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Return to work after breast cancer: Women's experiences of encounters with different stakeholders

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ABSTRACT

Objective: Long-term sickness absence is common among women with breast cancer and more knowledge, from the individuals' perspective, is needed regarding factors that influence their return to work (RTW). The aim was to gain knowledge about women's experiences of encounters regarding RTW after breast cancer surgery.
Methods: Qualitative content analysis was applied to data obtained in four focus group interviews with 23 women treated for breast cancer regarding aspects of RTW.
Results: The women talked about encounters regarding RTW they had had with the following stakeholders: social insurance staff, employers, colleagues, healthcare personnel, family, and friends. Three categories of such encounters were identified, involving: (i) adjustments associated with the women's needs (e.g., at work, handling sickness benefits, or care), (ii) information shared with the women (e.g., concerning sickness insurance or side effects of treatment), and (iii) attitudes perceived and appraised by the women, respectively. The third category comprised two subcategories of stakeholders' attitudes: those concerning work adjustments or being sickness absent, and those directed towards the women themselves, respectively.
Conclusions: Women with breast cancer experience that encounters with many different types of stakeholders affect their RTW. Important aspects of the encounters are what attitudes the professionals convey, what information the women receive, and whether adjustments of relevance are discussed. A mutual knowledge about other stakeholders involved in the RTW process and how the women are encountered by others, may be useful for each stakeholder to facilitate a closer collaboration in order to find flexible solutions and adjustments for individuals which in turn may facilitate RTW.

Introduction

Breast cancer is the most prevalent malignancy among women globally, with approximately 1.38 million new cancer cases yearly (WHO, 2008). Of these, several are in working ages, and e.g. in Sweden 54% of all women diagnosed with breast cancer are below 65 years of age (National Board of Health and Welfare, 2007). Both the number of women diagnosed and the survival rate are increasing; the 5-year survival rate now is 89% in Western countries (Parkin et al., 2005). Accordingly, a vast number of young and middle-aged women in the workforce already have, or will get, breast cancer, and hence most of them face the issue of return to work (RTW) during or after treatment.

Several studies have focused on quality of life of women with breast cancer (Ganz et al., 2002; Ahles et al., 2005), and in some studies attention has also been given to the process of RTW among survivors (Maunsell et al., 1999; Drolet et al., 2005a; Main et al., 2005; Bouknight et al., 2006; Fantoni et al., 2010; Johnsson et al., 2010). Work is an important factor in the lives of individuals, providing not only financial security, but also health, social contacts, and a sense of contributing (Ferrell et al., 1997; Friesen et al., 2001; Holland-Elliot, 2004). It has been shown that having gainful employment has a positive influence on the quality of life and that women with cancer describe work as a normalizing factor (Bowling, 1995; Kennedy et al., 2007; Rasmussen and Elverdam, 2008; Frazier et al., 2009; Johnsson et al., 2010). However, some studies have shown RTW after breast cancer to be associated with

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several problems, such as discrimination, demotions, and diminished work capacity (Maunsell et al., 2004; Bouknight et al., 2006). Therefore, more detailed knowledge, from different perspectives, about various aspects of RTW is needed.

The following factors have been identified to affect RTW among cancer survivors; severity of disease, type of treatment, individual characteristics and the physical and social environment of the patient (Bouknight et al., 2006; Nachreiner et al., 2007; Amir et al., 2008; Amir and Brocky, 2009; Boykoff et al., 2009; Hassett et al., 2009; Steiner et al., 2010). In addition, there are large differences between different cancer diagnoses, regarding effect on work capacity and duration of sick leave. Examples are individuals with prostate cancers having a lower risk for unemployment compared to women with breast cancer, and an even lower risk compared to e.g. cancers in the central nervous systems. Furthermore, individuals with breast cancer have been shown to have longer time to RTW, regardless of grade of RTW, in comparison to those diagnosed with genital cancer or skin cancer, although women with breast cancer have a much shorter time to RTW than among those with lung cancer or blood malignancies (de Boer et al., 2009; Roelen et al., 2010). Therefore, more diagnosis-specific knowledge is warranted. Moreover, in studies of RTW when sickness absent with other diagnoses, mainly musculoskeletal or mental, also another factor has been found to impact RTW, namely how the patient experiences encounters with different healthcare or social insurance professionals (Svensson et al., 2003, 2006; Verbeek et al., 2003; MacEachen et al., 2006; Müssener et al., 2008). In one study it was found that encounters from healthcare professionals had the same impact on RTW as the rehabilitation measures provided (Östlund et al., 2001).

Women with breast cancer encounter several professionals from different stakeholders, e.g. from healthcare, insurance, and work, however, more knowledge is needed about the content of these encounters concerning RTW, from the perspective of the women. Studies in this group of women are needed in order to gain knowledge whether women with breast cancer and e.g. women with musculoskeletal diseases are encountered differently and whether the cancer trajectory, its acuteness and its potential life threat influence the encounters.

Aim

The aim of this study was to gain knowledge about women's experiences of encounters with stakeholders regarding RTW during and after breast cancer trajectory.

Subjects and methods

Transcribed data from four focus group interviews with 23 women were subjected to qualitative content analysis.

Sampling

The sampling frame comprised the participants in an ongoing large-scale prospective cohort study of women, aged 20–63, who lived in an urban area of Sweden and had had breast cancer surgery. Inclusion criteria were; first time diagnosed with breast cancer, no known metastases, Swedish speaking, having answered a baseline questionnaire in the project, worked prior to diagnosis, and had had surgical treatment 3–13 months prior to the interviews. The specified timeframe was chosen to ensure that each woman at least had the opportunity to consider RTW. The included women may also have had different types of post-surgical treatment, e.g. chemotherapy or hormone therapy. Women with previous breast cancer or metastasized cancer were excluded since they have significantly poorer prognosis, which may have consequences for the length of sickness absence or overall RTW possibilities.

To increase the homogeneity of the focus groups, as has been recommended to facilitate discussions (Krueger, 1994; Wibeck, 2000), we chose to include women strategically to each focus group, according to type of treatment (chemotherapy: yes vs. no) and age (<55 vs. ≥55), respectively. This means that four focus groups were organized; two with women given chemotherapy (one with older and one with younger women), and two with women not given chemotherapy (one with younger and another with older women). The rationale for the composition of the groups was that chemotherapy often effect work capacity during a longer period (Drolet et al., 2005b; Bouknight et al., 2006; Balak et al., 2008; Johnsson et al., 2009) and that RTW possibilities might differ with age (Drolet et al., 2005b). Also, the women in all four groups could have been given additional types of treatment after the surgery, e.g. radiotherapy and/or hormonal treatment.

All 59 women who fulfilled the inclusion criteria at the time of sampling in 2008 received a letter inviting them to participate in a focus group interview at a specific date. As each woman was invited to a certain focus group, fitting the strategic sampling, it was not possible to change group if the woman was unable to attend that date. Nevertheless, as many as 23 of the women (39%) participated.

Interview guide

An interview guide was developed based on findings in previous studies (Svensson et al., 2003,2006; Müssener et al., 2008) and on experiences and discussions in the multi-professional project group. The guide included an introduction to the focus of the interview (RTW), the procedure, and topics relevant for the study such as which different stakeholders the women had had communication with regarding RTW, how this was conveyed, and how the women felt about these encounters.

Procedure

A letter of invitation explaining the aim of the focus groups was sent by regular mail to the home address of each woman. Voluntariness was stressed, and the women were informed about confidentiality.

The four focus group interviews were conducted on evenings in November 2008 at a hospital, in a location separate from the treatment facilities. Moderator was one of the authors (MO), who is an experienced group leader. The first author (MN) was assistant moderator, observing and handling the technical apparatus. Each interview was summarized orally at the end of the session, giving the participants the opportunity to correct and add statements (Krueger, 1998). The interviews were audio recorded and transcribed verbatim. After the first focus group, the transcript was read to determine whether there was a need to modify the guide or the interview procedure. No changes were found to be necessary. To ensure the validity of transcripts, they were read simultaneously with listening to the audio files.

Distribution and characteristics of the participants of each group were as follows:

- four, aged 55–61, received chemotherapy,
- seven, aged 37–51, received chemotherapy
- seven, aged 57–62, received no chemotherapy
- five, aged 42–54, received no chemotherapy

Other demographic characteristics are presented in Table 1. Data on demographics, occupation, work situation, and type of treatment were obtained from the baseline questionnaires and from medical