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Exploring patient experiences of neo-adjuvant chemotherapy for breast cancer

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ABSTRACT

Background and purpose: Neo-adjuvant chemotherapy is recommended for 'inoperable' locally advanced and inflammatory breast cancers. For operable breast cancers, trials indicate no survival differences between chemotherapy given pre or post-surgery. Communicating evidence based information to patients is complex and studies examining patient experiences of neo-adjuvant chemotherapy are lacking. This study aims to explore the experiences of women who received neo-adjuvant chemotherapy for breast cancer.

Methods: A qualitative approach using in-depth interviews with 20 women who had completed neo-adjuvant chemotherapy for breast cancer. Interview data were analysed using thematic analysis.

Results: The sample included a relatively young group of women, with caring responsibilities. Five main themes emerged: coping with the rapid transition from 'well' to 'ill', information needs and decision making, needing support and empathy, impact on family, and creating a new 'normal'. More support was needed towards the end of chemotherapy, when side effects were at their most toxic, and decisions about forthcoming surgery were being made. Some women were referred to psychological services, but usually when a crisis point had been reached.

Conclusion: Information and support would have been beneficial at key time points. This information is vital in developing services and interventions to meet the complex needs of these patients and potentially prevent late referral to psychological services. Specialist oncology nurses are able to develop empathetic relationships with patients and have the experience, knowledge and skills to inform and support women experiencing neo-adjuvant chemotherapy. Targeting key time points and maintaining relationship throughout neo-adjuvant chemotherapy would be highly beneficial.

1. Background

Chemotherapy has become a major cancer treatment modality, with increasingly toxic regimes aimed at improving outcomes (Del Mastro et al., 2002). Side effects of chemotherapy are numerous and can be immediate (e.g. facial and bodily flushing, hypotension, abnormal tastes and smells), short term (e.g. nausea, vomiting, gastro-intestinal disturbances, stomatitis) and long term (e.g. alopecia, renal toxicity, sexual dysfunction, fatigue) (Dougherty and Bailey, 2008). Given the severity of side effects, patients are likely to have a number of concerns, many of which may not be identified by nurses (Farrell et al., 2005), with discrepancies between patient and health care professional (HCP) perceptions of priority concerns (Mulders et al., 2008).

While there is much literature on the physical side effects of chemotherapy, there is far less evidence on the psychosocial impact of chemotherapy. Chemotherapy is distressing and can have a long term impact on quality of life (Ganz et al., 2002). Women undergoing chemotherapy have reported priority concerns relating to current illness, the future, inability to do things and physical symptoms (Farrell et al., 2005). For breast cancer survivors the most important issues in relation to the impact of cancer and chemotherapy have been reported as fear of metastases, fatigue, consciousness of one's own vulnerability, hair loss and nausea (Mulders et al., 2008). A qualitative study carried out in the UK with both male and female patients has shown that chemotherapy imposes drastic changes in social and emotional wellbeing as well as

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negative impacts on concentration and memory (Mitchell 2007). Mitchell (2007) reported on a desire to return to normality and regain control over life compounded by concerns over children. Although partners and spouses were reported as supportive, teenage children were described as unsupportive (Mitchell 2007).

For women diagnosed with breast cancer who require adjuvant treatment, it is usual to offer chemotherapy after surgery. However, chemotherapy can also be given prior to surgery. Neo-adjuvant chemotherapy (also referred to as pre-operative chemotherapy or primary systemic therapy) is commonly recommended for locally advanced and inflammatory breast cancers; cancers often defined as *inoperable* with a poor prognosis (Chia et al., 2008). The advantages of neo-adjuvant therapy in locally advanced and inflammatory breast cancers include earlier treatment of subclinical micro metastases, downstaging of the primary tumour (which may allow an inoperable tumour to become operable) and the ability to assess response to therapy (Chia et al., 2008). For some patients with locally advanced disease (but not inflammatory cancer) conservative surgery may emerge as a treatment option (Gralow et al., 2008). A major disadvantage of pre-operative chemotherapy is the potential for considerable delay before surgery for patients whose tumours prove resistant to neo-adjuvant chemotherapy (Van der Hage et al., 2009). Neo-adjuvant chemotherapy for women with *operable* breast cancer is not clearly defined as yet although trials indicate no difference in survival between women treated pre or post-surgery (Van der Hage et al., 2009).

Selecting patients for neo-adjuvant therapy and communicating evidence based information is clearly complex, particularly for women diagnosed with more aggressive and/or advanced cancers. It can be argued that surgery, cutting out the problem, is readily understood whereas systemic treatment is more complex to understand (Beaver et al., 2005). It has been shown that breast care nurses (BCN) are an important source of information and support, helping women cope with their disease (Beaver et al., 2009; Cruikshank et al., 2008). However, for those women who receive neo-adjuvant treatment, it is not clear what their specific needs and concerns are and how services can best be organised to meet those needs. Research is lacking on the specific needs, concerns and experiences of women who receive neo-adjuvant chemotherapy for breast cancer. Understanding these could help to target information, psychological support and interventions more appropriately. In addition, there is little research on how best to enable the decision making process for women who are faced with choices about whether to have chemotherapy before or after surgery. An understanding of the important factors determining patient preferences for different treatment options would enable more effective interventions to be developed and evaluated that would assist the decision making process. However, if neo-adjuvant chemotherapy is required due to the size or type of tumour and there are no choices presented then it is important to examine how this information is conveyed to patients and whether they fully understand the rationale behind clinical decisions.

2. Objective

This study aimed to explore the experiences of women who received neo-adjuvant chemotherapy for breast cancer to determine psycho-social, information and support needs.

3. Methods

Qualitative methods are well suited to exploring subjects where little is known and for gaining new insights and fostering deeper understanding of particular phenomena (Morse and Richards 2012). As we could find no evidence of previous studies that examined the experiences of women with breast cancer who undergo neo-adjuvant chemotherapy, a qualitative study was justified as an initial exploratory step. We did not take a theoretically driven qualitative approach but chose a more generic approach as our intention was to focus more pragmatically on the clinical research question than the philosophical underpinnings. We acknowledge that there are interesting debates on theoretical versus generic approaches in qualitative research (Smith et al., 2011; Sandelowski, 2000). We chose to use a qualitative descriptive approach as this involves remaining close to the data and is particularly suited to answering questions that have relevance for practitioners and policy makers (Sandelowski, 2000). Individual in-depth interviews were chosen as the most suitable method for obtaining rich and detailed data, exploring individual personal perspectives to generate an in-depth understanding of the particular subject area (Ritchie and Lewis, 2006).

3.1. Study location

Study participants were recruited from four hospitals across Lancashire and South Cumbria in the North West of England that served an estimated population of 1.6 million residents in diverse geographical areas, allowing for recruitment of participants who may have had different experiences in terms of service provision and support.

3.2. Sample and sample size

Women were identified as suitable to take part in the study if they had undergone neo-adjuvant chemotherapy for breast cancer between May 2012 and April 2013. To maximise women's recall of events we did not recruit any individuals who were further than 12 months post chemotherapy. The number of interviews conducted was limited by study duration but was also guided by emergent findings and reaching a point at which no new information emerged.

3.3. Access and recruitment

Ethical approval was obtained from the National Research Ethics Service in the UK and from the Research and Development departments at study sites. Specialist BCN's at the study locations were asked to identify suitable participants who met the inclusion criteria and to contact eligible women, describing the study and inviting participation. Potential participants were offered contact from a researcher, who discussed the study further and provided information sheets, consent forms and postage paid reply envelopes (for return of consent forms). Potential participants were asked to return a signed consent form, after which a suitable date and time for interview was arranged.

3.4. Interviews

In depth face-to-face interviews were carried out with participants by two researchers experienced in qualitative data collection and analysis. All interviews were audio-recorded and transcribed using a professional transcribing service. An interview guide was constructed for the study to address the following areas: how information and choices about chemotherapy were communicated; patients experiences of neo-adjuvant chemotherapy and the support needed; patient views on the delay to surgery; views on adequacy of service provision; any concerns experienced during treatment (physical, psychological, social); psychological distress and referrals to psychological support services; information needs: what information was needed, sources of information (Fig. 1). In

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