Psychosocial Distress Affecting Patients With Ductal Carcinoma in Situ Compared to Patients With Early Invasive Breast Cancer

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All nurses who care for patients with cancer should recognize the importance of the differences between ductal carcinoma in situ (DCIS) and early invasive breast cancer (EIBC). Most female patients with cancer hear only one word after being given a diagnosis: cancer. The nurses who care for these patients are the ones who help them understand their diagnosis. Whether the diagnosis is DCIS or EIBC, the severity and the perceived risk of recurrence or dying from the diseases needs to be addressed.

Prior to 1980, before the widespread use of screening mammography, DCIS was a rare diagnosis. DCIS accounted for 2%–5% of all newly diagnosed breast cancers (Cady & Chung, 2011). With the increased use of screening mammography, 40% of all breast cancers diagnosed by mammography are DCIS. DCIS is the fourth most common cancer diagnosed in women, and almost 60,000 new cases are diagnosed annually in the United States (Cady & Chung, 2011).

DCIS accounts for 20% of all newly diagnosed breast cancers (Cady & Chung, 2011). It often appears without warning in asymptomatic women, having been detected on routine screening mammography. The treatment of DCIS is basically the same as stage I EIBC, which includes a segmental mastectomy followed by radiation therapy (with or without tamoxifen if patients are sensitive to estrogen or progesterone) and, in the case of multifocal DCIS, with a mastectomy (Liu et al., 2010).

The general consensus is that pure DCIS has no metastatic potential. In addition, the cause-specific survival of DCIS, regardless of the type of therapy, is 96%–98%. It has been suggested that calling neoplastic cells that do not invade or metastasize carcinoma is an anomaly. Instead, it has been suggested that the term DCIS be replaced with ductal intraepithelial neoplasia (Veronesi, Zurrida, Goldhirsch, Rotmensz, & Viale, 2009).

EIBC is cancer that has spread from where it began, usually from the lobules (milk glands) or milk ducts. This occurs when cancer evolves from inside of the ducts or lobules and spreads into surrounding breast tissue. A difference between DCIS and EIBC is that, with DCIS, the cancer will grow inside the ducts; with EIBC, the cancer will have invaded surrounding breast tissue.
In advanced states, EIBC may spread cancer cells to other parts of the body via the bloodstream or lymphatic system. The axillary lymph nodes are usually the first area to which breast cancer will spread (Cancer.Net, 2014). DCIS is considered a noninvasive breast cancer.

Quality of Life

Quality of life in women with DCIS and EIBC is related to several issues, including the uncertainty of outcomes and an exaggerated fear of recurrence. In a study from Toronto, Canada, little difference was found between patients with DCIS compared to those with EIBC in their perception of risk of local recurrence (DCIS risk = 53%, EIBC risk = 45%), distant recurrence (DCIS risk = 36%, EIBC risk = 39%), and dying of breast cancer (DCIS risk = 27%, EIBC risk = 27%). Both groups expressed similar levels of psychological distress with anxiety and depression (Veronesi et al., 2009).

Fear of recurrence is a common concern among breast cancer survivors (Burstein, Polvak, Wong, Lester, & Kaelin, 2004) that results in a fear that the cancer could return in the same breast, opposite breast, or metastasizes to other parts of the body. It often results in psychological distress and lower quality of life (Liu et al., 2011). Patients appear to have difficulty differentiating DCIS from EIBC in terms of risk of recurrence or risk of dying despite that the risks associated with EIBC are 6–10 times greater. The risk of death for breast cancer at 10 years in DCIS is 2%, compared to 11.5% in EIBC (Rakovitch et al., 2003).

Perceived Risk of Recurrence

The perceived risk of recurrence is associated with psychological distress expressed by all patients with breast cancer. A lack of awareness between the different prognoses for DCIS and EIBC may be one cause of patients overestimating their actual risk of recurrence and death. Treatment for DCIS is similar to what patients with stage I EIBC receive (i.e., lumpectomy with radiation, segmental mastectomy with radiation, or a mastectomy). The similarity of treatment options may be, in part, responsible for some of the confusion women face when confronted with a diagnosis of DCIS (Liu et al., 2010).

Studies have found that women with DCIS report perceptions of risk recurrence and death similar to those found in women with EIBC despite the better prognosis with DCIS (Kennedy, Harcourt, & Rumsey, 2008; Liu et al., 2010). Fear of recurrence in DCIS has been found to be the most frequently reported unmet need for supportive emotional care (Liu et al., 2011). Nurses working with DCIS patients need to be aware of this, and treatment plans should include ongoing patient education to reduce the psychological and psychosocial distress that occurs from misperception of risk.

Anxiety and Depression

Women who overestimate their perceived risk of recurrence of cancer have elevated levels of anxiety and depression (Partridge et al., 2008). DCIS-related depression and anxiety could be reduced by adequate recognition from healthcare providers and appropriate established interventions. Research has shown that adequate information about EIBC and DCIS is related to decreased psychological stress and improved quality of life. Conversely, depression and anxiety were found to be increased in patients who believed that they had been poorly informed (Partridge et al., 2008). Understanding the factors associated with a patient’s perceived risk of recurrence and fear of death should be recognized and acknowledged by the nurse. Appropriate patient education and other interventions or protocols need to be developed so that nurses have a better understanding of ways to alleviate the psychological distress that results from these misperceptions.

Other Psychological Issues

Other important psychological and psychosocial issues in DCIS, in addition to perceived risk of recurrence and death, include the invisibility of DCIS, the uncertainty regarding the natural history of DCIS, the perception of DCIS (i.e., whether it is regarded as cancer or not), and the presence and degree of social support available to the patient.

Invisibility: The invisibility of DCIS is a significant issue (De Morgan, Redman, White, Cakir, & Boyages, 2002; Kennedy et al., 2008). Because DCIS is usually diagnosed in an asymptomatic woman on a routine mammogram, the diagnosis is unexpected and often occurs in women who feel well and healthy. Many women have never heard of DCIS. One study found that only 6% of women were aware that DCIS could be detected with mammography (Partridge et al., 2008). In addition, very little information is available about DCIS, and the information may be contradictory, compounding ambiguity and enhancing the patient’s distress (Kennedy et al., 2008). The invisibility of DCIS may also evolve from the lack of physical symptoms, which contributes to the shock and distress experienced when a diagnosis is made.

Unknown history: The unknown natural history of DCIS contributes to the uncertainty of the prognosis and long-term outcomes of the disease. This uncertainty is closely linked to the perception of recurrence. Patients are reassured that DCIS is noninvasive and not life threatening; however, patients are confused when they are then told that they will have surgery followed by radiation therapy, which is similar to EIBC treatment.

Perception: Because a diagnosis of DCIS is considered to have a generally positive prognosis, it may be assumed that the degree of psychological distress experienced would be less when compared to EIBC. However, that is not the case for patients diagnosed with DCIS because a different set of psychosocial issues can occur and cause the same degree of psychological distress. Studies have found that, in spite of the prognosis of DCIS, patients have serious concerns and similar psychological morbidity when compared to patients with EIBC (Kennedy et al., 2008). These uncertainties often interfere with an accurate perception of DCIS (Kennedy et al., 2008; Laenkholm, Jensen, Kroman, & Rank, 2008). Patients may ask questions that include the following.

• Do I have cancer or not?
• Is DCIS real breast cancer?
• Is this somewhere between normal and breast cancer?
• What does precancer mean?
• If I don’t have real cancer, why am I having a mastectomy?

The anxiety associated with the uncertainties and lack of an accurate perception is often heightened by the minimal risk associated with DCIS and expressed to the patient by the healthcare providers.
team. Therefore, DCIS provokes anxiety in the unsuspecting patient with a new diagnosis.

**Importance of Social Support**

The degree or lack of social support may influence the level of distress that results from inaccurate risk perceptions (Liu et al., 2011). By increasing social support, the anxiety and depression associated with inaccurate risk perceptions may help to alleviate psychological distress associated with DCIS. Lack of social support has been linked to poor health outcomes, and the availability of social support may decrease the recurrence of risk perceptions. Patients with greater availability of social

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**FIGURE 1. Questionnaire for Patients With DCIS and EIBC for Completion Prior to Initial Nursing Assessment**

Instructions: Please circle the answer that indicates your best response.

1. How would you describe your perception of your breast cancer risks for:
   a. Your cancer returning to the same breast?
      - Very low
      - Low
      - Moderate
      - High
      - Very high
   b. Your cancer spreading to other parts of your body?
      - Very low
      - Low
      - Moderate
      - High
      - Very high
   c. Your cancer spreading to the opposite breast?
      - Very low
      - Low
      - Moderate
      - High
      - Very high

2. How well do you feel your emotional needs are met by:
   a. Your healthcare providers, including your physician?
      - Not at all
      - Fairly well
      - Well
      - Very well
   b. Your spouse or significant other?
      - Not at all
      - Fairly well
      - Well
      - Very well
   c. Your family?
      - Not at all
      - Fairly well
      - Well
      - Very well
   d. Your friends?
      - Not at all
      - Fairly well
      - Well
      - Very well
   e. Your coworkers?
      - Not at all
      - Fairly well
      - Well
      - Very well

3. What do you think your risk is of dying from your disease?
   - None
   - Minimal
   - Moderate
   - High
   - Very high

4. Please rate your outlook for the future.
   - Not optimistic
   - Fairly optimistic
   - Optimistic
   - Very optimistic

5. Please rate your spouse/significant other’s understanding of your diagnosis and disease.
   - Limited
   - Minimal
   - Moderate
   - Well informed

6. Please rate your spouse/significant other’s support of your diagnosis and disease.
   - Limited
   - Minimal
   - Moderate
   - Well informed

7. Had you heard of DCIS or EIBC before you were diagnosed?
   - DCIS: Yes No
   - EIBC: Yes No

DCIS—ductal carcinoma in situ; EIBC—early invasive breast cancer

8. Did you gather information about your diagnosis? If so, how?
   a. Doctor or healthcare provider
   b. Internet
   c. Media (e.g., TV, radio, magazine, newspaper)
   d. National Cancer Institute, Cancer Information Services, or American Cancer Society
   e. Family, friends, or others. Please explain: ________________________
   f. Did not gather information

9. How satisfied were you with the information you received if you sought information?
   - Not satisfied
   - Fairly satisfied
   - Satisfied
   - Very satisfied

10. During your illness, have you experienced any of the following?
   a. Persistent fatigue .................................................Yes No
   b. Sleep disturbance ................................................Yes No
   c. Loss of interest in loved ones .................................Yes No
   d. Loss of interest in hobbies or activities ..................Yes No
   e. Social withdrawal ..............................................Yes No
   f. Feelings of worthlessness .....................................Yes No
   g. Hyperventilation ...............................................Yes No
   h. Recurrent thoughts of death .................................Yes No
   i. Feelings of helplessness ......................................Yes No
   j. Difficulty with memory .......................................Yes No
   k. Difficulty with concentration ...............................Yes No
   l. Difficulty with problem solving ............................Yes No
   m. Difficulty making decisions .................................Yes No

11. During your illness, have you experienced any of the following?
   a. Anxiety ..............................................................Yes No
   b. Panic attacks ......................................................Yes No
   c. Hypervigilance or increased alertness ....................Yes No
   d. Irrational fears ..................................................Yes No
   e. Irritability ........................................................Yes No
   f. Rapid heartbeat ..................................................Yes No
   g. Hyperventilation ...............................................Yes No
   h. Sudden feeling that you were going to die ..............Yes No
support have reported a decreased level of recurrence risk perceptions. Overall, social support can act as a buffer against poor psychological adjustment to stressful events, such as a diagnosis of breast cancer (Liu et al., 2010). Educating patients with EIBC and DCIS regarding the actual risk of the diseases may help influence more realistic risk recurrence perceptions. Increased social support also helps to alleviate the anxiety and depression that occurs with exaggerated risk perceptions (Liu et al., 2010).

Methods

A descriptive and qualitative design was used to explore psychological and psychosocial distress in patients with DCIS when compared to patients with EIBC. Patient ranged in age from 33–73 years for DCIS and from 37–74 years for EIBC, with a total of 32 patients enrolled in the study.

Each group of patients with DCIS and EIBC was asked to complete a questionnaire developed by the authors (see Figure 1), which helps to determine the perception of the degree of psychosocial distress. The questions dealt with breast cancer risks for returning cancer, what patients thought their risk of dying from their disease was, and how they rated their outlook for the future. They were also asked to rate their support system’s understanding of the diagnosis and the degree of support they received.

Written, informed consent was obtained by the Master’s-prepared nurse clinician who explained the nature of the study, objectives, and use of data for possible publication. Patients with DCIS and EIBC, regardless of their date of diagnosis, were eligible to participate. Patients with DCIS were eligible if they were without evidence of invasion, including microinvasion. Patients were enrolled in the study regardless of whether or not they had undergone surgical treatment. The study was conducted at the Ellis Fischel Cancer Center in Columbia, Missouri, a comprehensive cancer center that is part of a university-based healthcare system, and was approved by the institutional review board.

Findings

Both groups were asked to rate their perception of breast cancer risks on a five-point Likert-type scale, with 1 being very low and 5 being very high. Overall, responses showed little difference between the study groups. Despite the different medical risks of recurrence, the means of DCIS and EIBC groups showed low levels of psychological distress when asked to describe their perceived level of risk for the cancer returning to the same breast, spreading to the opposite breast, and spreading to other parts of the body (see Table 1).

Patients in this study indicated an optimistic outlook for the future regardless of the difference in diagnosis. This has significant meaning for nurses working with patients with DCIS and EIBC because the patients’ perception dictates plans for nursing care and the teaching plan, which are incorporated into the final medical plan of care. These findings shape the manner in which the nurse assesses and reassesses the plan of care and teaching about the respective diseases. It should differ for patients with DCIS and EIBC as the nurse develops the plan of care and teaching.

The mean scores for DCIS and EIBC were similar when examining perceived risk of dying on a five-point Likert-type scale where 1 indicated no perceived risk of dying and 5 indicated a highly perceived risk of dying. The responses suggested that both sets of patients experienced low levels of distress in terms of their disease causing death.

Given the more serious outcome of EIBC when compared to DCIS, both sets of patient groups also demonstrated an optimistic response when asked a general question on the outlook for the future. On a four-point Likert-type scale where 1 was not optimistic and 4 was very optimistic, both groups had similarly strong optimistic visions for the future. These similarities in optimism for their futures can be partially explained by the fact that both groups also received strong support and understanding from their spouses or significant others. When asked about their partner’s understanding of the disease on a four-point scale where 1 was no understanding and 4 was well informed, both groups felt that their partner’s understanding was moderate to well informed. Both groups felt that they received moderate to high support from their spouses or significant others.

<p>| TABLE 1. Perception of Breast Cancer Risk, Outlook for the Future, and Spousal Support and Understanding in Patients Diagnosed With DCIS and EIBC (N = 32) |</p>
<table>
<thead>
<tr>
<th>Response</th>
<th>DCIS (n = 17)</th>
<th>EIBC (n = 15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>SD</td>
<td>X</td>
</tr>
<tr>
<td><strong>Perceived Risk</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer returning to the same breast</td>
<td>1.6</td>
<td>1.1</td>
</tr>
<tr>
<td>Cancer spreading to the opposite breast</td>
<td>1.9</td>
<td>1</td>
</tr>
<tr>
<td>Cancer spreading to other parts of the body</td>
<td>2.4</td>
<td>1.3</td>
</tr>
<tr>
<td><strong>Perceived Outlook</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk of dying from the disease</td>
<td>2</td>
<td>0.9</td>
</tr>
<tr>
<td>Outlook for the future</td>
<td>3.5</td>
<td>0.7</td>
</tr>
<tr>
<td><strong>Spousal Support and Understanding</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding</td>
<td>3.3</td>
<td>1</td>
</tr>
<tr>
<td>Support</td>
<td>3.7</td>
<td>0.8</td>
</tr>
</tbody>
</table>

*Scale ranges from 1–5, with 1 being very low and 5 being very high.

**Scale ranges from 1–4, with 1 being not optimistic and 4 being very optimistic.

*Scale ranges from 1–4, with 1 being no understanding and 4 being well informed.

DCIS—ductal carcinoma in situ; EIBC—early invasive breast cancer
Implications for Practice

- Include a clear definition of psychological and psychosocial issues that are unique to each patient, including the level of depression or anxiety, in each nursing assessment.
- Perform ongoing patient education to reduce psychological and psychosocial distress that can result from misperception of the risk of recurrence.
- Educate patients with early invasive breast cancer and ductal carcinoma in situ about the actual risk of recurrence, which may lower perceived risk of recurrence.

References


