



## Breast and ovarian cancer survivors' experience of participating in a cognitive-existential group intervention addressing fear of cancer recurrence



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### A B S T R A C T

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**Purpose:** Currently, very few clinical approaches are offered to cancer survivors dealing with fear of cancer recurrence (FCR). This paper provides an overview of cancer survivors' experience and satisfaction after taking part in a six-week, cognitive-existential (CE) group intervention that aimed to address FCR. **Method:** In this qualitative descriptive study, 12 women with breast or ovarian cancer provided in-depth interviews of their experience in taking part in the CE group intervention.

**Results:** Analysis of their accounts revealed struggles to face their fears. Yet, by embracing their group experience, the women learned how to confront their fears and gain emotional control. The women reported that the group work was highly valuable.

**Conclusion:** From the women's analysed accounts, the authors have proposed recommendations for changes to the group work process before moving the study to a full clinical trial. The study's findings also provide valuable insights to other cancer survivor groups who may also be experiencing FCR.

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### Introduction

Fear of cancer recurrence (FCR) has been described as the sword of Damocles that hangs over patients' heads for the rest of their lives (Vickberg, 2003). Common themes that emerge include fear of death, further treatment, emotional distress, pain, suffering of and leaving behind loved ones, and loss of breast (Johnson Vickberg, 2001). The literature suggests that a little more than half of all cancer survivors will experience some form of moderate to high levels of FCR (Llewellyn and et al., 2008; van den Beuken-van Everdingen and et al., 2008). Unlike other forms of psychological distress, this form of distress does not dissipate over time (Lebel and et al., 2007).

Moderate to high levels of FCR can lead to psychological consequences, including anxious preoccupation and excessive checking (Lee-Jones and et al., 1997). Despite the prevalence of FCR, past studies are mostly descriptive with few psychosocial intervention studies to address FCR. A recent pilot intervention study reported findings from a group of women with breast or ovarian cancer who took part in a six-week cognitive-existential (CE) group intervention directly targeting FCR as the main outcome of change (Lebel and et al., 2014). One of the aims of the pilot study was to demonstrate participant acceptance and perceived benefits of a new intervention (Leon et al., 2011). This paper reports on findings obtained from interviews with 12 of the 44 women with breast or ovarian cancer who took part in the six-week CE group intervention from the pilot intervention study. The aim of conducting end-of-intervention interviews was to document the women's overall experience and satisfaction with their participation in the FCR group intervention, and to further inform the initial study intervention for refinement before moving to a full trial.

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## Counselling approaches to fear of cancer recurrence

Of the 191,300 new cases of cancer estimated in Canada in 2014, 26% will be women with breast cancer and 2.9% with ovarian cancer (CCS, 2014). In 2014, it is estimated that 24,400 women will be diagnosed with breast cancer and 2700 with ovarian cancer across Canada (CCS, 2014). The relative survival rate past five years post-diagnosis for ovarian cancer is 35% and 88% for breast cancer. This means that approximately 21,472 women will survive breast cancer, and individuals living with cancer are increasing at a rate of 2.4% per year (CCS, 2014). Cancer survivors have a unique subset of needs. While there is a variety of issues that might concern a cancer survivor, such as residual treatment impacts or altered body image, cancer survivors rank fear of cancer recurrence as one of their predominant psychosocial concerns (Hodgkinson and et al., 2007; Urbaniec and et al., 2011). Fear of cancer recurrence (FCR) has been defined as the “fear or worry that the cancer will return or progress in the same organ or in another part of the body” (Vickberg, 2003). FCR is common among cancer survivors, with reported ranges of prevalence from 22% to 99% (Crist and Grunfeld, 2012), and can be a profound and persistent difficulty affecting quality of life (Simard and et al., 2013). Despite such prevalence, to date there has been little attention in how to clinically address this fear. Other than a recently published pilot study on FCR (Lebel and et al., 2014), there has been only one published study of group intervention addressing fear of disease progression among a mixed population of individuals with cancer or chronic arthritis (Herschbach and et al., 2010). This study found that both a cognitive-behavioural group intervention and a supportive-expressive group approach (serving as the control condition and expected to be less effective in reducing FCR) succeeded in decreasing fear of disease progression among group participants. However, the study findings are limited by their sample selection being focused on inpatients and on those with recurrence or metastases. Additionally, external validity of the findings is limited, as the control group was recruited after both intervention groups were completed.

In general, cognitive-behavioural groups have been shown to be beneficial in cancer populations (Thewes and et al., 2013). For example, among women with breast cancer, cognitive behavioural therapy (CBT) is known to reduce psychological distress and improve coping (Sheldon and Barnett, 2012; Simard et al., 2010). Similar to CBT but with an existential component, CE therapy has also been used effectively to reduce psychological distress and enhance cognitive attitudes in women with breast cancer (Kissane and et al., 2003). In the authors' pilot study (Lebel and et al., 2014), a CE approach was used combining principles of CBT (e.g., cognitive reframing and relaxation techniques) and existential therapy principles (e.g., redefining life priorities, confronting fears). This combination is particularly relevant to FCR, where patients experience existential fears, such as the fear of premature death. Group work exercise in the pilot study aimed to address anxiety about cancer recurrence, living with continued heightened uncertainty, possible symptoms of cancer recurrence, misbeliefs about the benefits of worry, fear of further treatment, fear of death, and the de-catastrophizing of perceived worst-case scenarios. In the group, the women were also invited to set goals, with a particular emphasis on the making of future plans. Cognitive existential therapy further emphasizes education, cognitive reappraisal, and enhanced coping in conjunction with existentially oriented strategies (Kissane and et al., 2003). Group interventions specifically tend to focus on fear of treatment, fear of death, freedom of choice, personal responsibility and priority, developing future plans, and authentic living (Kissane and et al., 2003). In addition, relaxation exercises are often included, such as progressive muscular relaxation, guided imagery, mindfulness, body scanning, calming self-talk phrases, and grounding exercises.

The addition of a qualitative study to the initial pilot intervention study provides more in-depth descriptions of the experiences of the women who participated in the group sessions. For example, from the recently published findings from the pilot study on the FCR group intervention (Lebel and et al., 2014), we found that the intervention succeeded in decreasing FCR, cancer-specific distress, and uncertainty surrounding cancer. The group work also improved participants' quality of life and increased their use of two coping strategies: acceptance and positive coping. Yet, further participants' insight and feedback was needed to further document and understand what part of the clinical intervention experience was viewed as relevant and helpful at reducing FCR. Such an approach of obtaining findings from qualitative and quantitative studies enhances knowledge translation success.

## Methods

In order to provide a comprehensive understanding of the experiences and thoughts of women about their participation in the CE group intervention, a qualitative descriptive design was used (Magily and Thomas, 2009; Sandelowski, 2000) incorporating semi-structured in-depth interviews. The study's aim was to produce thick descriptions and interpretations of the meanings participants made of their participation in a CE group intervention. Ethics approval for the study was obtained from the Research Ethics Boards of each of the investigators' primary affiliated institutions and from the recruiting agency.

### *The cognitive existential group intervention*

In the pilot CE group intervention study (Lebel and et al., 2014), a total of 44 women received the intervention for a total of 9 groups of 5–8 women with either breast (7 groups) or ovarian cancer (2 groups). The group intervention ran for 90 min, once a week, for 6 weeks. Potential participants met with a psychosocial professional prior to the start of each new group to review group work expectations, such as the exchange of feelings on FCR. Each group exclusively comprised of either breast or ovarian cancer patients. Each group was led by two trained psychotherapists (i.e. psychologists, social workers, or nurses). All authors listed except for C.T. and M.J.E. led some of the intervention groups). Table 1 outlines the content of the six sessions. In each session, participants were given exercises to complete during the session as well as at home. Each session began with a review of previously assigned homework. The group leaders were instructed to process difficult feelings participants shared and encouraged each participant to share their experience with FCR.

The manualised group intervention was adapted from a previous model of a group CE therapy developed by Kissane et al. (Kissane and et al., 2003) for women with breast cancer. Our intervention was also guided by the Leventhal's Common Sense Model (Lee-Jones and et al., 1997) and Mishel's Uncertainty in Illness Theory (Mishel, 1988). Our group approach included teaching coping strategies such as cognitive reframing and relaxation (Gil and et al., 2006; Mishel and et al., 2005) to manage the accompanying distress associated with FCR. A visit by a nurse specialist in either breast or ovarian cancer also provided an educational 45-min presentation on the possible signs and symptoms of cancer recurrence; this visit occurred in session 2.

### *Recruitment and sampling*

The methods and study sample are reported in further detail in the published pilot intervention study (Lebel and et al., 2014). In this qualitative study, women were recruited from January 2010 to

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