

Have I got cancer or haven't I? Medical staff confuse women with ductal carcinoma in situ

March 21 2012

Women diagnosed with ductal carcinoma in situ (DCIS) need clear communication and tailored support to enable them to understand this complex breast condition, which has divided the medical profession when it comes to its perception and prognosis. That is the key finding of a study published in the April issue of the *Journal of Advanced Nursing*.

Research carried out at the University of the West of England, Bristol, UK, looked at how 45 women felt when they were diagnosed with DCIS and how their experiences changed over time. It found that many of the women were very confused about whether or not they had cancer and that medical staff often added to this confusion by providing conflicting messages.

"DCIS is a non-invasive condition where the [cancer cells](#) are contained in the ducts of the breast" explains lead author Dr Fiona Kennedy, now a research fellow at Sheffield Hallam University. "It currently makes up 20 per cent of breast cancers detected by UK screening programmes.

"However, uncertainty surrounds whether it will progress into invasive [breast cancer](#) and this has created two factions in the medical profession. Some view DCIS as a [carcinoma](#) in situ, emphasising that the majority of cases have a high risk of progression and need treatment to reduce the incidence of invasive breast cancer. Others view DCIS as a pre-cancerous condition.

"DCIS patients have an excellent prognosis, but treatment is

controversial because it is similar to treatment for invasive breast cancer, including [mastectomy](#) and possibly radiotherapy and [hormone treatment](#).

"This can be confusing for women diagnosed with DCIS. On the one hand they are being reassured that the condition is not life-threatening, yet on the other hand clinicians are recommending extensive, [invasive treatment](#)."

The women, who were recruited from nine UK breast clinics, ranged from 34 to 84 years-of-age with an average age of 59. Seventy-six per cent had been diagnosed following screening and the rest had presented with symptoms. Some women had more than one surgical procedure, including wide local excision to remove the affected breast tissue (56%) or breast removal (44%).

Twenty-seven of the women took part in follow-up interviews nine to 13 months after diagnosis. All had completed their treatment and, during surgery, five had been diagnosed with DCIS in numerous sites (multifocal disease) or invasive breast cancer.

Key findings of the study, funded by the charity Breast Cancer Campaign, included:

- Many women felt confused and conflicted by their diagnosis. Some were told it was cancer, some were told it wasn't cancer and some medical staff used the terms DCIS, pre-cancer and early breast cancer. As one woman said: "Sometimes they refer to it as breast cancer and then when I went to oncology last week they said it's not breast cancer it's pre-cancer..."
- Women spoke about the contradictions of being told it was pre-cancer or non-cancerous, their perceptions of what this meant and then being recommended extensive, invasive treatment. One

woman's surgeon said he didn't know why she was so worried when she didn't have cancer. "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?" she replied.

- Some women were more affected than others by their condition, especially if they had more extensive surgery. Many experienced mixed and fluctuating emotions. As one woman said: "At worst I feel mutilated and angry and upset...At best I feel relieved that it was nothing more."
- One of the most enduring emotions was one of on-going risk, which ranged from fleeting concerns to significant, intrusive thoughts. They worried about DCIS reoccurring, or developing invasive breast cancer, and felt vulnerable and uncertain about the future.
- Body image was also a big issue and impacted on the women's confidence and sexuality. "I felt that I wasn't perfect in that area...I felt very exposed" said one woman. "I don't know how I can go into a relationship and that makes me angry" said another after reconstructive surgery.
- Women who were confused about their own diagnosis found telling others very challenging. "I wanted them to know that there was a cancer in the title...you need to justify why you're having such major surgery" said one. "If I said I've got breast cancer she [mum] would have been hysterical" said another, adding that she chose instead to describe it as "a really, really, really tiny area of pre-cancerous cells".

"It was clear from our research that women's perceptions and experiences of DCIS shifted and developed over time during the diagnosis, treatment and post-treatment phases" says Dr Kennedy.

"Confusion about their medical condition was also very common as they received mixed messages about their diagnosis and whether it was or wasn't cancer.

"One of the key recommendations of this study is that clinicians should think carefully about the language they use to describe DCIS and that further work is needed to explore the potential for the development of clear, coherent and flexible communication guidelines. There is also a need for appropriate and tailored help, support and information to meet the specific and evolving needs of women diagnosed with DCIS."

Baroness Delyth Morgan, Chief Executive of the Breast Cancer Campaign, has welcomed the findings. "A diagnosis of DCIS can leave women confused about their treatment options as currently even clinicians don't know which cases will progress to [invasive breast cancer](#)" she says. "For now we must give clearer messages to patients about what their diagnosis means and the potential risks to them if it is left untreated. Improving awareness of DCIS when [women](#) attend routine breast screening appointments is a key part of this process."

More information: The shifting nature of women's experiences and perceptions of ductal carcinoma in situ. Kennedy et al. Journal of Advanced Nursing. 68.4, pp856-867. (April 2012). [doi: 10.1111/j.1365-2648.2011.05788.x](#)

Provided by Wiley

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