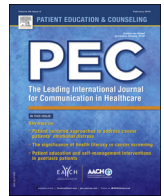




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Review article

Treatment decision-making in ductal carcinoma in situ: A mixed methods systematic review of women’s experiences and information needs

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ABSTRACT

Objective: Decision-making in ductal carcinoma in situ (DCIS) is complex due to the heterogeneity of the disease. This study aimed to understand women’s experience of making treatment decisions for DCIS, their information and support needs, and factors that influenced decisions.

Methods: We searched six electronic databases, conference proceedings, and key authors. Two reviewers independently applied inclusion and quality criteria, and extracted findings. Thematic analysis was used to combine and summarise findings.

Results: We identified six themes and 28 subthemes from 18 studies. Women with DCIS have knowledge deficits about DCIS, experience anxiety related to information given at diagnosis and the complexity of decision-making, and have misconceptions regarding risks and outcomes of treatment. Women’s decisions are influenced by their understanding of risk, the clinical features of their DCIS, and the benefits and harms of treatment options. Women are dissatisfied with the decisional support available.

Conclusions: Informed and shared decision-making in this complex decision setting requires clear communication of information specific to DCIS and individual’s, as well as decision support for patients and clinicians.

Practice implications: This approach would educate patients and clinicians, and assist clinicians in supporting patients to an evidence-based treatment plan that aligns with individual values and preferences.

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1. Introduction

Ductal carcinoma in situ (DCIS) is variously described as pre-cancerous, pre-invasive, non-invasive or Stage 0 breast cancer [1]. It accounts for 15–40% of all new screen-detected cases of breast cancer internationally [2–6]. Treatment for DCIS reduces the risk of recurrence or progression [7,8], but can have adverse consequences [9–11]. Currently available treatments include mastectomy (with or without reconstruction) or breast conserving surgery (with or without radiotherapy), and adjuvant endocrine therapy (e.g. tamoxifen) [12]. Breast cancer-specific mortality of patients treated with these therapies is low [13,14].

Treatment decision-making for DCIS is complex; controversy exists about the optimal management of DCIS resulting in variations in practice [15]. Over-treatment of low risk DCIS is a growing concern because of potential consequences including psychological and behavioural effects of disease labelling, reduced quality of life (QOL) from unnecessary treatment, increased costs to individuals, and wasted resources to the health system [16]. At present, treatment decisions for DCIS are guided by the clinical and radiological features of the tumour and their prognostic significance. However, since prognosis is excellent [13], there is considerable scope for patient preference to be integral in decision-making [17].

Deciding about treatment for DCIS can be difficult and stressful for patients. This is due both to the complexity of information provided about prognosis, treatment benefits, side-effects and the risk of recurrence or developing invasive disease, and perhaps most importantly the way this information is communicated [18–21]. Communicating information about disease status and prognosis can be difficult for health professionals, and some women have difficulty understanding this information [21]. DCIS patients often do not distinguish between DCIS and invasive breast cancer, and often overestimate their risk of breast cancer recurrence [17]. Thus, it is important to understand the information and decisional support needs of women diagnosed with DCIS to provide appropriate care, support and information [14].

The aim of this systematic review was to identify and synthesise evidence about women's experience of making treatment decisions for DCIS, factors that influence treatment decisions (patient, medical and organizational), and information needs to facilitate informed treatment decision-making.

2. Methods

2.1. Searches

We searched six electronic databases: AMED, MEDLINE, Embase, PsycINFO, CINAHL and Scopus from database inception

to November 2015. The search strategy comprised of terms for "DCIS" and "decision-making" (Appendix A). No language restrictions were applied. To supplement this, we searched: 1) the reference lists of included studies and relevant systematic reviews; 2) conference proceedings; and 3) electronically by author name of key researchers identified in relevant literature.

2.2. Study selection and eligibility

Studies were included if they met the following criteria:

2.2.1. Qualitative

- The sample was clearly defined as women diagnosed with DCIS; and
- The study aimed to explore/identify/describe women's experience of deciding treatment for DCIS (e.g. knowledge about DCIS, risks and treatment options; satisfaction with information and decision-making; fear of recurrence; decisional regret) or factors that influenced decisions (e.g. toxicities, family history) by direct patient-reports.

2.2.2. Quantitative

- The study included only women diagnosed with DCIS or reported results for DCIS women separately (e.g. in studies that also included invasive breast cancer patients);
- The DCIS sample was ≥10 per outcomes assessed;
- The study aimed to compare decision-making outcomes or determine factors/predictors of treatment choice; and
- Data was collected using a valid, self-reported instrument.

We were specifically interested in experiences and outcomes related to *treatment* decision-making. We therefore excluded studies focused on decisions regarding breast screening.

Retrieved titles and abstracts were reviewed for eligibility by one reviewer (CR). If all criteria were met, or relevance was ambiguous, full-text papers were obtained. A second reviewer (research assistant) screened 25% of excluded abstracts, selected at random. Two researchers (CR, research Assistant) independently assessed papers against the eligibility criteria. Disagreements were resolved through team discussion.

2.3. Quality assessment

The QualSyst quality appraisal tool [22] was used to assess the quality of included studies. Each quality criterion was assessed as being met (yes/partial/no) by two reviewers independently (CR and RMB or JLW). Quality assessments were cross-checked for consistency. In the case of scoring disagreements, a third reviewer

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