

## **STTI/CNF Grant Project Report**

Project Title: A study of coping with fear of cancer recurrence among ovarian cancer survivors living outside of large metropolitan centres: The FEARLESS Study

### **Summary of project aims**

The purpose of this study was to examine how ovarian cancer survivors living outside of large urban centres cope with one of their most common concerns, their fear of cancer recurrence (FCR). A small number of interventions to help survivors cope with FCR are currently being tested, however, the majority of these interventions are only available to survivors living in large urban centres. Given that that survivors living outside of urban settings report higher psychological morbidity than their urban counterparts, suggests that the FCR of non-urban cancer survivors is an important topic to explore so that relevant interventions (e.g., online group interventions) can be developed. To this end, this qualitative study was undertaken to explore the coping strategies and styles of ovarian cancer survivors living outside of major urban centres. Specific study objectives were: (1) to explore the strategies used by ovarian cancer survivors to cope with FCR; and (2) to explore ovarian cancer survivors' styles of coping with FCR.

### **Conceptual Framework**

Coping is a broad concept that can be described as having two components: coping responses and coping styles (Beutler, Moos, & Lane, 2003; Moos & Holahan, 2003). Coping responses are situation-specific and based upon an individual's perceptions, emotions and behaviours that prepare them for an adaptation or change (Beutler et al., 2003; Moos & Holahan, 2003), whereas coping style is a general construct that describes an individual's disposition to respond a certain way (Beutler et al., 2003; Moos & Holahan, 2003). The view of coping presented by Carver and colleagues (Carver, Scheier, & Weintraub, 1989) includes a description

of both coping responses (similarly referred to as “strategies” ( Carver et al., 1989)) and coping styles. Furthermore, Carver and colleagues’ (Carver et al., 1989) view of coping, as presented in their COPE (Carver et al., 1989) and Brief-COPE (Carver, 1997) measures, has been explored in relation to FCR (Freeman-Gibb, 2012; Galica, Metcalfe, Maheu, & Townsley, 2017; Llewellyn, Weinman, McGurk, & Humphris, 2008; Lydon, 2008), and both coping responses and coping styles are underlying components in theoretical presentations used to explain FCR (Fardell et al., 2016; Lee-Jones, Humphris, Dixon, & Bebbington Hatcher, 1997). These points identify coping as an important consideration in FCR research and illustrate the appropriateness of using Carver and colleagues’ (Carver et al., 1989) view of coping to define the current study’s conceptualization of coping. This conceptualization is summarized in Table 1.

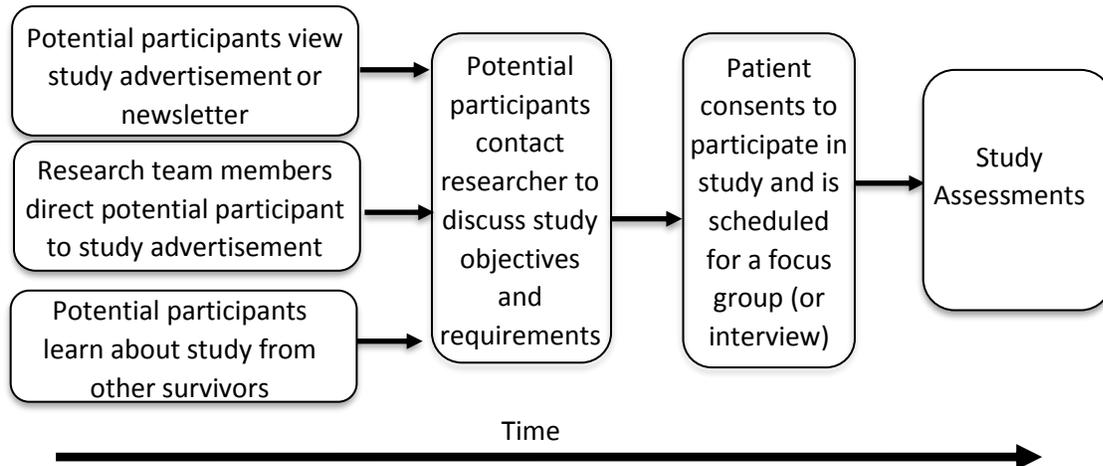
**Table 1: Coping Styles and Associated Coping Strategies** (Carver, 1997; Carver et al., 1989)

<b>Coping Style</b>	<b>Coping Strategies</b>
<b>Problem-focussed</b>	Active coping; planning; acceptance; restraint; seeking instrumental support
<b>Adaptive Emotion</b>	Seeking emotional support; positive reframing; acceptance; religion; humour.
<b>Maladaptive Emotion</b>	Venting; self-distraction (mental disengagement); behavioural disengagement; substance use.

## **Methods**

A qualitative descriptive design was used to address the study objectives. A PDF version of the study protocol was stored on the Open Science Framework (Open Science Framework, n.d.) to serve as an open-access registration of the study protocol prior to data collection and analysis (<https://osf.io/p9zww/>). The procedures and features of this study’s methods are consistent with reporting guidelines for qualitative research (COREQ (Tong, Sainsbury, & Craig, 2007; Tong, Flemming, McInnes, Oliver, & Craig, 2012)). A study overview is illustrated in Figure 1.

**Figure 1: Study Schemata**



## Sampling

Potential participants telephoned/emailed the researcher (JG) after learning about the study by: (1) a study advertisement posted in the treatment or clinic areas of the recruiting centre (located in as the 24<sup>th</sup> largest census metropolitan area (CMA) in Canada (Statistics Canada, 2011)) or at the local cancer support group; (2) from an ovarian cancer survivor or clinician affiliated with one of the recruiting centres; or (3) from national ovarian cancer association's newsletter or social media.

Women meeting the following criteria were invited to participate in this study: (1) older than 18 years; (2) received an ovarian cancer diagnosis of any FIGO (Prat, 2015) stage; (3) had not received radiation to the brain; (4) able to read, write and speak English; (5) were willing and able to complete all study requirements, including attendance in a one-time focus group (or 1:1 interview), and completion of a demographic form, Fear of Cancer Recurrence Inventory (FCRI (Simard & Savard, 2009)), and for cancer diagnostic and treatment-related data to be extracted from their medical chart; and (6) willing and able to provide informed consent.

## **Sample Size**

The intent of focus a group method is to collect data until data saturation occurs, which typically occurs after three to four groups are conducted (Krueger & Casey, 2015). Considering this, four focus groups each allowing up to six participants (for a total sample size of 20-24 participants) was planned by the researchers on dates and at a variety of times to optimize convenience for ovarian cancer patients and survivors. Participants unable to attend a scheduled focus group were scheduled for a 1:1 telephone interview at a mutually convenient date and time. The same semi-structured questions were asked of participants regardless of data collection modality.

## **Data Collection Methods**

Eligible, consenting participants were emailed or mailed an envelope containing a Demographic Form and Fear of Cancer Recurrence Inventory (Simard & Savard, 2009) and asked to complete these documents at home and bring them to the focus group (or interview). The study instruments are explained below.

***Demographic Form:*** The Demographic Form captured information about participants' age, marital status, number of children and their ages, level of education, employment status, ethnicity, cancer diagnosis, cancer treatment, and the first 3 characters of the participant's postal code (Canada Post Corporation, n.d.).

***Fear of Cancer Recurrence Inventory (FCRI):*** The FCRI is a multi-dimensional self-report measure developed for use in mixed-cancer samples. It is comprised of 42 items on seven subscales, which have demonstrated a consistent factorial structure across cancer types representing 64% of the variance in FCR (Simard & Savard, 2009). Responses to items are based on a 5-point Likert-like scale, where 0 indicates 'not at all or never', and 4 indicates 'a great deal

or all the time' (Simard & Savard, 2009). An overall higher FCRI score (Range 1-164) indicates higher FCR (Simard & Savard, 2009), and a Receiver Operating Curve analysis (sensitivity 87.5%, specificity 75%) determined that a score  $\geq 13$  on the Severity subscale indicates clinically significant FCR (Simard & Savard, 2008; Thewes et al., 2012). The FCRI has been found to be highly reliable (Cronbach's alpha = 0.95, test-retest reliability = 0.89) (Simard & Savard, 2009), and its validity (convergent, concurrent, and divergent) has been supported (Simard & Savard, 2009).

***Focus Groups (or 1:1 Interviews):*** Open-ended questions were conceptualized in alignment with the definitions of coping responses and coping styles (Carver, 1997; Carver et al., 1989) (see Conceptual Background), and structured in accordance with focus group recommendations (Krueger & Casey, 2015). Questions four through six were referred to as the *Key Questions* (Krueger & Casey, 2015) that required the greatest attention in the analysis and therefore most of the focus group (or interview) discussions were spent addressing these questions. All questions are listed in the Appendix.

***Chart Review:*** A Data Extraction Form was used to collect diagnostic and treatment data from participants' medical charts. The International Federation of Gynecology and Obstetrics (FIGO) staging classification (Prat, 2015) was used and dates of ovarian cancer diagnosis(es) and treatment(s) were collected.

## **Data Analysis**

SPSS software (IBM Corporation, 2011) was used to generate descriptive statistics for the sample's demographic and clinical information and level of FCR. Qualitative data was transcribed verbatim and data analysis occurred in accordance with a qualitative descriptive method. Initially, verbatim transcripts of responses to the focus group (or interview) questions

were read and re-read to identify codes, categories and overall theme(s) (Krueger & Casey, 2015) that were analyzed and described in alignment with the conceptualization of coping (Carver, 1997; Carver et al., 1989).

### **Summary of Findings**

Among the fifteen participants, the mean age was 62.8 years (SD=6.6, Range 51-76 years) and most identified as Caucasian (93.3%) and were married (80.0%). Sixty percent of participants lived beyond the city limits of where the research took place. The average time since diagnosis was 2.7 years (SD = 4.6, Range 1-19 years) and most women (60.0%) had been diagnosed with FIGO stage 3 disease. The mean FCRI score was 92.13 (SD = 24.1, Range 49-128) and 14 (93.3%) of the participants had a level of FCR that was deemed as clinically-significant.

Overall, the women thought that they were doing a very good job coping with FCR. The most useful strategies for coping with FCR included the provision of post-treatment cancer information from their clinicians, striving to normalize life as it was prior to cancer diagnosis, and receiving cancer-specific psychosocial support (e.g., from professionals with oncology experience or informally from cancer survivors). At the time of writing this report, the qualitative data analysis for this study is ongoing. Mature results will be submitted for peer-review publication.

### **Recommendations**

These findings illuminated that FCR is a significant issue for ovarian cancer survivors living outside of major metropolitan areas. Although the women thought that they were doing well to cope with FCR, improvements to existing resources and identification of needed supports were identified. These findings are useful to inform program development and/or subsequent

research within inter-professional and/or inter-organizational teams to reduce geographical disparities of psychosocial cancer survivorship care.

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## Appendix

Focus Group (or Interview) questions:

1. In a discussion like the one we're about to have, it is important to spend a few moments learning about the people in this room. Could you please tell us your name, where you live (e.g., in or outside of the city), and one thing that you enjoy doing in your spare time?
2. So now I'd like to begin to ask you some questions about the topic that we're here to discuss: fear of cancer recurrence. By fear of cancer recurrence I mean the "fear, worry, or concern relating to the possibility that cancer will come back or progress" (Lebel et al., 2016) (have definition written in a central place for participants to refer to). Could you please describe what you believe makes you feel fearful about a cancer recurrence?
3. If or when you experience any fear of cancer recurrence, how do you believe that fear affects you (Fardell et al., 2016)?
4. If or when you experience fear of cancer recurrence, what are some of the strategies and/or resources that you use to cope (Simard & Savard, 2009) with fear of cancer recurrence? Try to be as specific as you can.
5. What do you believe are some of your personal characteristics or attributes (Fardell et al., 2016) that help you cope with any fear of cancer recurrence that you may have?
6. Considering the strategies and or characteristics that you just identified, what is your opinion about your ability to cope (Fardell et al., 2016) with fear of cancer recurrence?
7. What do you believe is most useful to help you cope with fear of cancer recurrence?
8. If any, what resources do you believe that ovarian cancer survivors treated at the Southeast Ontario Cancer Centre would use to help them cope with fear of cancer recurrence?

9. I would like to now ask as question to the patients here who have had a recurrence: knowing what you know now, what do you believe would have helped you cope with the thoughts of cancer possibility recurring?
10. What do you think is the most important topic that we discussed during this discussion?
11. This wraps up the questions I wanted to ask. Do you have any additional comments or questions?