although not significantly), possibly because at this point women were typically awaiting their first mammogram post-diagnosis, which is reportedly a source of considerable and ongoing anxiety for IBC patients.^{42, 43} It has recently been reported that DCIS patients' adherence to follow-up screening reduces over time,⁴⁴ however to date research has not explored DCIS patients' feelings about this.

Similar to Partridge et al, the current study found no discernible changes in QoL over time. However both studies used generic tools to measure QoL and it is possible that conditionspecific measures may be more sensitive to the unique impact of DCIS upon QoL. Overall, the psychosocial measures used are well validated, standardised tools used extensively in breast cancer research. However, since these measures were distributed at discrete time points they might not capture the complexity of women's experiences. For this reason, women in the current study also took part in semi-structured interviews, which are reported elsewhere.⁴⁵

Levels of body image distress were relatively stable over time, indicating the enduring nature of these concerns. Women undergoing mastectomy with immediate reconstruction reported significantly greater body image distress. No prior research has specifically examined the psychosocial impact of immediate reconstruction after mastectomy following diagnosis of DCIS. A large population study ²⁰ 'early in the treatment recovery period' (p.1476) supports the current results, although the exact time since diagnosis is unclear. Their sample comprised both DCIS (n = 555, 44%) and IBC patients, and the analysis showed no differences between the diagnostic groups.²⁰ Previous work with IBC patients undergoing mastectomy with or without reconstruction (immediate and delayed) has not demonstrated the widely assumed psychosocial benefits of breast restoration.⁴⁰ Greater distress among reconstruction patients may be due to a longer recovery period and the likelihood of requiring several operations to gain an acceptable aesthetic outcome.^{20, 40} Furthermore, incorporating the reconstructed breast into a patient's body image is a

considerable psychological task which is likely to still be in progress 9 months postdiagnosis. Women opting for immediate reconstruction may have a greater investment in their body image prior to diagnosis and higher expectations of the aesthetic outcome, which, if unmet, could evoke distress and dissatisfaction.^{46, 47} Finally, previous qualitative work has indicated that women find the paradox between the diagnosis of early, noninvasive disease and extensive treatment (e.g. mastectomy) challenging,²² and this may be compounded when adjusting to breast reconstruction.

Clearly some women with DCIS experience significant levels of distress both in the short and longer term. The challenge is identifying those who are at risk of, or currently experiencing, this distress and how best to offer appropriate support. This task has been acknowledged for some time by those treating IBC.^{37,48} Previous DCIS research has proposed that levels of distress may be influenced by factors including confusion about the diagnosis, conflict resulting from the recommendation of extensive surgery and inaccurate risk perceptions.^{19, 22, 24} The present study did not explore whether women were aware of their risk (e.g. grade, Van Nuys prognostic index) and whether their perception of that risk influenced their psychosocial adjustment. Prior research has argued that perceived risk of cancer is more strongly related to distress than objective indicators.⁴⁹ This is an important question for future research, which has important implications for provision of care.²⁴

Providing appropriate support in clinical practice is difficult and requires additional time and training for professionals such as BCNs who are already often overstretched. Although our findings suggest that women undergoing extensive surgery may be particularly

susceptible to heightened levels of distress, it is important that *all* DCIS patients are assured by clinic staff that support is readily available for them.

In order to inform the provision of effective and appropriate care, further prospective research needs to examine the psychosocial impact of DCIS beyond the first year, including the issues of follow-up mammograms, body image distress, and patients' experiences of reconstruction.

Conclusion

Whilst research continues to unravel the medical complexities of DCIS, the psychosocial distress experienced by patients diagnosed with the condition needs to be addressed. The current study adds to the growing body of literature aiming to equip health professionals treating and caring for women diagnosed with DCIS to develop effective communication, information and support for patients.

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Table 1 – Surgery details of the participants (n = 43)

Characteristic	Number (%)
Surgery (awaiting or received) at baseline:	
WLE	24 (55.8)
Mastectomy #	19 (44.2)
Final surgery received at 9 months:	
WLE	23 (53.5)
Mastectomy [#]	11 (25.6)
Mastectomy with immediate reconstruction	9 (20.9)

incl. 1 patient who underwent a bilateral mastectomy and 1 who at baseline had already undergone immediate reconstruction

	Baseline	6 months	9 months*
Anxiety 0-7	22 (51.2%)	29 (67.4%)	28 (66.7%)
Anxiety 8-10	4 (9.3%)	9 (20.9%)	9 (21.4%)
Anxiety >10	17 (39.5%)	5 (11.6%)	5 (11.9 %)
Depression 0-7	29 (67.4%)	39 (90.7%)	38 (90.5%)
Depression 8-10	8 (18.6%)	2 (4.7%)	1 (2.4%)
Depression >10	6 (14%)	2 (4.7%)	3 (7.1%)

Table 2 – HADS cut-off caseness results

* n = 42 at 9 months

	Overall	Baseline	6 months	9 months
Anxiety ^a : *		8.86 (6.00)	5.07 (4.73)	5.32 (4.40)
WLE	5.75 (3.67)	8.39 (5.18)	4.78 (4.81)	4.09 (3.32)
Mastectomy	5.52 (4.46)	7.60 (6.60)	4.00 (3.43)	4.95 (4.75)
Reconstruction	9.11 (5.35)	11.44 (7.18)	7.00 (5.64)	8.89 (4.99)
Depression ^a : [*]		4.93 (5.04)	3.19 (3.44)	3.12 (3.68)
WLE	2.57 (2.81)	3.39 (4.23)	2.22 (2.47)	2.09 (2.91)
Mastectomy	4.17 (3.26)	6.10 (5.53)	3.30 (2.83)	3.10 (2.64)
Reconstruction	6.30 (4.78)	7.56 (5.55)	5.56 (5.08)	5.78 (5.24)
Body image ^a :		6.42 (7.88)	6.27 (7.49)	6.24 (7.74)
WLE	3.75 (6.04)	4.28 (6.21)	3.57 (6.46)	3.39 (5.84)
Mastectomy	6.09 (5.82)	6.72 (7.90)	5.68 (4.54)	5.87 (7.69)
Reconstruction #	13.10 (6.98)	11.54 (9.95)	13.83 (7.99)	13.93 (7.52)
Global QOL ^b :		71.43 (19.23)	72.22 (20.47)	73.61 (18.31)
WLE	74.88 (14.81)	74.28 (16.65)	73.19 (20.71)	77.17 (16.52)
Mastectomy	76.11 (16.42)	75.00 (21.15)	76.67 (21.44)	76.67 (21.44)
Reconstruction	62.04 (15.90)	60.19 (21.15)	64.81 (21.15)	61.11 (15.02)

Table 3 – Mean (Sd) psychosocial distress scores according to time and surgery (n = 42)

* Significant main effect over time (p < 0.001). # Significant main effect for surgery (p = 0.001)

a Scores range from 0 - 21 (or 0-30 in body image), lower score is preferable and indicates lower anxiety/depression/BI distress

b Scores range from 0 - 100, higher score is preferable and indicates a higher level of quality of life

	Baseline	6 months	9 months
WLE (n = 23)	16.7	13.0	8.7
Mastectomy $(n = 10)$	36.4	18.2	10.0
<i>Reconstruction</i> $(n = 9)$	62.5	44.4	55.6

Table 4 – Percentage of each surgery group reporting 'priority' body image distress scores

	Overall	Baseline	6 months	9 months
Anxiety:				
Screen-detected (n=33)	6.82 (4.42)	9.52 (5.96)	5.36 (4.96)	5.58 (4.55)
Symptomatic (n=9)	4.94 (4.18)	6.44 (5.68)	4.00 (3.84)	4.39 (3.92)
Radiotherapy (n=12)	6.94 (4.15)	10.50 (6.50)	5.33 (5.02)	5.00 (3.69)
No radiotherapy (n=30)	6.21 (4.53)	8.20 (5.77)	4.97 (4.69)	5.45 (4.71)
<i>Hormone therapy (n=8)</i>	6.50 (3.83)	9.50 (6.33)	5.00 (4.04)	5.00 (4.93)
<i>No hormone therapy</i> $(n=34)$	6.40 (4.56)	8.71 (6.01)	5.09 (4.93)	5.40 (4.35)
Depression:				
Screen-detected	3.97 (3.83)	5.12 (5.32)	3.45 (3.55)	3.33 (3.93)
Symptomatic	2.93 (2.90)	4.22 (4.06)	2.22 (2.95)	2.33 (2.60)
Radiotherapy	3.50 (3.67)	5.00 (6.00)	2.75 (2.70)	2.75 (3.57)
No radiotherapy	3.84 (3.70)	4.90 (4.72)	3.37 (3.72)	3.27 (3.78)
Hormone therapy	3.21 (2.75)	4.88 (4.55)	2.88 (3.14)	1.87 (1.96)
No hormone therapy	3.87 (3.85)	4.94 (5.22)	3.26 (3.55)	3.41 (3.95)
Body image:				
Screen-detected	6.20 (7.37)	6.18 (8.14)	6.26 (8.06)	6.17 (7.78)
Symptomatic	6.70 (6.38)	7.29 (7.20)	6.31 (5.26)	6.49 (8.05)
Radiotherapy	4.59 (6.52)	5.93 (7.39)	4.00 (6.56)	3.83 (6.18)
No radiotherapy	7.00 (7.30)	6.61 (8.18)	7.18 (7.74)	7.20 (8.18)
Hormone therapy	4.51 (5.69)	5.14 (6.07)	3.25 (4.30)	5.13 (8.53)
No hormone therapy	6.73 (7.40)	6.72 (8.29)	6.98 (7.94)	6.50 (7.66)
Global QOL:				
Screen-detected	72.48 (16.93)	71.72 (20.62)	70.96 (21.16)	74.75 (17.61)
Symptomatic	72.22 (12.95)	70.37 (13.89)	76.85 (18.06)	69.44 (21.25)
Radiotherapy	75.46 (13.07)	75.00 (18.12)	77.08 (19.50)	74.31 (13.04)
No radiotherapy	71.20 (17.10)	70.00 (19.77)	70.28 (20.84)	73.33 (20.22)
Hormone therapy	77.08 (12.92)	73.96 (18.60)	77.08 (18.77)	80.21 (11.73)
No hormone therapy	71.32 (16.63)	70.83 (19.60)	71.08 (20.95)	72.06 (19.34)

Table 5 – Mean (Sd) psychosocial distress scores according to detection, radiotherapy and hormone treatment (n=42)