The experiences of women diagnosed with ductal carcinoma in situ (DCIS), key communication challenges, and strategies to address them

Simone Elizabeth De Morgan
BMedSci (Hons)
Doctor of Philosophy (Behavioural Science)
School of Medicine and Public Health
University of Newcastle
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Simone De Morgan
University of Newcastle
May 2012
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two women who died of breast cancer
during the period of my study

my mother
Margaret Josephine Brown

and

my supervisor
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Abstract

The incidence of ductal carcinoma in situ (DCIS) has increased substantially since the advent of widespread breast screening mammography. Unlike invasive breast cancer, DCIS cannot metastasize and a woman cannot die from DCIS unless it develops into invasive breast cancer. However, the natural history of DCIS is not well understood and it is currently not possible to accurately predict which women with DCIS will go on to develop invasive breast cancer. Clinicians are faced with unique communication challenges arising from the fact that DCIS is not an invasive cancer and that the diagnosis, prognosis and treatment of DCIS involve much uncertainty. This thesis sought to understand the experiences of women diagnosed with DCIS by conducting a systematic review of the qualitative and quantitative evidence about the experiences of women with DCIS and a cross-sectional survey of women with DCIS in Australia (N=144). Based on this evidence, recommendations were developed for clinicians about how to effectively communicate with women diagnosed with DCIS. The author examined how and to what extent doctors currently communicate in accord with these recommendations by analysing audio-taped initial diagnostic consultations (N=30) with surgeons (n=13) and women with DCIS at BreastScreen centres in Australia. This study identified factors that are likely to impede women’s understanding about their diagnosis and demonstrated the need to develop strategies to improve practice. A DCIS communication aid (CA) was developed and pilot tested to assist clinicians to communicate the diagnosis and treatment of DCIS with women. The CA is currently available in print and online at Cancer Australia. Further evaluation and dissemination of the CA into routine clinical practice, further development and implementation of the recommendations, and incorporation of the CA and recommendations into communication skills training programs has the potential to improve doctor-patient communication about DCIS and increase the well-being and health outcomes of women with DCIS.