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Fear of Recurrence in Ovarian Cancer Survivors and Their Spouses

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FEAR OF RECURRENCE IN OVARIAN CANCER SURVIVORS AND THEIR SPOUSES

A Thesis
Submitted to the Faculty
of the Department of Nursing
College of Nursing and Health Sciences
of Winona State University

by
Brandon R. Crouley
Jennifer L. Skaden

In Partial Fulfillment of the Requirements
for the Degree of
Master of Science

April 22, 2020
ABSTRACT

Problem: Fear of Cancer Recurrence (FCR) is a frequent and prevalent phenomenon experienced by ovarian cancer survivors and spouses throughout survivorship.

Purpose: The purpose of this secondary analysis was to analyze the perceived level of FCR by the years of survivorship in women with ovarian cancer and their spouses.

Theoretical/Conceptual Framework: The theoretical framework for this research study was based on the Common-Sense Model of Illness developed by Leventhal, Diefenbach, & Leventhal (1992) and further expanded by Lee-Jones et al. (1997).

Method: This was a secondary analysis of data from a large study of predictors of adjustment using the demographic and Fear of Cancer Questionnaire (FRQ) results. The secondary analysis is a descriptive correlational design to analyze cross-sectional data from the primary study of subset of cancer survivors who experienced recurrence(s) of ovarian cancer and their spouses (n = 32 dyads).

Results: No significant correlation with FCR scores and years of survival in ovarian cancer survivors ($r = -0.18, p = 0.33$) and spouses ($r = -0.31, p = 0.08$). ANOVA yielded no difference in FCR scores by age in survivors ($F = 0.16, p = 0.69$) with 95% CI (76.08, 89.92) and spouses ($F = 0.17, p = 0.69$) with 95% CI (86.9, 95.9).

Conclusions/Implications: It is recommended future research of this study sample perform multiple linear regression or factor analysis statistical tests to demographic variables which may influence FCR scores in ovarian cancer survivors and their spouse.
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CHAPTER I

Introduction

Chapter one introduces the phenomenon fear of cancer recurrence (FCR) in ovarian cancer survivors and their spouses. A problem and purpose statement of this study is included. Furthermore, research questions are stated, and definition of terms are discussed.

Ovarian cancer is the second most common gynecological malignancy and accounts for 2.5% of all malignancies among females in the United States (Duska, 2018; Torre et al., 2018). Nearly 22,530 new cases of ovarian cancer will be diagnosed in 2019 (Torre et al., 2018; America Cancer Society, 2019). The five-year ovarian cancer survival rate is 93.7% for stage I and II, less than 50% for stage III, and less than 20% for stage IV (Duska, 2018; Torre et al., 2018). Approximately 25% of survivors are diagnosed with stage I or II ovarian cancer while 75% of survivors are diagnosed with stage III or IV ovarian cancer (Crist & Grunfeld, 2013; Duska, 2018; Thewes et al., 2012; Torre et al., 2018; van de Wal, van de Poll-Franse, Prins, & Gielissen, 2016). Ovarian cancer recurrence is typically within 18-22 months (Duska, 2018; Thewes et al., 2012; Torre et al., 2018). Nearly 80% of ovarian cancer survivors will enter remission after the initial treatment regardless of stage of disease (Duska, 2018). However, the recurrence rate for stage I and II is approximately 25% and stage III and IV is as high as 80% (Duska, 2018). The ovarian cancer mortality rate has decreased by 33% from 1976
(10 per 100,000) to 2015 (6.7 per 100,000) due to advances in ovarian cancer detection and treatment (Torre et al., 2018). Increased survival rates may be attributed to remission surveillance techniques such as: serum cancer antigen 125 tumor markers, ultrasound, computed tomography, positron emission tomography (Duska, 2018).

Women with ovarian cancer experience major physical and psychological challenges. Physical challenges with women who have ovarian cancer range from gastrointestinal distress, chemotherapy side effects, loss of fertility, and sexual dysfunction (Beesley, Alemayehu, & Webb, 2018; Duska, 2018; Ozga et al., 2015). Psychological challenges present in individuals with ovarian cancer can be attributed to advanced disease upon diagnosis (Roland, Rodriguez, Patterson, & Trivers, 2013), the likelihood of recurrence, the adjustment to living with cancer, frequent healthcare utilization (Jeppesen, Jensen, Hansen, Christensen, & Mogensen, 2018), and hypervigilance of symptoms (Koch, Hansen, Benner, & Amdl, 2013). Negative physical and psychological experiences during survivorship can cause distress, anxiety, depression, and fear (Crist & Grunfeld, 2013; van de Wal, van de Poll-Franse, Prins, & Gielissen, 2016).

FCR has been defined as “fear that cancer could return or progress to the same place or in other part of the body” (Crist & Grunfeld, 2013, p. 978; Thewes et al., 2012, p. 772; van de Wal et al., 2016). FCR has also been defined in current literature as “the fear, or worry, or concern about cancer returning or progressing” (Jeppesen et al., 2018, p. 2).

FCR is a commonly reported experience among all cancer survivors and can be considered a rational response to the threat of cancer recurrence (Crist & Grunfeld, 2013;
Jeppesen, et al., 2018). However, FCR has been associated with increased distress, decreased quality of life, poorer psychological functioning and increased use of healthcare services such as contacting treatment teams, physical examinations, and consults with psychologist (Crist & Grunfeld, 2013; Jeppesen, et al., 2018). Ovarian cancer survivors who have reported FCR at some point during their survivorship have ranged from 22-99% (Crist & Grunfeld, 2013; van de Wal et al., 2016). FCR is reported as one of the most distressing consequences of cancer survivorship and is prevalent among cancer survivors during long term remission (Crist & Grunfeld, 2013; Duska, 2018; Koch et al., 2013).

FCR is not limited to cancer survivors and has been documented with spouses or and caregivers (Hodges & Humphries, 2009; Kim & Given, 2008; Ponto, 2008). Spouses cope with an unknown cancer trajectory, face a wide range of stressors, and must adjust to altered family dynamics which can evoke psychological challenges (Girgis et al., 2013). FCR is one of the most prevalent concerns among spouse’s (Han et al., 2015; Shilling et al., 2017). FCR may affect psychological functioning of spouses immediately after diagnosis and remain throughout survivorship (Butow et al., 2014; Lebel & Petricone-Westwood, 2016).

FCR is not limited to time of diagnosis and FCR has been present through survivorship (Ozga et al., 2015). Many cancers survivors experience increased FCR during survivorship due to treatment side effects, somatic symptoms, cancer specific social media, (i.e. Caringbridge, social media posts, cancer commercials) and frequent healthcare visits (Hall et al., 2017; Lee-Jones, Humphris, Dixon, & Hatcher, 1997). FCR
that is unmanaged during survivorship may lead to anxiety, depression, decreased quality of life, physical and emotional dysfunction (Ozga et al., 2015; Simard et al., 2013).

**Problem Statement**

FCR has been widely studied in many individuals with various types of cancer (Crist & Grunfeld, 2013; Jeppesen, et al., 2018). However, few studies addressed FCR in patient and spouse dyads with ovarian cancer (Ozga et al., 2015). Ovarian cancer has the highest mortality rate among gynecological cancers and the recurrence rate is high (Torre et al., 2018). Due to the multiple stressors of ovarian cancer including high recurrence rate in ovarian cancer survivors, spouses may experience fear of recurrence which at times can be higher than cancer survivors FCR (Hodges & Humphris, 2009; Ozga et al., 2015; Ponto, 2008; Shilling et al, 2017). FCR has been identified quantitatively and qualitatively among ovarian cancer survivors and spousal dyads as one of the most distressing experiences in survivorship (Hodges & Humphris, 2009; Jeppesen et al., 2018; Shilling et al, 2017; van de Wal et al., 2016).

**Purpose of the Study**

The purpose of this secondary analysis was to analyze the perceived level of FCR by the years of survivorship in women with ovarian cancer and their spouses.

**Research Questions**

The following two research questions were addressed in this study:

1) Is there a correlation between the level of FCR in women with ovarian cancer by years of survivorship and demographic variables?

2) Is there a correlation between the level of FCR in spouses by years of survivorship and demographic variables?
Definition of Terms

In this section definition of terms is presented for this study. Operational and conceptual definitions of variables provide clarity and a framework for this study. Variables used within this study are fear of cancer recurrence, years of survivorship, ovarian cancer survivors, spouse, ovarian cancer, and ovarian cancer recurrence.

Fear of Cancer Recurrence

Conceptual Definition: For purposes of this study, FCR will be defined as fear of the possibility of cancer returning in the future by the degree of concern reported by individuals (Hodges & Humphris, 2009; Thewes et al., 2012). The proposed definition of FCR was chosen for this study design to include both the ovarian cancer survivor and their spouse FCR experiences.

Operational Definition: FCR was measured utilizing the 22-item Fear of Recurrence Questionnaire (FRQ) (Northouse, 1981). Cronbach’s alpha for ovarian cancer survivors was .92 and .91 for spouses (Thewes et al., 2012). The primary study yielded a Cronbach alpha for ovarian cancer survivors of .89 and for spouses .88 (Ponto, 2008).

Years of Survivorship

Conceptual Definition: Years of survivorship is defined living with cancer, through cancer treatment, and beyond a cancer diagnosis (National Coalition for Cancer Survivorship, 2014).

Operational Definition: Years of survivorship was measured using the date of diagnosis item number two of the 5-item Meaning and Adjustment in Ovarian Cancer
Spouse Dyads Illness Profile (see Appendix A) (Ponto, 2008). Years of survivorship was calculated by subtracting the date of diagnosis from the date of survey completion.

**Ovarian Cancer Survivors**

Conceptual Definition: Ovarian cancer survivors are defined as individuals who are living with, in remission from, or have a history of ovarian cancer (Duska, 2018; Roland et al., 2013).

Operational Definition: Ovarian cancer survivors were determined by self-report of date of diagnosis by item two of the by 5-item Meaning and Adjustment in Ovarian Cancer Spouse Dyads Illness Profile (see Appendix A) and primary study inclusion criteria (Ponto, 2008).

**Spouses**

Conceptual Definition: Spouses of ovarian cancer survivors are defined as martial or cohabiting partner in a spouse-like relationship as determined by the study dyad (Ponto, 2008).

Operational Definition: Spouses were defined by self-report of meeting eligibility criteria of primary study (Ponto, 2008).

**Ovarian Cancer**

Conceptual Definition: Ovarian cancer is defined as cancer originating in the ovaries which also encompasses ovarian cancer subtypes and disease stages (Torre et al., 2018).

Operational Definition: Ovarian cancer diagnosis was determined by self-report on item number one of the 5-item Meaning and Adjustment in Ovarian Cancer Spouse Dyads Illness Profile (Ponto, 2008).
**Ovarian Cancer Recurrence**

Conceptual Definition: Recurrence is defined as tumor regrowth at the primary site or as metastasis after initial treatment (Duska, 2018; Torre et al., 2018).

Operational Definition: Recurrence was determined by self-report on item number two (see Appendix A) of the 5-item Meaning and Adjustment in Ovarian Cancer Spouse Dyads Illness Profile (see Appendix A) (Ponto, 2008).

**Summary**

Chapter one introduced the phenomenon of FCR in ovarian cancer survivors and their spouses. Gaps in literature have identified lack of research related to FCR and years of survival in ovarian cancer survivor and spouses. The purpose of this study was to determine if there are differences in FCR scores with ovarian cancer survivors and their spouses by years of survivorship. Definitions of terms for ‘fear of recurrence’, ‘years of survivorship’, ‘ovarian cancer survivors’, ‘spouses’, ‘ovarian cancer’, ‘ovarian cancer recurrence’ were defined operationally and conceptually to provide clarity and framework in guiding this study.
CHAPTER II

Review of the Literature

This chapter describes the search strategy used to obtain our database abstraction and provides a review of the literature in relation to FCR in survivors and their spouses. The topics addressed include literature search strategies, survivors and fear of cancer recurrence, spouses and fear of cancer recurrence, fear of cancer recurrence in survivors and spouses, measuring fear of cancer recurrence, and a theoretical framework. Additionally, a literature review table is provided to describe the key articles (see Appendix B).

Search Strategies

A computerized literature search was performed using CINAHL, Proquest, Embase, PscyINFO, and Medline (Pubmed). The database abstraction process is described in Table 1. Search terms used for relevant literature included fear of recurrence, recurrence, cancer survivor, neoplasm, tumor, carcinoma, ovarian cancer, gynecological cancer, significant other, survivorship, survivor years, caregiver, spouse, and husband. Search parameters included dates were limited from 2008 to 2019, and included peer-reviewed journals. Searches produced 369 publications and abstracts were reviewed in relation to the proposed research questions. The reference lists from articles that were the most relevant to our research questions were reviewed and extracted resulting in 56 articles.
Table 1.

Database Abstraction Process

<table>
<thead>
<tr>
<th>Date of Search</th>
<th>Keywords Used</th>
<th>Database/Source</th>
<th>Restrictions (e.g. Peer-Reviewed Journals)</th>
<th>Dates Included in Search</th>
<th># of Hits</th>
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<tr>
<td>5/24/18</td>
<td>Spouse or significant other and survivor and ovarian cancer and fear of recurrence or fear of cancer recurrence</td>
<td>CINAHL Medline PsychINFO</td>
<td>Peer-Reviewed Journals English Language</td>
<td>January 2008-June 2018</td>
<td>123</td>
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<td>5/30/18</td>
<td>“Caregiver and family caregiver or spouses or significant other or partner or carer or husband” and cancer tumor or malignancy or carcinoma and cancer recurrence”</td>
<td>CINAHL Embase PsychINFO Medline</td>
<td>Peer-Reviewed Journals English Language</td>
<td>January 2008-June 2018</td>
<td>154</td>
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<td>20</td>
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<tr>
<td>8/22/18</td>
<td>Cancer Survivor or cancer survivorship or long-term survivor and fear of recurrence</td>
<td>CINAHL Embase PsychINFO</td>
<td>Peer-Reviewed Journals English Language</td>
<td>January 2008-August 2018</td>
<td>50</td>
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<td>12</td>
</tr>
<tr>
<td>9/28/18</td>
<td>cancer trajectory and “time and diagnosis” and fear of recurrence and cancer survivor and caregiver</td>
<td>CINAHL Medline PsychINFO</td>
<td>Peer-Reviewed Journals English Language</td>
<td>January 2008-August 2018</td>
<td>17</td>
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<td>5</td>
</tr>
<tr>
<td>10/23/18</td>
<td>Fear of cancer recurrence ovarian cancer or gynecological cancer and number of recurrences</td>
<td>CINAHL Medline PsychINFO</td>
<td>Peer-Reviewed Journals English Language</td>
<td>January 2008-October 2018</td>
<td>25</td>
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Review of Literature

In-depth synthesis of FCR terms and concepts within the literature was undertaken. FCR themes were separated by cancer survivors, spouses, cancer survivor/spouse themes, and FCR measurement tools. A theoretical framework is provided to help guide the research study.

Fear of Cancer Recurrence in Survivors

Syntheses of cancer survivors and FCR themes were identified from literature. In this section reported FCR among cancer survivors, years of survivorship, antecedents to FCR, and outcomes of FCR are discussed.

Fear of Cancer Recurrence

One study found that 82% of a mixed population of cancer survivors reported low levels of FCR with 11% reporting moderate levels and 6% experiencing high levels of FCR (Koch et al, 2015). Comparatively, two studies found moderate to high levels of FCR affect 33% to 56% of breast cancer survivors (Lebel, Beattie, Ares, & Bielajew, 2012). Cohee et al. (2015) found 53.6% of breast cancer survivors reported notable levels of FCR even though they were considered disease free. Ames et al. (2007) suggested more than half of cancer survivors with various cancer types indicated some degree of concern with the possibility that their disease would recur. Ames et al. (2007) reported over 63% of the patients experience some FCR during survivorship. Another study suggested that the problems for which the lowest proportion of ovarian cancer survivors felt they had received adequate help were fear of dying and fear of recurrence (Fitch et al, 2009). FCR was triggered by new symptoms, ongoing side effects of
treatment, exposure to cancer related media, annual checkups, and completing treatment (Crist & Grunfeld, 2013; Simonelli, Siegel, & Duffy, 2017).

Literature identifies FCR is a common experience amongst various cancer survivor cohorts. Literature has suggested that FCR is not a continuous phenomenon but is prevalent across survivorship. FCR may increase with treatment, media exposure, and follow up appoints. FCR in cancer survivors was identified from single cohort and descriptive studies.

**Years of Survivorship**

Years after diagnosis and completion of therapy, when follow-up care has normally ended, FCR is an issue for women that can negatively affect quality of life (QOL) and interfere with activities of daily living (ADLs) (Koch et al., 2013). van de Wal et al. (2015) found a significant association ($\beta = -0.07, p < 0.05$) between FCR and years since diagnosis with multiple primary cancer survivor populations. Other studies suggested the highest reported FCR scores shortly after diagnosis (Fitch et al., 2001; Roland et al., 2013). Koch-Gallenkamp et al. (2016) suggested that the time since diagnosis and recurrence may determine moderate to high FCR scores in mixed cohort long term cancer survivors. Conversely, another study found time since diagnosis did not appear to be related to increased FCR scores with mix cancer survivor cohorts (Koch et al., 2015).

Significant levels of FCR have been reported in early and advanced staged ovarian cancer survivors (Roland et al., 2013). One study suggested at three-six months post-treatment, FCR was the highest reported source of distress during survivorship (Champagne et al., 2018). Beesly et al. (2018) found FCR was rated as moderate-to-high
levels of unmet needs among mixed gynecological cancer subtypes during survivorship. At the two year follow up, 64% of maxillofacial cancer survivors expressed at least some concern about recurrence (Hodges & Humphries, 2003). A randomized control trial conducted by Jeppesen et al. (2013) found one in five women struggled with FCR after their primary treatment for ovarian cancer.

Long term cancer survivors (greater than 5 years) of mixed cancer types did not experience FCR consistently but if a trigger such as a new symptom was experienced the cancer survivor reported a higher FCR score (Jeppesen et al., 2018; Koch et al., 2013; Kronk-Shoen, et al., 2018). Kock-Gallenkamp et al. (2016) found the majority of long-term cancer survivors reported lower FCR scores (87%) versus moderate FCR scores (9%), and high FCR scores (4%) in mixed cancer cohorts. Long-term survivors (greater than five years) reported moderated to low FCR scores which suggest FCR persists across the cancer trajectory (Koch et al., 2013).

In summary, literature has suggested that FCR scores are reported higher at time of diagnosis. Although, FCR scores decrease with years of survivorship, FCR scores with long term cancer survivors (greater than five years) suggest that FCR is persistent throughout survivorship. Literature identifying years of survivorship contained one randomized controlled clinical and six descriptive studies.

**Demographics of Fear of Cancer Recurrence**

Younger survivors were found to have higher FCR scores in cancer survivor cohorts (Champagne et al., 2017; Crist & Grunfeld, 2013; Janz et al., 2016; Koch-Gallenkamp et al., 2016; Roland et al., 2013; van de Wal et al., 2015) Less FCR was reported in older women who had higher education and were partnered than younger
women (Koch et al., 2013). Four studies suggested that younger women report more anxiety and FCR when compared to older women (Lebel, 2012; Liu et al., 2018; Roland et al., 2013; van de Wal et al., 2015). This may be due to less life experience with health and illness, have fewer coping strategies to manage crisis and illness, and less experience with the healthcare system (Lebel, 2012; van de Wal et al., 2015). One study of middle-aged and younger women with high FCR cited greater fears associated with the unexpected, off-time event of cancer, interference on life's goals (children, career), the lack of peers with serious illness, and fewer coping resources than their older counterparts (Krok-Schoen et al., 2018). Another study found motherhood was associated with higher FCR, as mothers reported higher overall FCR scores than women without children (Lebel et al., 2012). Lebel et al (2012) found no significant main effect with age of children and age of mother.

Three studies reported African American women tend to report less worry about recurrence than Caucasian and Hispanic women in various cancer survivors (Crist & Grunfeld, 2013; Koch et al., 2013; Janz et al., 2016). Three studies with mixed cancer populations reported Latino women tended to worry about recurrence more than women of other ethnicities (Koch et al., 2013; Crist & Grunfeld, 2013; Janz et al., 2016). One study also suggested that Latino women were more likely to express worry of recurrence than Caucasian and African American breast cancer survivor’s (Janz et al., 2016).

Women who were widowed or never married reported lower FCR scores (Crist & Grunfeld, 2013; Krok-Schoen et al., 2018; van de Wal et al., 2016). One study has suggested there is no clear association of FCR and married status (Crist & Grunfeld, 2013). Another study reported that women who are married and young tend to care how
their health status affects their social networks which induce higher FCR scores (Krok-Schoen et al., 2018). Boehmer et al. (2016) found survivors’ FCR did not differ by sexual orientation. Koch et al. (2013) found race, age, no children, and partnership to be associated with FCR.

Female gender is associated with the higher FCR scores (Baker et al, 2005; Champagne et al., 2017; Humphris et al, 2003; Kock-Gallenkamp et al., 2016; Lebel et al, 2012; Simard & Savard, 2009; van de Wal et al., 2015). Two studies found female survivors reported greater fear of recurrence compared to male survivors (Stephens et al, 2016; Koch-Gallenkamp et al., 2016).

In summary, literature has suggested that demographic characteristics such as younger age, female gender, marital status, and being Latino may influence high reported FCR scores with cancer survivors. Most studies that reported higher FCR scores with demographic characteristics were single descriptive studies. One randomized control trail reporting higher FCR scores with patient initiated follow up (CI= -5.9 (-10.9,-0.9, $p = 0.02$) (Jeppesen et al., 2018).

**Consequences of Fear of Cancer Recurrence**

Women who experience more cancer related symptoms, had lower reported general health scores and have higher FCR scores (Koch et al., 2013; Krok-Schoen et al., 2018). One study found pain was the most commonly associated symptom with FCR (Crist & Grunfeld, 2013). Two studies suggested FCR represents a prevalent and persistent unmet psychosocial need for cancer survivors (Ames et al, 2009; Simonelli et al., 2017). Qualitative studies found FCR is one of the most challenging and common problems among ovarian cancer survivors (Han et al., 2015; Schilinget al., 2017).
FCR scores were strong determinants of anxiety and depression symptoms (Koch et al., 2013; Lui et al., 2018). Multiple studies reported depression scores among ovarian cancer survivors reduced post-diagnosis, but anxiety related to FCR was found to increase over time (Roland et al., 2013). Liu et al. (2018) found FCR scores were positively correlated with anxiety and depressive symptoms. Three studies found strong association with low mood or psychological distress and FCR (Koch et al., 2013; Champagne et al., 2017; Crist & Grunfeld, 2013). A systematic review found FCR was associated with lower scores on spirituality, increased impact on psychological health, more post-traumatic symptoms, lower positive well-being (Ozga et al., 2015). One study suggested that psychosocial (e.g. family distress, intrusive cognitions) and sociodemographic factors (e.g. communication with healthcare providers) were significantly associated with FCR scores (Koch et al., 2013). Survivors FCR was associated with poorer mental and physical health (Kim et al., 2011).

Stage of disease and comorbid conditions were found to be independent predictors of FCR in mixed cancer survivor cohorts (Koch et al., 2013; van de Wal et al., 2016). One study found a strong association among risk of recurrence and FCR in ovarian cancer survivors (Ozga et al., 2015). These findings are comparable to other cancer types such as lung, head and neck, colorectal, and breast cancer survivors which may suggest different cancers effect survivors differently (Clarke & Bailey, 2010; Han et al., 2015; Janz et al., 2016; Koch-Gallenkamp et al., 2016; Mosher et al., 2017; van de Wal et al., 2016;). Weak associations were found with mixed cancer type, stage of cancer, treatment type, socio-demographic factors, and social resources with FCR (Champagne et al., 2017; Crist et al., 2013; Roland et al., 2013). Two studies found no
association of FCR scores and cancer type (Koch-Gallenkamp et al., 2016; van de Wal et al., 2015).

Five studies specifically addressed FCR in ovarian cancer patients (Cox et al., 2010; Koch et al., 2013; Krok-Schoen et al., 2013; Ponto et al., 2008; Roland et al., 2013) Roland et al. (2013) review of six studies, ovarian cancer survivors experience high levels psychological distress (depression and anxiety), when compared to non-gynecological cancer survivors. In studies aimed at multiple primary cancers, women with ovarian cancer receiving chemotherapy reported high levels of FCR (Koch et al., 2013; Krok-Schoen et al., 2018). Studies that included ovarian cancer survivors included mixed cancer cohorts which ovarian cancer survivors represented a small percentage of the cancer survivor cohorts (Hall et al, 2017; Ness et al., 2013).

In summary, FCR is a multidimensional phenomenon which affects cancer survivors throughout their cancer trajectory. Literature has suggested demographic characteristics such as age, ethnicity, marital status, and gender may increase FCR scores of cancer survivors. Cancer survivors experience FCR throughout survivorship which may affect quality of life, psychological wellbeing, and physical health. Literature that identified FCR experiences of cancer survivors included one systematic review and nine descriptive studies.

**Fear of Cancer Recurrence in Spouses**

A synthesis of the spousal themes related to FCR was identified from the literature. This section presents a summary of FCR among spousal partners, years of survivorship, demographics to FCR, and consequences of FCR.


Fear of Recurrence

In the literature reviewed, caregivers were also susceptible to experience FCR. Mellon et al. (2007) found that family caregivers had significantly more FCR than survivors. Caregivers were frequently cited throughout the literature to have similar or greater FCR than their spousal survivor (Beesly et al., 2018; Cohee et al., 2017; Han et al., 2015; Janz et al., 2016; Kim & Given, 2008; Maguire et al., 2017; Mellon et al., 2007; Ponto, 2008).

Many factors have been shown to affect caregivers FCR. A higher level of family stress, a less positive meaning of the cancer illness, a decline in the survivor’s physical and mental health, greater time spent caring for the survivor, and increasing cancer severity have all been identified in increasing the spouse’s FCR (Kim et al., 2011; Mellon et al., 2007). Results revealed that FCR was lower in caregivers of survivors who underwent more extensive surgery (Maguire et al., 2017). This could be because caregivers perceive major surgery as a more conclusive treatment, thereby mitigating chances of recurrence (Butow et al., 2014). In contrast, when survivors have not undergone surgery the future may appear more uncertain (Maguire et al., 2017). Janz et al. (2016) found caregivers of survivors who received chemotherapy were more likely to report worry of recurrence than individuals/caregivers whose partners who did not receive chemotherapy.

Increased FCR in caregivers can affect their own mental health (Han et al., 2015; Mellon et al., 2007; Northouse et al., 2002). Han et al. (2016), conducted a qualitative study of male and female caregivers of female cancer survivors and found that caregivers appeared anxious from a constant fear of recurrence, especially when new physical symptoms arose from adverse effects. Their fear and anxiety intensified with each new
physical symptom or impairment. A caregiver stated, “Recurrence is my biggest concern. The treatment process is difficult to endure, and it seems that her physical strength is deteriorating. I’m always worried” (Han et al., 2016, p. 53). Caregivers are often afraid to express their own fear of the cancer recurring as they worry it may negatively affect the survivor (Mellon et al., 2007). The caregiver’s hesitation to communicate their concerns may increase their own FCR (Mellon et al., 2007; Northouse et al., 2002). Because many caregivers feel guilty communicating their fears, they may be less likely to work through or resolve their own fear of the cancer returning. If FCR is not addressed, it could have important implications for long-term quality of life and role functioning outcomes within the family (Mellon et al., 2002).

Years of Survivorship

Years of survivorship in cancer survivors in correlation with spousal FCR is inconsistent in the studies reviewed. Several studies found years of survivorship was not statistically significant or correlated with FCR and caregivers (Mellon et al., 2007; Cohee et al., 2015; Cohee et al., 2017). Maguire et al. (2017) found a significant correlation between FCR and years of survivorship. Boehmer et al., (2016) indicated that even after five years or more after the cancer diagnosis, FCR remained a persistent concern for caregivers. Similar findings were reported by Janz et al. (2016) that partners were more likely to report worry about FCR four years after diagnosis than survivors. Butow et al. (2014) found FCR to be the highest with spouses at 0-3 months and 10-12 months post diagnosis. Girgis et al. (2013) study suggested FCR was reported the highest at six months post-diagnosis and remained a dominant unmet need for caregivers during the cancer continuum.
Persistent psychological distress and role adjustment problems among spouses have been reported approximately one year after the completion of cancer treatment (Kim & Given, 2008). Heightened uncertainty and FCR remains as a major concern among family members even when patients showed improvement and no cancer-symptoms (Kim & Given, 2008). Similar findings in head and neck caregivers FCR was positively associated with emotional distress among caregivers at 3-and 6-months post-diagnosis (Longacre et al., 2012). Cancer severity has also been shown to negatively affect FCR in the spouse. Kim et al., (2012) showed that the relationship between cancer severity and FCR was stronger among caregivers.

**Characteristics and Fear of Cancer Recurrence in Spouses**

Age is a common antecedent to spousal FCR in the literature. Younger age has consistently been shown to be associated with FCR in spouses (Maguire et al., 2017; Mellon et al., 2007; Koch-Gallenkamp et al., 2017; Petricone-Westwood & Lebel, 2016; van de Wal et al., 2016). Younger caregivers were found to adjust poorly to the cancer diagnosis and found to have a higher incidence of anxiety (Petricone-Westwood & Lebel, 2016). According to Maguire et al., (2017) age was the only survivor characteristic found to be associated with caregiver FCR and younger age consistently was identified to be associated with FCR in caregivers. Mellon et al., (2007) also found that when the age of the survivor decreased, the caregiver’s fear increased. Similarly, when the age of the caregiver decreased, the survivor’s fear increased.

Inconsistent study findings related to caregiver gender were found within the literature. Maguire et al. (2017), found a significant correlation between FCR and the
spouse’s gender. However, Mellon et al. (2007), showed no correlation between male or female caregivers and a higher level of FCR.

Only one study in the literature was found to discuss caregiver ethnicity. Janz et al. (2016), found Latino caregivers had the highest level of FCR while African American caregivers had the lowest FCR level. FCR was also more likely among partners with lower education level irrespective of their ethnicity (Janz et al., 2016).

**Consequences of Fear of Cancer Recurrence**

The psychological distress of cancer not only affects the survivor but also the spouse (Hodges & Humphries, 2009; Kim & Given, 2008; Ponto, 2008). Persistent psychological distress and role adjustment problems among spouses are reported with heightened uncertainty and FCR. FCR remained a major concern even when survivors showed no cancer symptoms (Kim & Given, 2008). Kim et al., (2012) found that higher levels of FCR in caregivers correlated with poor mental health but not physical health. Petricone-Westwook & Lebel (2016), found that depression and anxiety tended to be lower at the beginning of the disease trajectories and anxiety would increase overtime in correlation to FCR. Higher levels of FCR were associated with cancer severity, which in turn related to poorer psychological adjustment of caregivers (Kim et al., 2012).

In summary, FCR may play a more significant role in spouses. Literature that identified FCR experiences in the spouse includes fourteen studies with the majority being descriptive and cross-sectional quantitative studies and one longitudinal randomized control trial. The level of evidence within these studies was primarily levels IV and V with the inclusion of a Level II study. This research shows variability in the correlation between spouses and years of survivorship. Further research is needed to
understand the effects of FCR on the spouses of ovarian cancer survivors, including the relationship between years of survivorship and FCR in spouses.

**Fear of Cancer Recurrence in Survivors and Spouses**

Syntheses of the survivors and spouse themes were identified from the literature. This section will discuss FCR among survivors and spouse, demographics to FCR, and consequences of FCR.

**Fear of Recurrence**

Survivors and spouses have similar levels of FCR (Cohee et al., 2015; Kim et al., 2011; Mellon 2002; Shilling et al., 2017). Kim et al. (2011) reports cancer survivors and their caregivers experience similar degrees of FCR, suggesting dyadic mutuality. Caregiver FCR is significantly associated with survivor FCR suggesting the interdependence between the survivors and caregivers FCR (Mellon, 2002). When the caregivers fear increased, so did the survivors and vice versa (Janz et al., 2016 & Mellon 2002).

A caregiver’s level of FCR can directly affect the survivor’s FCR. Turner et al. (2011) recognized that couples with a cancer diagnosis had a strong need for help managing their fear of recurrence. The physical health of the survivor has been shown to decrease when their caregiver’s FCR is higher (Kim et al., 2011). Mellon et al. (2007) found that caregiver and survivors FCR levels affect one another.

The psychological distress of cancer not only affects the survivor but also the spouse (Hodges et al., 2005; Northouse et al., 1995; Mellon et al., 2007; Ponto., 2008; Turner et al., 2013). Shilling et al. (2017) found survivors and caregivers reported concerns around recurrence which led to the inability to move forward with life plans. Turner et al. (2013) found that agreement between couples was the highest on the need
for help to manage FCR. Conversely, survivors and spouses who reported more positive meaning associated with the illness had significantly less FCR (Mellon et al., 2007).

Characteristics and Fear of Cancer Recurrence

Age continues to be one of the most common characteristics predicting FCR. In all dyads, when the partner’s age decreased, both the survivor’s and caregiver’s FCR increased. Thus, in survivors with younger caregivers both experienced more FCR (Beesley et al., 2018; Mellon et al., 2007; Petricone-Westwood & Lebel, 2016). Caregivers with younger survivors may worry about the potential loss of their loved one earlier than expected in life. Similarly, survivors may worry about the well-being of their younger caregiver who may be left with greater family disruption and economic hardship if the cancer returns (Mellon et al., 2007).

Janz et al. (2016) looked closely at different ethnicities and reports on FCR. Latina caregivers and survivors were more likely to report higher levels of FCR than Caucasians. Caucasian and African Americans survivors and spouses were the least likely to report FCR of any ethnic group (Janz et al., 2016). The survivor’s poor physical health also correlated with the caregiver’s higher levels of FCR (Janz et al., 2016; Kim et al., 2011).

Consequences of Fear of Cancer Recurrence

Several consequences to FCR for cancer survivors and their spouses were identified in the literature. Higher levels of cancer severity correlated with higher levels of FCR in both survivors and their spouses (Kim et al., 2011). Survivors and caregivers also stated they had increased FCR when going to doctor appointments, pain increase, or when they experienced problems with blood pressure (Mellon, 2002). Survivors and
spouses who reported more family stressors in their lives and less meaning associated with the illness had increased FCR (Mellon et al., 2007).

**Measuring Fear of Cancer Recurrence**

Literature synthesis identified multiple FCR measurement tools utilized with cancer survivors. A synthesis of measurement tools found in literature is presented in Table 2.

One study measured the FCR by utilizing the Health Worries Scale of the Impact of Cancer [HWSIC] (van de Wal et al., 2016). HWSIC assesses psychometric properties which have been proven sufficient with cancer survivors [$\alpha = 0.83$] (van de Wal et al., 2016). FCR is assessed by a 3-item questionnaire scored by a five-point intensity scale. High scores reflected more severe FCR. Clinical significance was not stated with the HWSIC FCR Scale (van de Wal et al., 2016).

Three studies measured FCR utilizing the Cancer Worry Scale [CWS] (Humphris et al., 2003; Krok-Schoen et al., 2018; Maguire et al., 2017). CWS validated for mixed cancer cohorts and among survivors of 88 years of age [$\alpha = .87$] (Krok-Schoen et al., 2018). CWS is an eight-item questionnaire to assess distress cause by the possibility of cancer, degree of intrusive thoughts, and frequency of thoughts about cancer (Thewes et al., 2012). A cutoff score of 14 is indicative of those who may be experiencing FCR. CWS-A psychometric soundness among breast cancer cohorts, has not been validated against a clinical cutoff score for FCR all cancer types (Krok-Schoen et al., 2018; Thewes et al., 2012).

Four studies measured FCR using the Fear of Cancer Recurrence Inventory [FCRI] (Jeppesen et al., 2018; Lin et al., 2016; Liu et al., 2018; Simard & Savard, 2009). FCRI is a multidimensional tool used to assess different aspects of FCR such as
triggers, psychological distress, reassurance-seeking, coping strategies, and functional impairment (Thewes et al., 2012). High internal consistency was found among studies (Cronbach $\alpha = 0.71-0.94$). Test-retest reliability varied across studies ($r = 0.56-0.87$). Clinical FCR was measured by a score of greater than 16 (Jeppesen et al., 2018; Lin et al., 2016; Liu et al., 2018; Simard & Savard, 2009; Thewes et al., 2012).

FCRI- Severity subscale was utilized in two studies (Champagne et al., 2017; Lui et al., 2018). The FCRI-Severity subscale is a nine items questionnaire intended to assess behavioral-cognitive formulation of FCR (Thewes et al., 2012). Score of 13 or higher had optimal sensitivity (87%) and specificity (75%) for clinically significant FCR with mix cancer cohorts (Thewes et al., 2012, Champagne et al., 2017; Lui et al., 2018).

Seven studies administered the Fear of Progression Questionnaire Short Form (FoP-Q-SF) to measure FCR (Koch-Gallenkamp et al., 2017; Northhouse, 1981; Boehmer et al., 2016; Mellon & Northhouse, 2001; Mellon et al., 2007; Simard & Simard, 2009). The short form consists of 12 items pertaining to four scales. Reliability of FoP-Q-SF ranged in six different studies ($\alpha=0.87-.89$) (Koch-Gallenkamp et al., 2017; Northhouse, 1981; Boehmer et al., 2016; Mellon & Northhouse, 2001; Mellon et al., 2007; Simard & Simard, 2009; Thewes et al., 2012).

The Concerns About Recurrence Scale (CARS) was utilized in five studies to assess FCR (Northhouse, 1981; Cohee et al., 2015; Dempster et al, 2011; Lebel et al., 2013; Ozga et al 2015). CARS-1 is divided into two sections. The first section assesses overall FCR (Thewes et al., 2012). The second section of the CARS assesses the nature of a woman’s fears such as; health worries, womanhood, role worries, and death worries (Thewes et al., 2012). Internal consistency ranged in studies for survivors’ cohorts ($\alpha = \ldots$)
0.87-0.94) (Lebel et al., 2013; Northhouse, 1981) and remained similar for one study of caregivers (α = 0.87-0.91) (Thewes et al., 2012).

The Fear of Recurrence Questionnaire (FRQ) was used in two studies (Northhouse, 1981; Ponto, 2008). The FRQ was used in the primary study due to its high internal consistency and use with cancer survivors and spouses (personal communication with Dr. Julie Ponto, September 18, 2019). FRQ is a 22-item scale that measures FCR on a 1-5-point Likert scale from “Strongly Agree” to “Strongly Disagree” (Northouse, 1981; Thewes et al., 2012). The 22 items are summed to provide a total score that can range from 22 to 110; higher total scores indicate a higher level of FCR (Thewes et al., 2013; Northhouse, 1981). FRQ has high internal consistency reported with cancer survivors (α = 0.92) and carer’s (α = 0.91) (Northhouse, 1981; Thewes et al., 2013). FRQ may be applied to mix cancer populations (Thewes et al., 2013). Internal validity has not been assessed (Thewes et al., 2013).

In summary, literature has identified various ways of measuring fear of recurrence. To the authors knowledge there are currently no clearly defined and/or clinically significant levels of FCR. Thus, making comparisons across the multitude of studies difficult to assess. Future research is warranted to determine the optimal cutoffs for clinically significant FCR with measurement tools. Clinical consensus is needed to optimally measure FCR and implement such a measurement tools for future clinical practice.
<table>
<thead>
<tr>
<th>FCR Measurement</th>
<th>Reference</th>
<th>Item Number</th>
<th>Response format</th>
<th>Cancer Stage</th>
<th>Cancer Type</th>
<th>Reliability</th>
<th>Clinical FCR Cut Off</th>
<th>Validated Cancer Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Worries Scale and Impact of Cancer (HWSIC)</td>
<td>van de Wal et al., 2016</td>
<td>3</td>
<td>Likert Scale</td>
<td>Stage I and II</td>
<td>Endometrial Colorectal Hodgkins non-Hodgkins lymphoma Melanoma</td>
<td>α = .83</td>
<td>Not stated</td>
<td>Not Stated</td>
</tr>
<tr>
<td>Cancer Worry Scale (CWS)</td>
<td>Humphris et al., 2003; Krokschoen et al., 2018; Maguire et al., 2017</td>
<td>8</td>
<td>Likert Scale</td>
<td>Mixed</td>
<td>Ovarian Endometrial Colorectal Head/Neck</td>
<td>α = .87</td>
<td>Clinical significant &gt; 14.</td>
<td>Breast Cancer</td>
</tr>
<tr>
<td>Fear Of Recurrence Inventory (FCRI)</td>
<td>Jeppesen et al., 2018; Lin et al., 2016; Liu et al., 2018; Simard &amp; Savard, 2009</td>
<td>42</td>
<td>Likert Scale</td>
<td>Mixed</td>
<td>Ovarian Head/Neck Endometrial Brain Cervical Breast Pancreas Lymphomas</td>
<td>r = 0.56-0.87</td>
<td>Clinical significant &gt; 16</td>
<td>Mixed Cancers</td>
</tr>
<tr>
<td>FCR Measurement</td>
<td>Reference</td>
<td>Item Number</td>
<td>Response format</td>
<td>Cancer Stage</td>
<td>Cancer Type</td>
<td>Reliability</td>
<td>Clinical FCR Cut Off</td>
<td>Validated Cancer Type</td>
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<tr>
<td>FCRI Severity Subscale</td>
<td>Champagne et al., 2017; Lui et al., 2018</td>
<td>9</td>
<td>Likert Scale</td>
<td>Mixed</td>
<td>Ovarian</td>
<td>Optimal sensitivity (87%) and specificity (75%)</td>
<td>Clinical significant &gt; 13</td>
<td>Mixed Cancers</td>
</tr>
<tr>
<td>Fear of Progression Questionnaire Short Form (FoP-Q-SF)</td>
<td>Koch-Gallenkamp et al., 2017; Northhouse, 1981; Boehmer et al., 2016; Mellon &amp; Northhouse, 2001; Mellon et al., 2007; Simard &amp; Simard, 2009</td>
<td>12</td>
<td>Likert Scale</td>
<td>Mixed</td>
<td>Breast</td>
<td>Survivors α = 0.87-0.94</td>
<td>Not Stated</td>
<td>Cancer Diabetes Rheumatic disease</td>
</tr>
<tr>
<td>Concerns About Recurrence Scale (CARS)</td>
<td>Northhouse, 1981; Cohee et al., 2015; Dempster et al, 2011; Lebel et al., 2013; Ozga et al 2015</td>
<td>30</td>
<td>Likert Scales</td>
<td>Mixed</td>
<td>Breast</td>
<td>Survivors α = 0.87-0.94</td>
<td>Not Stated</td>
<td>Breast</td>
</tr>
<tr>
<td>Fear of Recurrence Questionnaire (FRQ)</td>
<td>Northhouse, 1981; Ponto, 2008</td>
<td>22</td>
<td>Likert Scale</td>
<td>Breast</td>
<td>Ovarian</td>
<td>Survivors α = 0.89-0.92</td>
<td>22 to 110 which higher scores indicate higher FCR</td>
<td>Mixed Cancers and caregivers</td>
</tr>
</tbody>
</table>
Theoretical Framework

The theoretical framework for this research study was based on the Common-Sense Model of Illness developed by Leventhal, Diefenbach, & Leventhal (1992) and further expanded by Lee-Jones et al. (1997). The Common-Sense Model suggests that when individuals are confronted with a health threat, an illness representation of two motivational processing systems (cognitive and emotional) is triggered which act in parallel to inform a person’s response (Leventhal et al., 1992). This activation of the health threat leads to coping strategies used to manage the illness representation, and criteria used by the individual to evaluate the outcomes of the coping processes (Leventhal et al., 1992). When a serious condition such as a cancer diagnosis emerges, the motivational processing system experiences a significant amount of emotional distress and overrides the cognitive system (Leventhal et al., 1992).

According to the Common-Sense Model, the individual is an active problem solver who deals with two phenomena simultaneously; (a) the perceived reality of the health threat and (b) the emotional reactions to that threat (Diefenbach & Leventhal, 1996). The Common-Sense Model identifies factors involved in processing the information regarding the disease or illness to provide a personal view of the illness and how this view guides coping behaviors and outcomes (Diefenbach & Leventhal, 1996). The individual view of the illness helps to explain coping behaviors and outcomes in chronic illness.

Fear of recurrence is further adapted in the model by Lee-Jones et al. (1997). The authors proposed that FCR encompasses cognitions and emotions, where the cognitive system consists of perceived risk of recurrence and is influenced by factors such as past
experiences with cancer. In contrast, the emotional processing system is associated with worry about the cancer returning, anxiety about cancer, and regret about different treatment decisions (Lee-Jones et al., 1997). Lee-Jones et al. (1997) hypothesized that a survivor’s illness representation is key in determining the level of FCR they will experience. Survivors who view cancer as a chronic illness with uncontrollable negative consequences are more likely to have high FCR. An adaptation of Lee-Jones et al. (1997) formulation of FCR is presented in Figure 1. This model is not unidirectional, but that the resulting consequences will influence both cognitive processes and the interpretation of antecedents (Lee-Jones et al., 1997). The model proposes that both internal and external cues play a role in activating cognitive responses associated with FCR. Somatic cues are interpreted and function as indicators that the illness may have returned (Lee-Jones et al., 1997).

Years of survivorship is the main part of the model being assessed and studied in Figure 1. The influence of year of survivorship on FCR has produced contradictory evidence. Some studies suggest that time enhances FCR, while others suggest that time does not make any difference on FCR (Lee-Jones et al., 1997). External cues associated with the cancer diagnosis, such as follow up appointments or chance exposure to social media articles related to cancer may increase anxiety and thoughts about possible recurrence (Lee-Jones et al., 1997).
Figure 1. Adaptation of the Lee-Jones et al. (1997) Formulation of FCR
These external cues may occur at any point in the cancer trajectory and stimulate an anxious and fearful emotion for the survivor increasing FCR. The representation of illness may evolve over time due to personal experiences, myths, and the media. The stimuli perceived by some survivors may influence the cognitions and beliefs they hold, resulting in a fear response (Lee-Jones et al., 1997).

**Summary**

In summary, chapter two described the search strategy utilized for database abstraction and provided a review of the literature in relation to the FCR in relation to years of survivorship in survivors and their spouses. Key articles were summarized in the literature table located in Appendix B. The literature supports the need for further research regarding how FCR and years of survivorship are related to survivors with recurrent ovarian cancer and their spouses. Additionally, chapter two explained the theoretical basis that will help guide the study.
CHAPTER III

Research Methodology

Introduction

This chapter describes an overview of components of the primary study from Ponto (2008) and a secondary analysis of the primary study data set. A secondary analysis of Ponto (2008) was undertaken to examine the difference in FCR of ovarian cancer survivors with history of recurrence and spouses. This chapter will provide an overview of the research design, and further information of the primary study and the current study setting, sample, ethical considerations, instruments and measures, data collection procedure, data analysis, and limitations.

Research Design

The secondary analysis utilized a descriptive correlational design to analyze cross-sectional data from the primary study. A secondary analysis was conducted to answer the following questions:

1) Is there a correlation between the level of FCR in women with ovarian cancer by years of survivorship and demographic variables?

2) Is there a correlation between the level of FCR in spouses by years of survivorship and demographic variables?

Primary Study

The primary study by Ponto (2008) utilized the family system framework to explore the adjustment and growth among ovarian cancer survivors and their spouses.
The primary study utilized survey methodology using reliable and validated instruments to collect data regarding ovarian cancer survivor and their spouse demographics, adjustment, and growth information (Dillman, 2000; Ponto, 2008). Data were collected using a paper or an online format. Individuals who preferred paper format or unable to complete web-based survey were mailed paper surveys. Participants were encouraged to contact the primary investigator regarding questions or to verify on-line or in paper eligibility. Survey participants who had not returned the paper survey within two weeks after initial mailing and were sent reminder cards at six and eight weeks (Ponto, 2008).

Online data collection was completed using SurveyMonkey (www.SurveyMonkey.com) (Ponto, 2008). SurveyMonkey is survey software that allows subscribers to complete surveys confidentially and securely (Ponto, 2008). Participants were asked three questions to verify eligibility. The survey was estimated to take 45-60 minutes which participants needed to fully complete once they started the online survey (Ponto, 2008). Consent was given by the participants of the study when the surveys were returned. Participants were informed the results would remain confidential and used solely for the study and were thanked for their participation once the survey was completed (Ponto, 2008).

Data obtained from survey results were stored in an electronic format using SPSS. Any mailed results, contact information, and returned participant information was stored in a locked cabinet which was separated from study data. The primary investigator was the only person who could access participant information. The study was approved by the University of Utah and Winona State University Institutional Review Boards.
The sample consisted of 60 ovarian cancer survivors and 32 dyads who were over 21 years of age, could speak and write English, and had a significant other who agreed to participate. Dyads were recruited through network and snowball sampling from the National Ovarian Cancer Coalition (NOCC), ovarian cancer support groups, and local healthcare organizations (Ponto, 2008). Recruitment flyers with the study details were distributed to individuals who had contact with potential participants of the study (Ponto, 2008). Participants may have completed surveys in their home setting or other settings that allowed for survey completion.

The purpose of the Ponto (2008) study was to:

1) Analyze predictors of adjustment and growth in women with recurrent ovarian cancer.

2) Describe relationships among demographic, illness, appraisal and dyad resource variables and adjustment and growth in recurrent ovarian cancer survivors and spouses.

The primary study design utilized a correlational, cross-sectional design to describe relationships among demographic, illness appraisal, dyad resource variables, and adjustment and growth in recurrent ovarian cancer survivor and spouse dyads (Ponto, 2008).

**Secondary Analysis**

**Setting and Sample**

This secondary analysis setting reflects the primary study. The sample consisted of data from all 32 spouse dyads from the primary study.
Ethical Considerations

Approval for the secondary analysis was obtained from the Winona State University Institutional Review Board. Permission to use data for the secondary analysis was obtained from the principal investigator (see Appendix C). Investigators for the secondary analysis received only de-identified electronic data in an SPSS file that were utilized on a password protected computer to protect the participant’s confidentiality.

Instruments and Measures

Fear of Cancer Recurrence (FCR) was measured using the Fear of Recurrence Questionnaire (FRQ) (Northouse, 1981). FRQ is a 22-item scale that measures FCR on a 1-5 point Likert scale from “Strongly Agree” to “Strongly Disagree” (Northouse, 1981). The 22 items are summed to provide a total score that can range from 22 to 110; higher total scores indicate a higher level of FCR (Northouse, 1981). The FRQ is available in two forms, one worded for survivors and the other worded for spouses. Both forms included the same number of questions. Internal consistency reliability was high in the primary study with a Cronbach’s alpha of 0.83 for spouses and .93 for ovarian cancer survivors (Ponto, 2008).

Years of survivorship were measured using the date of diagnosis item on the 5-item Meaning and Adjustment in Ovarian Cancer Spouse Dyads Illness Profile (see Appendix A) (Ponto, 2008). Years of survivorship was calculated by subtracting the date of diagnosis from the date of survey completion.

Marital status was a self-reported measure utilizing item number six (see Appendix D) of the Demographic Questionnaire (Ponto, 2008). Length of marriage or living together was self-reported measure using item number seven (see Appendix D) of
the Demographic Questionnaire (Ponto, 2008). Age was determined by subtracting date of item 2 from item 3 (see Appendix D) of the Demographic Questionnaire (Ponto, 2008). Gender was self-reported measure of the Demographic Questionnaire (see Appendix D) (Ponto, 2008).

**Data Collection Procedure**

Data for the secondary analysis were obtained from a pre-existing de-identified database from the primary study investigator. The data were provided in an SPSS file and used to analyze relevant data to answer the current study’s questions.

**Data Analysis**

The following research questions were analyzed using Pearson correlation, means, medians, mode, standard deviations, and range. A $p$-value of less than or equal to 0.05 was considered statistically significant.

1. Is there an association between the level of FCR in women with ovarian cancer by years of survival?
   a. FCR scores were a calculated value of the total scale score of responses by ovarian cancer survivors from the FRQ assessment tool.  
   b. A correlation (Pearson) was used to determine if a significant relationship was found between the level of FCR and years of survival.  
   c. Self-reported age will be categorized and analyzed to determine whether a difference exists in FCR recurrence among categories.

2. Is there an association between the level of FCR in spouses who care for ovarian cancer survivors by years of survival?
a. FCR scores were a calculated value of the total scale score by spouses utilizing the FRQ assessment tool.

b. A correlation (Pearson) was used to determine if a significant relationship was found between the level of FCR and years of survival.

c. Self-reported age will be categorized and analyzed to determine whether a difference exists in FCR recurrence among categories.

Demographic data were analyzed using mean, standard deviation, number, and frequency to describe the sample and included length of marriage/living together, ovarian cancer survivor/spouse age, grade of school, employment, spirituality, and number of health problems.

**Limitations**

The primary study has design limitations including a relatively small sample size, and a sample of only Caucasians and English proficient participants. Results may not reflect other ovarian cancer survivors. The primary study is one of few studies that included the spouse and ovarian cancer survivor as a dyad. Thus, making it difficult to create a larger sample size. Snowball sampling method may introduce sampling bias due to limited control of the sample. Limitation of the secondary analysis is a small sample size, cross-sectional data, and self-reported data.

**Summary**

In summary, the purpose of this secondary analysis was to analyze the perceived FCR level by the years of survivorship in women with ovarian cancer and their spouses. This chapter provides the research design, primary study, sample and setting, ethical considerations, instruments, data collection and analysis, and study limitations.
CHAPTER IV

Analysis of Data

Introduction

This chapter discusses the results of the secondary analysis performed to address the proposed research questions. The goals of the analysis included describing the demographic data and determining if there is an association between the levels of FCR in women with ovarian cancer and their spouses by months of survival. Data were analyzed with the support of Dr. Julie Ponto at Winona State University – Rochester.

Description of Sample

Descriptive statistics were utilized to help explain the population included in the secondary analysis. See Table 3 for demographic characteristics.

The sample consisted of 32 ovarian cancer survivors. Average length of marriage or living with their spouse was 33.16 years ($SD = 13.67$), and ranged from 4-56 years. The mean age for ovarian cancer survivors was 61.5 years ($SD = 7.6$), and ranged from 47-77 years. The ovarian cancer survivors were mostly well educated with majority of the study participants attending or completing college level education.

The mean number of health problems with ovarian cancer survivors was 0.75 ($SD = .067$), and ranged from 0-2 health problems.

The sample consisted of 32 spouses. Spouse’s mean age was 63.88 ($SD = 8.98$), and ranged from 47-82 years. Spouse’s average length of marriage or living with survivor was 33.2 years ($SD = 33.2$), with a range from 3-57 years. The spouses were
well educated as most attended or completed college level education. The mean number of health problems for spouses was 1.16 ($SD = 1.9$), and ranged from 0-4 problems.

Table 3.

*Demographic Characteristics of Survivors and Spouses*

<table>
<thead>
<tr>
<th>Measure</th>
<th>N</th>
<th>%</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
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<td><strong>Length of Marriage or Living Together</strong></td>
<td></td>
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<tr>
<td>Survivor</td>
<td>32</td>
<td>33.2</td>
<td>13.7</td>
<td>4-56</td>
<td></td>
</tr>
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<td>Spouse</td>
<td>32</td>
<td>33.2</td>
<td>13.7</td>
<td>3-57</td>
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<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Survivor</td>
<td>32</td>
<td>61.5</td>
<td>7.6</td>
<td>47-77</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>32</td>
<td>63.9</td>
<td>8.9</td>
<td>47-82</td>
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</tr>
<tr>
<td><strong>Education - Survivor</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some High School</td>
<td>0</td>
<td>0.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>4</td>
<td>12.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Technical School</td>
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<td>0.0</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Some College</td>
<td>11</td>
<td>34.4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>College Graduate</td>
<td>7</td>
<td>21.9</td>
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<td>31.3</td>
<td></td>
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<tr>
<td><strong>Education - Spouse</strong></td>
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<td></td>
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<tr>
<td>Some High School</td>
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<td>3.1</td>
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<td>High School</td>
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<td>12.5</td>
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<tr>
<td>Technical School</td>
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<td>6.3</td>
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<td>Some College</td>
<td>6</td>
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<td></td>
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<tr>
<td>College Graduate</td>
<td>8</td>
<td>25.0</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Postgraduate and/or Professional</td>
<td>11</td>
<td>34.4</td>
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</tbody>
</table>
The first research question explored the correlation between the level of FCR in women with ovarian cancer, years of survivorship, and demographic variables. The mean level of FCR reported by ovarian cancer survivors was 83.93 (SD = 13.8). The
mean months of survivorship in the sample of ovarian cancer survivors was 65.52 ($SD = 32.97$). Pearson product-moment correlation found no statistically significant relationship between months of survivorship and reported level of FCR ($p = 0.33$) and a negative correlation coefficient ($r = -0.18$). Further analysis found age was not statistically significantly associated with reported FCR scores ($p = 0.69$) with 95% (CI = 76.08, 89.92). Table 4 summarizes the data analysis for research question one.

Table 4.

*Correlation between Level of FCR in Survivors, Years of Survivorship, and Demographics Data | N = 32*

<table>
<thead>
<tr>
<th></th>
<th>Survivors M (SD)</th>
<th>r2</th>
<th>F</th>
<th>p</th>
<th>CI</th>
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</thead>
<tbody>
<tr>
<td>Level of FCR</td>
<td>83.9 (13.8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Survivorship (Months)</td>
<td>65.5 (32.9)</td>
<td>-0.18</td>
<td>0.33</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>61.5 (7.6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

M = Mean; SD = Standard Deviation; CI = Confidence Interval

The second research question explored if there was a correlation between the level of spouse FCR, years of survivorship, and demographic variables. The mean level of FCR reported by spouses was 92.00 ($SD = 9.4$). The mean months of survivorship in the sample of spouses was 65.52 ($SD = 32.97$). Pearson product-moment correlation found no statistically significant relationship between months of survivorship and reported level of FCR ($p = 0.085$) and a negative correlation coefficient ($r = -0.31$). Further analysis found age was not statistically significantly associated with reported FCR scores ($p = 0.68$) with 95% confidence (CI = 86.95, 95.90). Table 5 summarizes the data analysis for
the second research question.

Table 5.

*Correlation between Level of FCR in Spouse, Years of Survivorship, and Demographic Data | N = 32*

<table>
<thead>
<tr>
<th></th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of FCR</td>
<td>92 (9.4)</td>
</tr>
<tr>
<td>Survivorship (Months)</td>
<td>65.5 (22.9)</td>
</tr>
<tr>
<td>Age</td>
<td>63.9 (9.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>r²</th>
<th>F</th>
<th>p</th>
<th>CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survivorship (Months)</td>
<td>-0.30</td>
<td>0.08</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of FCR</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.17</td>
<td>0.68</td>
<td>86.95, 95.90</td>
<td></td>
</tr>
<tr>
<td>Level of FCR</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

M = Mean, SD = Standard Deviation, CI = Confidence Interval

**Summary**

This chapter provided a description of the sample of participants included in the secondary analysis of data. It described how data were analyzed in relation to the research questions. Statistical results were also provided. Further discussion, conclusions, and implications for practice and research can be found in Chapter V.
CHAPTER V

Discussion and Conclusions

Introduction

The purpose of this secondary analysis was to examine the perceived level of FCR by the years of survivorship in women with ovarian cancer and their spouses. This chapter includes a description of the sample, discussions and conclusions, theoretical framework, scope and limitations, implications for practice, implications for research, and summary.

Description of the Sample

The sample consisted of ovarian cancer survivors and their spouses. A total of 32 dyads who were over 21 years of age, could speak and write English, and had a significant other who agreed to participate were included. Dyads were recruited through network and snowball sampling from the NOCC, ovarian cancer support groups, and local healthcare organizations (Ponto, 2008).

This sample is different from the majority of the other samples reviewed in the literature as it is one of few studies focused on women with ovarian cancer and their spouses. Within the 50 articles reviewed, only 12 studied FCR in ovarian cancer or any type of gynecological cancer survivors. Of those 12 articles, seven studied only the cancer survivor, one studied only the caregivers, and four studied both the survivor and caregiver as a dyad. Seven of the articles sampled only breast cancer survivors, one study only sampled the survivors and six of the articles studied both the survivor and
caregiver as a dyad. Five of the articles studied FCR in head and neck cancer survivors and their caregivers. Fifteen of the articles studied a variety of cancers. Of those 15 articles, eight studied only the cancer survivors, one studied only the caregiver, and six studied both the survivor and caregiver as a dyad. The remaining 11 articles were systematic literature reviews with a variety of inclusion and exclusion criteria.

The demographic characteristics for survivors and spouses in this study indicated that they were educated with the vast majority having at least some college education. The mean age of the survivor was 61.5 years and the mean age for the spouse was 64 years old. Interestingly, approximately 47% of the survivors had retired, while only 37.5% of their spouses were retired with 47% of spouses still working full-time. This could be due to increased medical expenses from cancer treatment keeping the spouses in the workforce to relieve some of the financial burden. In regard to spirituality, 28% of survivors thought of themselves as moderately spiritual and 44% believed they were quite spiritual. Similarly, 47% of spouses thought of themselves as moderately spiritual and 28% believed they were quite spiritual. The majority of survivors (87%) and spouses (75%) reported zero or one health problem prior to their cancer diagnosis.

**Discussion and Conclusions**

The first research question, examined the correlation between the level of FCR in women with ovarian cancer by years of survivorship and demographic variables. A Pearson product-moment correlation was used to determine the statistical correlation between FCR scores and years of survival which were treated as continuous variables (Gertsman, 2008). There was no statistically significant difference between months of survival and FCR scores ($p = 0.33$). Other studies have also suggested no significant
correlation with time since diagnosis and FCR scores (Crist & Grunfeld, 2013, Koch et al., 2013, Simard et al., 2013, van De Wal et al., 2016). One possible explanation of the study results is that average months of survival were 65.5 months, which covers a longer period of survival time. This result is similar to studies with long term cancer survivors (Jeppesen et al., 2018; Koch et al., 2013; Kronk-Shoen, et al., 2018). Secondly, one study suggested throughout survivorship in the ovarian cancer survivor sample and FCR has been reported as moderate to low reducing the chance of a detectable statistical correlation with years of survivorship without a very large sample (Koch et al., 2013).

Further analysis of the first research question was conducted to determine if age attributed to the variation of FCR scores in ovarian cancer survivors by years of survival. Analysis of variance (ANOVA) was used to determine if age attributed to a difference in FCR scores in ovarian cancer survivors. Age was treated as a continuous independent variable and FCR scores were treated as the dependent variable in the ANOVA test. The results yielded no statistically significant relationship with age and FCR scores ($F = 0.16$, $p = 0.69$) with 95% confidence (76.08, 89.92). The ANOVA results were similar to a previous study that found lower FCR scores in older women (greater than or equal to 60 years of age) who had higher education and were partnered than younger women (less than 60 years of age) (Koch et al., 2013). The sample demographics help provide a possible explanation of why age was not statistically significant with FCR scores over years of survival. First, the mean age of ovarian cancer survivors was 61.5(7.63) years of age and ranged from 47-77 years of age. Literature has suggested that advanced age may influence FCR scores due to more life experiences with health and illness, and enhanced
coping strategies to manage crisis compared to younger women (Lebel, 2012; van de Wal et al., 2015).

The second research question attempted to determine if a correlation between the level of FCR in spouses by years of survivorship and demographic variables. The statistical test used was a Pearson product-moment correlation to determine the correlation between FCR scores and years of survival which were treated as continuous variables (Gertsman, 2008). The Pearson product-moment correlation results yielded no statistical significance ($p = 0.085$) but suggested a moderate negative association ($r = -0.31$). These results are similar to studies that found no significant correlation with years of survivorship and FCR scores (Cohee et al., 2015; Cohee et al., 2017; Mellon et al., 2007). One possible explanation of why the results approached statistical significance is the spouse FCR scores were on average higher with smaller variation 92(9.4) than ovarian cancer survivors 83.9(13.8). Literature has suggested that increased FCR scores in spouses may be due to increasing cancer severity, increased family stress, greater time spent caring for the survivor, and spouses physical and mental health status (Han et al., 2015; Kim et al., 2011; Mellon et al., 2007). Second, moderate negative association suggest as years of survivorship increased, FCR scores decreased, but remained higher when compared to ovarian cancer survivors. These results do suggest that spouse FCR is persistent through the ovarian cancer survivorship in spouses which is similar to current studies (Boehmer et al., 2016; Girgis et al., 2013; Janz et al., 2016).

Analysis was conducted to determine if age attributed to the variation of FCR scores in spouses over years of survival. Analysis of variance (ANOVA) was used to determine if age attributed to a difference in FCR scores in spouses. Age was treated as a
continuous independent variable and FCR scores were treated and the dependent variable in the ANOVA. The ANOVA test yielded no statistically significant difference in age and FCR scores in spouses ($F = 0.17, p = 0.69$) with 95% confidence (86.9, 95.9). The ANOVA results differ from current literature which found significant interaction of age and FCR scores in spouses (Maguire et al., 2017; Mellon et al., 2007; Petricone-Westwood & Lebel, 2016; van de Wal et al., 2016). One possible explanation for our results is the age of spouses in the sample. The average age of spouses was 63.9 years of age (8.9) and ranged from 47 to 82 years of age. Age of the spouses may have influenced results due to large number of the sample who are 55-73 years old, and a larger sample size is needed to detect a small effect. Literature has suggested that an increase in the spouse’s age may influence more coping mechanisms, positive meaning associated with illness, and less family disruptions (Hodges et al., 2005; Northouse et al., 1995). Similar results were noted in the study by Mellon et al (2007) which found dyads with elderly survivors and caregivers did not have significant effect on FCR scores.

A notable result which suggested that spouses in our sample had similar FCR scores ($CI = 86.9, 95.9$) to the ovarian cancer survivors ($CI = 76.08, 89.92$) group. The overlapping confidence intervals suggest ovarian cancer survivor and spouse dyads experience similar FCR during survivorship. Literature has suggested that as caregiver FCR increased so did the cancer survivors FCR (Cohee et al., 2015; Kim et al., 2011; Mellon, 2002). One study suggested the severity of cancer in survivors was correlated with their caregivers FCR, while suggesting dyadic mutuality (Kim et al., 2011).

The results of our secondary analysis found no correlation between years of survivorship and FCR scores. It is recommended that future research of this study
sample perform multiple linear regression or factor analysis to explore demographic variables such as number of health problems, income, spirituality, age, and years of survival which may help identify variables that influence FCR scores in ovarian cancer survivors and spouses. Current literature suggest FCR scores may be influenced by health problems of the cancer survivor and spouse, spirituality, and education level (Kim et al., 2011; Koch et al., 2013; Krok-Schoen et al., 2018; Mellon et al., 2007; Ozga et al., 2015).

**Theoretical Framework**

After analyzing the data from the secondary analysis, the findings continue to support the theoretical framework based on the Common-Sense Model of Illness developed by Leventhal, Diefenbach, & Leventhal (1992) and further expanded by Lee-Jones et al. (1997). The adaptation of Lee-Jones et al. (1997) formulation of FCR can be viewed in Figure 1.

The theoretical framework is supported by this data because the model is multidirectional. Both internal and external cues play a role in activating cognitive responses associated with FCR. Internal cues associated with cancer diagnosis such as somatic stimuli that may be interpreted as cancer recurrence (Lee-Jones et al., 1997). External cues associated with the cancer diagnosis, such as follow up appointments or chance exposure to social media articles related to cancer may increase anxiety and thoughts about possible recurrence (Lee-Jones et al., 1997).

Years of survivorship was the main part of the model assessed and studied in Figure 1. Years of survivorship was not shown to have a significant correlation with FCR in either the survivors or their spouse. However, a potential moderate negative
correlation coefficient ($r = -0.31$) would suggest a decrease in FCR in the spouses as years of survivorship increased. These results suggest that spouse FCR is persistent through ovarian cancer survivorship. When internal or external cues alert the ovarian cancer survivor or their spouse, their level of FCR may increase for an unknown length of time despite the length of years of survivorship.

**Scope and Limitations**

One limitation of this study was the homogeneous sample. Second, the uncommon nature of the diagnosis makes it challenging to gather a robust sample that would be representative of the ovarian cancer and spouse populations. The sample dyads were Caucasian, educated, and had higher income, which may not generalize to a diverse ovarian cancer survivor and spouse populations. To address the sample limitations, a limited inclusion criterion was utilized to limit other covariates which may have influence effects of the primary study results. Also, the study sample consisted of participants from national advocacy groups, and from a multi-centered population which allowed for more robust analysis.

An additional limitation of the secondary analysis is data used for the study is from self-reported measures. Self-reported measures may introduce recall bias which can decrease accuracy of the response (Gray, Grove, & Sutherland, 2017). Data collection was completed in the cancer survivor’s home setting via survey methodology, and utilizing tools with high internal reliability which can reduce recall bias.

**Implications for Practice**

The results from this secondary analysis did not yield any statistically significant relationships. This indicates that the level of FCR for the ovarian cancer survivor or their
spouse does not increase or decrease with years of survivorship. Additionally, the results did not show a relationship between age of the survivor or spouse and FCR, which may explain how individuals can experience increased levels of FCR regardless of their age.

The demographic characteristics reviewed in this secondary analysis can be beneficial in implementing practice changes for healthcare providers who work with cancer survivors and their spouse. The data showed many survivors work part-time or are retired, while 47% of their spouses work full-time. It is important for the healthcare providers to appreciate the financial stressors the couple may be facing due to increased medical expenses and the inability for the survivor to work. Additionally, the vast majority of survivors and spouses identified themselves and moderately to quite spiritual. This would suggest that making an effort to identify resources such as a chaplain, meditation, religious support groups, etc. for the survivor and spouse could assist with decreasing their overall level of FCR. It is important for the healthcare providers to ask specific questions regarding employment, financial stress, spirituality, and other health problems to ensure they have addressing all internal and external cues in relationship to their level of FCR. Financial stress could be addressed by setting up an appointment with a financial counselor for every patient before starting treatment to discuss financial concerns and payment options to decrease that fear.

This information indicates that both the ovarian cancer survivor and their spouse need to be continually supported and treated throughout the trajectory of the illness. It is important for healthcare providers to understand the possibility of increased FCR levels with every internal and external cue observed by ovarian cancer survivors and their spouses. Efforts should be made to assist healthcare providers in assessing couples who
are most at risk for higher FCR levels. This information would allow for healthcare providers to be better equipped to care for the couple as a whole.

**Implications for Research**

These results suggest future research is warranted on the effects of FCR with the ovarian cancer survivor population and the variance of FCR scores during the cancer trajectory from longitudinal studies to explore changes in FCR throughout survivorship, which can inform healthcare providers and direct interventions.

It is recommended that future research also assess FCR in diverse populations, as current literature may not be representative of all cancer survivors. The study sample included participants from local, national and multi-centered networks but future ovarian cancer and spouse dyads should include samples from international cancer networks to generate more robust and representative samples to analyze FCR.

The multidimensional nature of FCR warrants further research on the effects of FCR on ovarian cancer survivors and their spouses. The current literature supports the need for further research regarding the relationship of FCR and years of survivorship and its effect on women with recurrent ovarian cancer and their spouses. Current literature has identified as FCR persist throughout survivorship which may have consequences to physical and psychological health for the ovarian cancer survivor and spouse. This study has found that ovarian cancer survivors and spouses experience similar FCR which will help guide future research in exploring the dyad experience of FCR.

Further research is warranted to determine the optimal cutoffs for clinically significant FCR with assessment tools. Literature has identified multiple FCR assessment tools which have limited validity with ovarian cancer survivors and spouses.
Secondly, due to the utilization of various FCR assessment tools in research which makes comparisons across studies difficult to explore FCR in cancer survivors and spouses. Clinical consensus is needed to optimally measure FCR and implement such assessment tools to direct healthcare providers in the management of FCR.

**Summary**

In summary, chapter five described the sample of the secondary analysis in relation to the literature. The results from the data were discussed. The theoretical framework continues to be supported by the data. Additionally, the scope and limitations, implications for practice, and implications for research were developed. The impact of previous health problems prior to a cancer diagnosis is an intriguing concept. An additional research question to develop if the secondary analysis was to be repeated could be, is there a correlation between the level of FCR in women with ovarian cancer and their spouses and the number of health problems? It is hypothesized that a higher number of health problems the survivor or spouse have the higher their FCR level would be. The results from this question could assist healthcare providers in identifying at risk cancer survivors and their spouses for increased levels of FCR.
REFERENCES


longitudinal study of caregiver’s quality of life, distress, and unmet needs. *Gynecologic Oncology, 132*, 690-697. Retrieved from

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doi:10.1097/NCC.0000000000000285 201809182312281231557012


Appendix A

Meaning and Adjustment in Ovarian Cancer Spouse Dyads
Illness Profile – Survivors

1. Date of first ovarian cancer diagnosis: __________/__________/__________
   month  day  year

2. Date(s) of ovarian cancer recurrence: (1st) __________/__________/__________
   month  day  year
   (2nd) __________/__________/__________
   month  day  year
   (3rd) __________/__________/__________
   month  day  year
   (4th) __________/__________/__________
   month  day  year

3. Date(s) and Type(s) of treatment:
   month/year  Type of treatment
   Surgery  Chemotherapy  Radiation
   Yes  No  Yes  No  Yes  No
   Yes  No  Yes  No  Yes  No
   Yes  No  Yes  No  Yes  No
   Yes  No  Yes  No  Yes  No
   Yes  No  Yes  No  Yes  No
   Yes  No  Yes  No  Yes  No
   Yes  No  Yes  No  Yes  No
   Yes  No  Yes  No  Yes  No

4. What is the state of your ovarian cancer at this time?
   ______ No known ovarian cancer at this time
   ______ High CA125 level
   ______ Known site of ovarian cancer recurrence
   ______ Other, please describe ____________________________

5. Are you currently receiving treatment:
   ______ (1) Yes, circle type: surgery  chemotherapy  radiation
   ______ (2) No
<table>
<thead>
<tr>
<th>Citation</th>
<th>Purpose/Objectives</th>
<th>Study population/ Sample/ Setting</th>
<th>Study Design/ Major Variables/ and Instruments</th>
<th>Results</th>
<th>Implications</th>
<th>Comments</th>
<th>Level of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Armes et al., (2009)</td>
<td>To estimate prevalence and severity of patients’ self-perceived supportive care needs in the immediate post-treatment phase and identify predictors of unmet need.</td>
<td>Cancer facilities in England participated between August and December 2005. Participants were assessed at the end of treatment and 6 months later. Eligibility Criteria: -Diagnosed w/ non-Hodgkin’s lymphoma, breast, prostate, colorectal, or gynecologic cancer -Metastasis free and no relapse -Older than 18 years -Read and understand English Total Sample: n = 1,152 survivors</td>
<td>Multicenter, prospective, longitudinal survey Supportive Care Needs Survey (SCNS) Health Concerns Questionnaire (HCQ)</td>
<td>The most frequently endorsed un-met need was FOR. The chance of having unmet moderate or severe needs was significantly greater for patients receiving hormone therapy or were younger. One third of survivors reported five or more moderate to severe unmet needs, including FOR.</td>
<td>Health care professionals are challenged to ensure patient awareness of signs of cancer recurrence w/o inducing excessive distress. Cognitive behavioral interventions need to be tested to help people cope with the negative impact posed by the threat of recurrence.</td>
<td>FOR was a significant predictor of unmet needs on all SCNS domains except physical and sexuality needs.</td>
<td>Level VI</td>
</tr>
<tr>
<td>Citation</td>
<td>Purpose/ Objectives</td>
<td>Study population/ Sample/ Setting</td>
<td>Study Design/ Major Variables/ and Instruments</td>
<td>Results</td>
<td>Implications</td>
<td>Comments</td>
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<tr>
<td>Beesley et al., (2018)</td>
<td>“Aimed to determine the prevalence of met and unmet needs, and the risk factors for unmet needs among people affected by gynecological cancer” (p. 701)</td>
<td>Total Sample: n = 37 articles reviewed</td>
<td>Systematic review of qualitative and quantitative studies. Fear of Cancer Recurrence in ovarian cancer survivors and spouses. Instruments: Preferred Reporting Items for systematic reviews and meta-analyses guideline.</td>
<td>Studies collectively found women who have gynecological cancer had fear of cancer returning across survivorship. Moderate to high levels of unmet needs found after first line treatment with caregivers and women in mixed gynecological care groups. Highest unmet need identified in studies with caregivers were reducing patients stress (42%), lack of recovery (42%), and fear of cancer recurring or spreading (39%)</td>
<td>Younger women with gynecological cancer were found to have anxiety, depression, insomnia, and post-traumatic stress symptoms, high symptom burden, and poor social support which may better guide healthcare provider interventions. Study suggests risk factors of psychological and physical unmet needs with women that have gynecological cancer would benefit improved interventions with fear of recurrence.</td>
<td>Study findings identified gaps in research related to gynecological cancers sub types, different unmet needs with cancer trajectories, and few quality studies involving patient-caregiver dyads. Study results suggest survivor and caregiver needs vary by phase of cancer continuum, type of gynecological cancers, population subgroups, although comparisons across different instruments and study designs are difficult.</td>
<td>Level V</td>
</tr>
<tr>
<td>Citation</td>
<td>Purpose/Objectives</td>
<td>Study population/Sample/Setting</td>
<td>Study Design/Major Variables/Instruments</td>
<td>Results</td>
<td>Implications</td>
<td>Comments</td>
<td>Level of Evidence</td>
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</tr>
<tr>
<td>Boehmer, et al., (2016)</td>
<td>Identify explanatory factors of fear of recurrence in breast cancer survivors of different sexual orientations and their caregivers and to assess the directionality in the survivor and caregiver dyads.</td>
<td>Recruited from an earlier comparative study and community-based recruitment in Boston, Massachusetts. Eligibility Criteria: -Women with breast cancer -No recurrences -Age 21 or older Total Sample: ( n = 167 ) survivors and their caregiver</td>
<td>Quantitative, Cross-sectional survey Fear of recurrence measured using the FOR Questionnaire (Northouse, 1981).</td>
<td>Survivors FOR did not differ by sexual orientation. Both caregiver groups reported similar FOR. There was a significant correlation between caregiver FOR and survivor FOR ( (p &lt; .0001) ) Years since diagnosis was associated with survivors FOR ( (p &lt; .10) ) Sexual orientation had a significant effect on survivor FOR. Sexual minority women reported less FOR than heterosexual women ( (p &lt; .10) ) Caregiver FOR had a positive relationship with survivor FOR. Time since diagnosis was negatively correlated with caregivers’ FOR.</td>
<td>This study is unique as it reveals greater details about the dynamics within caregiver-survivor dyads that have implications for interventions for survivors and caregivers related to FOR. Further need for studies on the survivor-caregiver communication Finding demonstrates how the dynamics are unidirectional; caregivers’ FOR directly affected survivors’ FOR, while survivors’ FOR did not affect caregivers’ FOR.</td>
<td>This study links survivors’ sexual orientation and the survivors’ and caregivers’ FOR.</td>
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<td>Butow et al., (2014)</td>
<td>“Caregiver burden, quality of life and unmet needs are poorly understood, particularly at the end of life in caregivers of women with ovarian cancer” (p. 690)</td>
<td>Women taking part in the Australian Ovarian Cancer Study and their caregivers. Range from 3 months to 2 years since time of diagnosis. Total Sample: n = 188 women n = 99 caregivers</td>
<td>Descriptive</td>
<td>Mean distress levels in caregivers increased over time (p = 0.01) Unmet needs 0-3 months: Disappointment about recovery 42% Fears of cancer spreading 39% Unmet needs 10-12 months: Reducing patient's stress 24% Managing concerns about recurrence 22%</td>
<td>Study suggested caregiver distress impacted by needs not being met by cancer services and treatment teams. Caregiver unmet needs changed over time which can guide healthcare provider interventions at different points of cancer trajectory. Patient change in quality of life did not influence caregiver quality of life which may relate to overwhelming challenges with recurrent cancer diagnosis.</td>
<td>Women with caregivers were more likely to be married or partnered (56% versus 18%), no statistically or clinically significant differences in age, quality of life, distress, social support or needs at the first assessment in their last year of life.</td>
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<td>Champagne et al., (2017)</td>
<td>“Examine the association of clinical levels of Fear of Cancer Recurrence with the utilization of health care services and medication usage, at 6 time points over a period of 18 months” (p. 1959).</td>
<td>Participants were recruited at L'Hôtel Dieu de Québec and Hôpital du Saint Sacrement in Quebec, Canada. Total Sample: n = 955 Participants</td>
<td>Correlational Design Variables: Fear of Cancer Recurrence with cancer survivors. Fear of Cancer Recurrence Inventory—Short form.</td>
<td>Women who are cancer survivors were more likely to have significant FCR (p &lt; 0.001). Survivors with clinical FOR consulted a psychosocial professional by proportion of 7.9% versus 4.7% for those with a non-clinical level.</td>
<td>Cancer survivors with clinically elevated FCR on average seek reassurance from medical professionals resulting in increased consultation rates. Study results showed increased early consultations after post-treatment suggest post-treatment phase as a top-rated source of distress. Results suggest importance of early detection of elevated FCR and intervention to decrease patient cost associated with healthcare utilization.</td>
<td>Significant differences were found between clinical and non-clinical FCR cohorts on age, sex, main occupation, and cancer site. Younger cancer survivors, working or on sick leave were more likely to have higher FCR scores.</td>
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<td>Cohee et al. (2015)</td>
<td>Test the efficacy of the Social Cognitive Processing Theory in predicting fear of recurrence in long-term breast cancer survivors diagnosed at age 45 years or younger and their partners</td>
<td>Data was collected for a larger QOL study looking at the long-term impact of breast cancer on survivors and their partners. Total sample: n = 222 dyads Eligibility criteria: - Female breast cancer survivor - Diagnosed with stage I – IIIa - 45 years old or younger - 3-8 years past initial treatment - No BCS recurrence - Treated with chemotherapy regimen Partner eligibility: must be currently living with the survivor.</td>
<td>Cross-sectional, Quantitative design Instruments: Fear of Recurrence (FOR) / Concerns About Recurrence Scale (CARS). (survivors only) Social Constraints / 14 items from Lepore Social Constraints Scale. Cognitive Processing/Impact of Event Scale (IES).</td>
<td>FCR negatively correlated with age (r = -0.239, p = 0.01) FCR positively correlated with education (r = 0.164, p = 0.015). Most partners in the sample (53.6%) reported moderate to high FCR. No difference found in FCR scores relative to time since diagnosis (SD = 5.83). BCS reported notable levels of FCR even though they were deemed disease free. (SD = 5.38). FCR scores between breast cancer survivors and partners are comparable (p &lt; 0.196)</td>
<td>Caregivers reported higher levels of FCR than BCS, suggesting partners need to be offered supportive care services to help reduce FOR. Survivors and their partners must process the trauma of cancer and deal with FCR. Interventions to promote open communication and enhance cognitive processing can decrease FCR. Correlations between BCS &amp; partner comparable, suggesting partners need to be offered supportive care services as well to reduce FCR. No relationship found in FCR and time since diagnosis.</td>
<td>FCR is increased for breast cancer survivors and their partners when they feel unable to talk about breast cancer. The sample in the study was mostly Caucasian and highly educated and may not be representative of the true breast cancer population.</td>
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<td>Cox et al., (2008)</td>
<td>Evaluate a nurse led telephone intervention which encouraged a proactive approach to ovarian cancer management, with a holistic attitude to patient well-being.</td>
<td>Women post-treatment for ovarian cancer in the UK who were eligible for follow-up care were invited to receive nurse led telephone follow-up. Eligibility Criteria: -Women with stage II-IV stable disease -Completed initial cancer treatment -Access to a telephone -Speak English. Total Sample: ( n = 56 )</td>
<td>Pilot study Survivors received a telephone call every 3 months during the 10-month intervention period. Baseline evaluations of experience and satisfaction conducted. Phone calls focused on the detection of recurrent disease. Then discussed coping strategies and level of anxiety about FOR. FACT Ovarian scale used to determine physical, functional, social, and emotional wellbeing.</td>
<td>A significant improvement was shown in emotional well-being between pre- and post-measures ( (p = 0.016) ). 33% of survivors discussed FOR in their telephone interview.</td>
<td>Psychological concerns need to be addressed throughout the patient pathway. Alternative approaches to follow-up care helps ensure the patients’ needs are being met.</td>
<td>Ovarian cancer survivors FOR was not a main topic in the study. FOR was not discussed with the patient’s caregiver</td>
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<td>Crist and Grunfeld (2013)</td>
<td>“Identify factors associated with fear of recurrence in cancer Survivors” (p. 978).</td>
<td>43 articles were synthesized.</td>
<td>Systematic Review Variables: FCR Ethnicity Factors associated with FCR Instruments: Adapted Quality assessment tool for literature.</td>
<td>Study suggests younger age is associated with greater FCR. Latino women with cancer were reported to have the highest levels of FCR. Cancer treatment and type of cancer reported inclusive evidence as a risk factor for FCR. Strong association was found between low-mood or psychological destress and FCR. Strong association with new or ongoing side effects or symptoms was associated with greater level of FCR Cancer recurrence or progression was associated with high FCR.</td>
<td>Further research is needed to examine FCR with cancer trajectories and providing stability for FCR over time. Experimental evidence suggests that a somatic cue such as trigger beliefs regarding vulnerability thus increases FCR.</td>
<td>Research design with varied measures for FCR makes it difficult to compare across studies. Limitation of research found majority of fear of cancer recurrence studies included white, well educated, female, breast and gynecological cancers which may make it difficult to generalize to diverse populations.</td>
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| Dempster, et al., (2010) | Determine the extent to which illness cognitions and coping explain psychological distress among family caregivers of survivors of oesophageal cancer. | Participants were recruited via the Oesophageal Patients’ Association (OPA) UK database. Total sample: \( n = 382 \) | Descriptive, Correlational, Cross Sectional Study  
- The Hospital Anxiety and Depression Scale (HADS)  
- The Concerns About Recurrence Scale – Part I (CARS-1)  
- Illness Perception Questionnaire-Revised (IPQ-R) | The correlations indicate that the more strongly caregivers believe that they understand the condition the lower the caregivers psychological distress. The more a caregiver reports engaging in any coping strategies, the higher their reported psychological distress. | Most caregivers of oesophageal cancer survivors are in good health and do not require formal interventions. | Continued theme of anxiety with recurrent cancer diagnosis. | Level IV          |
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<td>Fitch (2009)</td>
<td>“...To describe the psychosocial issues affecting women with recurrent ovarian cancer and provide suggestions for screening to provide appropriate referrals.” (p. 40)</td>
<td>Data sources: Research articles and textbooks.</td>
<td>Descriptive Literature Review Major variables and instruments not stated.</td>
<td>Psychosocial issues affecting women with recurrent ovarian cancer: -Treatment-induced menopause and loss of fertility -Altered body image -Sexual function -Relationships with family members and friends -Daily functioning and work -Financial Concerns -Spiritual well-being Considerations for women with recurrent disease Psychosocial support guidelines -Screening -Clinical assessment and management Nursing Interventions: -Assessment -Practical support -Informational support -Emotional support -Referral</td>
<td>Health care providers should be familiar with guidelines regarding distress management. Healthcare providers play an important role in helping to improve the QOL for women with recurrent breast cancer.</td>
<td>Addresses recurrent ovarian cancer in depth</td>
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<td>Girgis et al., (2013)</td>
<td>“Identify caregivers’ unmet needs and the psychosocial variables associated with unmet need count within the first 24 months post-survivor diagnosis” (p. 1557).</td>
<td>Caregivers recruited from two Australian cancer state-based registries. Total Sample: 6 months n = 547 caregivers, 12 months n = 444 caregivers, 24 months n = 372 caregivers.</td>
<td>Descriptive design Variables: FCR in caregivers. Instruments: Supportive Care Needs Survey-Partners and Caregivers Brief COPE survey for coping. Medical Outcome Survey-Social Support. Physical Component Score for physical wellbeing. Hospital Anxiety and Depression Scale. Adaptation of Australian Omnibus Survey for caregiving tasks.</td>
<td>Unmet needs decreased significantly over time (p &lt; .01) with 37% reporting a decrease in un-met needs at 24-month period. 6-month post diagnosis 18.7% of caregivers reported FCR as the most prevalent unmet need. Variables associated with unmet needs were tasks of caregiving, expenses, depression, avoidance, and coping (p &lt; .05) Study suggests 48% of unmet needs were found with FCR within study population.</td>
<td>Top ranking unmet need among caregivers were managing FCR and reducing stress for person with cancer. Study suggest healthcare providers can focus caregiver interventions for unmet needs early in survivorship to prevent unmet needs from escalating.</td>
<td>Caregivers who withdrew reported lower income and were older. Additional caregivers at 12-month survey were more likely than initial consenters to be without a partner (p = 0.001), not the survivor’s partner (p = 0.002) or live with the survivor (p = 0.004)</td>
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<td>Hall et al., (2017)</td>
<td>“…provide preliminary evidence as to whether fear of recurrence or progression is an intermediary between somatic symptom severity and perceived stress among heterogeneous cancer survivors.” (p. 1401)</td>
<td>Study comprised of patients receiving care at the cancer survivorship clinic at the Massachusetts General Hospital Cancer Center. Total Sample: ( n = 67 )</td>
<td>Quantitative cross-sectional study Assessment of Survivor Concerns (ASC) measured FOR. Perceived Stress Scale (PSS-4)</td>
<td>Survivors endorsed moderate levels of both FOR or progression ( (SD = 0.95) ) FOR or progression was independently positively associated with both somatic symptom severity ( (r = 0.29, p = 0.02) ) The indirect effect on perceived stress via FOR was statistically significant controlling for time since diagnosis ( (p &lt; 0.001) ).</td>
<td>Handling FOR is one of the most prominent concerns with moderate to high levels in 30-70%. Vigilance to signs of a potential recurrence may motivate health-promoting behaviors. FOR may prompt interpersonal connectedness, with survivors calling on social support from formal or informal caregivers.</td>
<td>The results suggest that one third of stress levels among cancer survivors is accounted for by somatic concerns and resulting FOR.</td>
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<td>Han et al., (2015)</td>
<td>Exploration of caregiver experience with family member with cancer.</td>
<td>Face-to-face interviews and journals of primary caregivers at two University Hospitals in South Korea.</td>
<td>Phenomenological design</td>
<td>Caregivers expressed anxiety and uncertainty of cancer recurrence and metastasis during radiation therapy.</td>
<td>Study themes suggest the need for clinical intervention with FCR within the family setting and including family in treatment plans.</td>
<td>Study results show caregivers and spouses have similar fears with different types of cancer diagnosis. Limitation to study findings is dyads were comprised of South Korean families which make it hard to generalize to other cultures and ethnicities.</td>
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<td>Hodges &amp; Humphries (2009)</td>
<td>Compare cancer survivors and caregivers psychological distress and Validate a predictive model for fear of recurrence.</td>
<td>Patients diagnosed with head and neck cancer and their caregivers. Large multi-center of newly diagnosed head and neck cancer patients. Total Sample: n = 101 Patients n = 101 Caregivers</td>
<td>Correlational design. Variables: Fear of cancer recurrence in survivors and their spouses. Instruments: Electronic health record reviewed FCR Instrument: FCR/Worry of Cancer Scale Psychological distress/HADS</td>
<td>Caregivers were found to have higher levels of FCR than cancer survivors (p &lt; 0.001) Survivors FCR scores were stable three- and six-months post-diagnosis (3 months: p &lt; 0.01; 6 months: p &lt; 0.01) Predictive model of psychological distress and FCR patients (3 months: p &lt; 0.01; 6 months: p ≤ 0.01) and caregivers (3 months: p ≤ 0.01; 6 months: p &lt; 0.01) show positive correlation for each data interval.</td>
<td>Proposed FCR model suggests that survivor and caregivers FCR independently determine future distress which could be determined by psychological attributes of the FCR. Study results suggest patient and caregiver FCR is related. Not all participants experienced FCR and authors suggest more research is needed to identify risk factors of FCR. Study results suggested that demographic characteristics did not predict FCR.</td>
<td>FCR/Worry of Cancer Scale is a two item Likert scale and is a preliminary assessment tool. Nature and size of sample limits the generalization of study findings. Participants composed of early stage of cancer which findings cannot be generalized to advanced cancer stages.</td>
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<td>Humphris et al., (2003)</td>
<td>Assess FOR and psychological morbidity in orofacial cancer patients.</td>
<td>Part of a program of research conducted at the Regional Maxillofacial Unit in the United Kingdom.</td>
<td>Prospective, cross-sectional survey</td>
<td>80% of patients in Sample 1 expressed FOR at 3 months following treatment. 72% expressed FOR when re-examined at 7 months ($p = 0.057$). 68% of patients in Sample 2 reported FOR at their 2-year follow-up appointment ($p = 0.068$). FOR was greater in women in Sample 1 &amp; 2 but the results were not statistically significant. Survivors 65 years and older were had less FOR in all samples ($p &lt; 0.002$).</td>
<td>FOR was found to be closely associated with general anxiety rather than depression.</td>
<td>A consistent reduction in FOR was found in both samples, however neither reached statistical significance.</td>
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| Janz et al., (2016)      | “To describe racial/ethnic differences and clinical/treatment correlates of worry about recurrence and examine modifiable factors in the healthcare experience to reduce worry among breast cancer survivors, partners, and pairs.” (p. 4669) | Women with non-metastatic breast cancer identified by the Detroit and Los Angeles SEER registries between June 2005 and February 2007. Surveyed at 9 months and 4 years. Latina and black women were oversampled Total Sample: n = 510 pairs of survivors and their partners | Correlational design Fear of recurrence “Worry” was measured using the 3-point Likert worry scale. | Partners were more likely to report worry about FCR 4 years after diagnosis than survivors (p < .001).  
**Survivors:** Higher FCR with younger age, lower education levels and worse health status. Latinas were most likely to express FCR (50%)  
**Partners:** FCR more likely among less educated, and/or worse health. Latino partners had highest worry (67.2%)  
Both survivor and partner had FCR in 18% of the pairs at 4 years post diagnosis. | Partners reported more worry than survivors, likely due to the perceived loss of control which can help inform healthcare providers to provide interventions.  
Further resources need to be devoted to language support services for survivors and partners to increase the likelihood that what is being discussed is understood.  
Interventions focused on psychoeducation, skill building, mindfulness training, finding meaning, and benefit may be beneficial for both the survivor and partner. | African Americans are most likely to rely on religious coping.  
Younger survivors and partners reported more worry.  
Latina’s were the most vulnerable to worry. | Level IV                                                                 |
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<td>Jeppesen et al., (2018)</td>
<td>“Test patient-initiated follow up reduces fear of cancer recurrence when compared to hospital follow up visits” (p.1)</td>
<td>Four Danish departments of gynecology Women with stage I and II endometrial cancer Total Sample: Control Group $n = 212$ Intervention Group $n = 156$</td>
<td>Randomized Control Trial. Variables: Fear of cancer recurrence Instruments: Fear of Cancer Inventory CONSORT guidelines for colligated data.</td>
<td>Control group mean FCR score was 48.5 ($SD = 28$), and overall reduced score of 41.9. Intervention group mean FCR score was 44.8 ($SD = 27.3$), and overall score 43.3. FCR significantly decreased in control group by -5.9 ($p = 0.02$) No differences were found between two groups with cancer-related visits ($p = 0.77$) and intervention group had fewer examinations ($p &lt; 0.01$).</td>
<td>Large variation of FCR scores suggests endometrial cancer survivors experience high levels of fear. Study has provided validation to the Fear of Cancer Inventory for minimal clinical difference of 6% of scale width or 10 points of scores. Large variation in scores with standard deviations of 26.5 and 29.5, suggests endometrial cancer survivors experienced high levels of fear (p.8)</td>
<td>Study suggests that a benefit of phone calls to survivors may expedite patients calling for symptom changes which may reduce FCR. No baseline characteristics or disease characteristics were found with women of complete data set and non-responders. Non-responders FCR scores showed no difference when compared to participants ($p = 0.88$)</td>
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<td>Kim &amp; Given (2008)</td>
<td>Review literature on QOL of family caregivers at acute and middle to long-term survivorship phases</td>
<td>Literature was reviewed during the acute phase beginning around the time of diagnosis to 1-2 years post diagnosis. Literature databases searched included MEDLINE, PsychINFO, PubMed, and CINAHL between 1996-2007. Excluded studies of family members of patients who had pediatric cancer.</td>
<td>Systematic Literature Review Keywords searched included cancer, carcinoma, family, family member, caregivers, and quality of life.</td>
<td>Cancer recurrence is reportedly one of the most stressful events for both survivor and caregivers. FOR remained a concern among caregivers even when survivors showed physical improvement and no cancer-related symptoms. Caregiver FOR was related to decreased caregiver QOL.</td>
<td>Positive experiences through cancer illness can be enhanced by targeting interventions.</td>
<td>None</td>
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| Kim et al., (2011) | Examine the extent to which survivors and their family members fear that the cancer will return mediated the association between severity of the cancer and each person’s QOL at 2 years post-diagnosis. | The American Cancer Society’s Study of Cancer Survivors-I (SCS-I) identified participants by state cancer registries.  
Eligibility criteria:  
-18 years or older  
-Diagnosed with 1 of 10 most highly incident cancers  
-Fluent in either English or Spanish  
-Resident of the US.  
Exclusion criteria:  
-new cancer diagnosis or recurrence prior to completed survey.  
Total sample:  
*n* = 455  
28 dyads specific to ovarian cancer | Cross-sectional, quantitative study  
Cancer severity (Cancer severity Index 0-1)  
In survivors, FOR was measured using a 3-point Likert scale.  
In caregivers, FOR was measured using a 5-point Likert scale. | The more severe the cancer the higher the level of FOR in survivors (*p* > 0.05) and caregivers (*p* > 0.05)  
Higher levels of FOR in caregivers correlated with poor mental health (*p* > 0.01), but not physical health.  
Caregivers’ FOR correlated with survivors’ poor physical health (*p* > 0.01).  
Severe cancer was related to greater levels of survivors (*p* > 0.05) and caregivers (*p* > 0.01) FOR.  
Caregiver age not related to FOR (*SD* = 13.01). | The association between cancer severity and FOR was stronger among caregivers (*p* < 0.001).  
Higher levels of FOR was related to both survivors and caregiver’s poorer mental health (*p* > 0.05, *p* > 0.01).  
Cancer diagnosed over 2 years ago remains related to FOR more among caregivers than survivors. | FOR, anxiety, and QOL outcomes were self-reported and therefore may not reflect objective distress and health status. | Level VI |
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<td>Koch, Bertram, Eberle, Holleczek, Schmid-Hopfner, Waldman… Arndt (2013)</td>
<td>Describe FOR in long-term breast cancer survivors and to identify possible determinants and the association of FOR with QOL and depression.</td>
<td>The study population is from the population-based CAESAR-study. This study was initiated for long-term breast, colorectal and prostate cancer survivors in six German cancer registries. Eligibility criteria: -confirmed cancer -diagnosed between 1994-2004 -age 20-74 at time of diagnosis. Total sample: ( n = 2671 ) cancer survivors</td>
<td>Descriptive design The short form of the Fear of Progression Questionnaire (FoP-Q-SF) was used to measure FOR.</td>
<td>82% of survivors reported low levels of FOR, 11% experiencing moderate and 6% experiencing high FOR. Younger married women or women who had children had a twofold risk of experiencing moderate to high levels of FOR. Survivors with more advanced cancer at time of diagnosis had higher risk of FOR. The highest risk for moderate/high FOR was for survivors who considered themselves patients with cancerous tumors. Depression was found to be statistically associated with FOR ( (p &lt; .0001) ).</td>
<td>Results indicate that even years after diagnosis and completion of therapy, FOR remains an issue for survivors and negatively affects their QOL. Psychosocial and sociodemographic factors played a bigger role in FOR than clinical factors. Cognitive and psychoeducative interventions could help decrease dysfunctional levels of FOR. Therapies should not completely eliminate FOR, but use it as a motivation for self-care.</td>
<td>Differences in responder and non-responders were small but selection bias cannot be fully ruled out which FOR of survivors maybe over- or under-estimated. Study results were cross-sectional and cannot draw associations from results.</td>
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| Koch-Gallenkam et al., (2017) | “Determine the prevalence of Fear of Cancer Recurrence, specifically moderate to high Fear of Cancer Recurrence in long-term cancer survivors. Also, to increase knowledge on the associations of Fear of Cancer Recurrence and cancer-type, sex, time since diagnosis, and social support” (p. 1330). | Participants were identified and recruited via six German population-based cancer registries of the CAESER study which investigated quality of life in longer term cancer patients (5 years post-diagnosis). Total Sample: \( n = 6,057 \) breast, colorectal, and prostate cancer survivors. | Descriptive Study design
Variables: Fear of Cancer Recurrence
Age
Gender
Time since diagnosis
Instruments: Fear of Progression Questionnaire.
Lubben Social Network Scale. | The mean total FCR score 26.9 (\( SD = 9.4 \)).
Mean score for survivors < 60 years of age were higher than older survivors (\( p < 0.001 \)).
Less time since diagnosis was significantly associated with moderate to high FCR with the total study population (\( OR = 1.47, 95\% \) CI (1.12 –1.92)).
Less time since diagnosis was significantly associated with moderate to high FCR in survivors without recurrence/metastases (\( OR = 1.44, 95\% \) CI (1.05 – 1.99)).
Female survivors were more likely to have moderate to high FCR (\( OR = 2.13, 95\% \) CI (1.78 – 2.55)). | Study suggest long term cancer survivors who are younger, and female are more likely to experience moderate to high FCR.
Study suggest education, age, time since diagnosis are precipitating factors that may affect FCR. | Statistically significant differences found between responders and non-responder’s characteristic’s such as female gender, younger age, breast cancer survivor, time since diagnosis (\( p < 0.001 \)).
Time since diagnosis and survivors with recurrence or metastasis did not show significance with FCR. | Level V |
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<td>Koch, Bertram et al., (2013)</td>
<td>Summarize the results of quantitative studies on fear of cancer recurrence in long-term survivors and to provide an overview of the current knowledge, including possible determinants and consequences (p. 2).</td>
<td>Seventeen articles met inclusion criteria for synthesis.</td>
<td>Systematic Review Variables: Fear of cancer recurrence in cancer survivors. Demographic determinants associated with FCR: Ethnicity Age Triggers Years since diagnosis</td>
<td>FCR scores 5 years post-diagnosis were low to moderate range across studies reviewed. Risk factors identified in literature reviewed found association with FCR with women, who have had at least one child, less educated, and young age. Determinants for FCR identified in literature were associated with years since diagnosis, chemotherapy, healthcare utilization, and treatment side effects. Literature collectively suggested FCR was associated with psychosocial factors such as post-traumatic stress, stressful events, and mental health disorder.</td>
<td>Literature findings suggest that FCR persists over time and is usually not constant. Validity and comparability of study results were limited due to lack of clinical consensus with self-reported scores and assessments tools utilized. FCR was negatively associated with quality of life scores, anxiety, depression, and psychosocial well-being.</td>
<td>Study gave operational definition to FCR as “fear/worry about recurrence”, “fear of progression”, “distress of recurrence”, “trouble some thoughts about recurrence”, and “cancer worry”. Data from studies reviewed were self-reported measures or cross-sectional measurements.</td>
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<td>Krok-Schoen et al., (2018)</td>
<td>“Identify the prevalence of FCR and factors associated with FCR among older, long-term cancer survivors within the Women’s Health Initiative: Life and Longevity After Cancer Study” (p. 1811)</td>
<td>Participants were selected from the Life and Longevity After Cancer Study. Participants selected were diagnosed with breast, ovarian, endometrial, or colorectal cancer. Total Sample: n = 4259 Participants with: Breast cancer (n = 3124) Ovarian Cancer (n = 83) Endometrial Cancer (n = 493) Colorectal Cancer (n = 559)</td>
<td>Descriptive study design Variables: FCR with ovarian cancer survivors Age Marriage status Instruments: Cancer Worry Scale RAND-36 physical functioning subscale Symptom scores, self-rated health, and financial toxicity results were obtained from self-reported questionnaire</td>
<td>Women who received chemotherapy (OR = 1.35, 95% CI = 1.11 - 1.63) were more likely to report high FCR. The final model found that women who were older at diagnosis (OR = 0.98, 95% CI = 0.97-1.00 for 1-year increase) and were widowed (OR = 0.73, 95% CI = 0.60-0.90) and never married (OR = 0.62, 95% CI = 0.39-0.96) were less likely to report high FCR. Women who reported a symptom score of 8 to 13 (OR= 1.60, 95% CI = 1.25-2.06) and 14 to 72 (OR= 3.59, 95% CI = 2.82-4.56) were more likely to report high FCR than those who reported 0 to 7 symptoms scores</td>
<td>FCR was experienced by a small (15%) but significant proportion of cancer survivors and is associated with multiple demographic (age, marital status) and clinical (chemotherapy, symptom score, general health) variables. These results may better inform researchers and clinicians regarding the individuals who are at risk of FCR.</td>
<td>The average number of years since their cancer diagnosis was 9.5 years (SD = 4.9). There were no significant differences in FCR by cancer type (p = .75). The mean FCR score was 10.84 (SD = 2.87) for all cancer types combined. Cancer. Cancer site was not associated with high FCR among these older, long-term survivors (p = .93). Large sample of breast cancer with lack of diversity of race or ethnicity which study results may be hard to generalize to other cancer cohorts.</td>
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<td>Lambert et al., (2017)</td>
<td>Identify different trajectories of QOL over time and distinguish different QOL scores from cohorts.</td>
<td>Sample spouses from two Australian cancer registries with cancer diagnosis within six months. Total Sample: n = 299</td>
<td>Quantitative, Cross-Sectional study Variables: Stress Coping Instruments: Theory Brief Cope to measure coping. Supportive Care Survey Social Support Survey Hospital Anxiety and Depression Scale.</td>
<td>Higher mental health function decreased from normal population mean at 3.5-5 years (p &lt; 0.01) No demographic variables were significant with different cancer trajectories. Risk factors identified: negative social interactions, supportive care needs, education, and male caregiver were associated with decreased mental QOL</td>
<td>Mental health scores overtime decreased due to low emotional support, information support, and avoidance of caregiver duties. Limitation of this study is the sample was only taken from two Australian cancer registry which may be hard to generalize to other cultures or ethnic backgrounds.</td>
<td>Appraisal, resilience, and self-efficacy were not assessed in this study. Findings of this study provide useful insight into future intervention strategies.</td>
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<td>Lebel, Beattie, Ares, &amp; Bielajew (2013)</td>
<td>Examine four possible mechanisms of the relations between age and FOR, motherhood, severity of cancer, and illness intrusiveness.</td>
<td>Recruited online by the Avon Army of Women and through advertisement on Canadian and American web pages. Eligibility Criteria: -Previously treated for breast cancer -Read and comprehend English -Older than 18 years Exclusion Criteria: -Previous cancer history -Previous chemotherapy or radiation -Advanced disease -Unstable psychiatric, neurological, or substance use disorder. Total Sample: ( n = 3,239 ) survivors</td>
<td>Quantitative, Cross-sectional study Concerns about Recurrence Scale (CARS) State Trait Anxiety Inventory (STAI)-State</td>
<td>Women age 35-49 experienced significantly more FOR than women age 50-64 and 65 &gt; Motherhood was associated with greater FOR ( (p &lt; .001) )</td>
<td>No significant main effect of age of youngest child on FOR. Women with children &lt;18 were not more likely to report greater FOR than women with children &gt;18. Young cancer survivors reported greater FOR than older survivors regardless of their motherhood status or age of their children.</td>
<td>Younger women reported more FOR than older women. Possibly due to less life experience with health and illness, fewer coping strategies, and less experience in the health care system. Mothers of all ages worry about the possibility of dying and not seeing their children grow up.</td>
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| Lewis & Deal (1995) | Examine the married couple’s experience with breast cancer recurrence from each partner’s own perspective. | Married couple’s homes in the Pacific Northwestern United States. Total Sample: n = 15 married couples of women with recurrent breast cancer | Descriptive, Qualitative study Face to Face interviews by trained nurse interviewer | **Domains** (p. 947-950)  
Managing the Woman’s Everyday Illness  
-Talking about Treatment  
-Educating ourselves about the disease  
-Checking in  
-Not dwelling on it  
-Felling down  
-Hitting the unknowns  
Surviving  
-Learning to live w/ it  
-Struggling with the relational parts  
-Talking about the kids  
-Being in control  
Healing  
-Making progress and moving on  
-Maintaining optimism  
-Keeping stress down  
Preparing for Death  
-Talking about dying  
-Talking about afterwards | Health care professionals should facilitate couples’ processing of their sad, negative, or tense emotions. Helping couples work through these emotions instead of avoiding them. | Limited discussion about cancer recurrence as the women chosen already had a cancer recurrence. | Level VI |


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Variable(s): Fear of cancer recurrence with spouses  
Instruments: Fear of cancer Recurrence Inventory-Caregiver version (FCR measure).  
Medical Outcomes Short-Form Health Survey (quality of life measures) | Experience  
Result: Caregivers required reassurance regarding their FCR.  
Coping strategies were used by more than 50% of spouses most of the time with FCR.  
Caregivers 3-6 months and > 6-12 months had highest FCR scores than any other cohort (p = .043)  
Higher FCR scores had negative correlation to: high trigger levels (r = -.34), FCR severity (r = -.21), high psychological distress related to FCR (r = -.38), functional impairment related to FCR (r = -.36) | Duration of FCR after treatment was suggestive to be clinically significant for assessing for FCR to provide interventions.  
Caregivers experience multi-facetted experience with FCR.  
Healthcare providers should proactively assess caregivers for FCR and its effects on quality of life. | Recommendations to develop and examine interventions for FCR.  
Authors recommend duration of post-treatment as a risk factor for caregivers.  
Limitation of this study is that it may be hard to generalize FCR to different cancer cohorts.  
This study was conducted in Taiwan and may be hard to generalize to different cultures. | Level IV |
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<td>Longcare et al., (2012)</td>
<td>Identify psychological health of caregivers and what factors are associated with deficits in psychological health with caring for spouses with head and neck cancer.</td>
<td>11 studies reviewed</td>
<td>Integrative review</td>
<td>Studies found two-six-month post diagnosis reporting highest burden, anxiety, stress. 6-24 months post treatment and time since diagnosis had shown improved psychological health. Younger caregivers had high reporting with FCR. A caregiver’s fear of cancer recurrence was also associated with elevated emotional distress.</td>
<td>Study results suggest that FCR in cancer caregiver cohorts have similar needs. Study suggests that a greater recognition of caregivers’ fears is needed to inform the development of resources for addressing such fears and concerns among cancer caregivers.</td>
<td>Cancer trajectory was not reported which may make results hard to generalize to caregivers during different points of cancer trajectory.</td>
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<td>Liu et al., (2018)</td>
<td>“Examine how FCR and rumination may relate to depression and anxiety symptoms among cancer survivors” (p. 121).</td>
<td>Participants were identified and recruited during their follow-up appointment at the National University Cancer Institute Singapore Total Sample: n = 388 survivors Brain tumor n = 2 Breast n = 146 Colorectal n = 54 Gynecological (cervical, ovarian) n = 103 Hematological (leukemia, lymphoma) n = 14 Lung n = 12 Nasopharyngeal (throat, oral) n = 14 Pancreas n = 2</td>
<td>Quantitative, cross sectional design Variables: Fear of Cancer Recurrence Gynecological cancer survivors Instruments: Socio-demographic information was self-reported. Fear of Cancer Recurrence Inventory. Ruminative Response Scale. Hospital Anxiety and Depression Scale.</td>
<td>FCR Inventory total scores were positively related to depression ((p &lt; .001)) and anxiety ((p &lt; .001)). The Fear of Cancer Recurrence Inventory total score was positively related To Fear of Cancer Recurrence Inventory severity subscale ((p \leq .001)). High FCR was significantly associated with more severe depressive symptoms regardless of rumination levels ((p &lt; 0.05)).</td>
<td>Study results suggest higher reported FCR is associated with increased anxiety and depression symptoms. Effects of FCR were observed with anxiety and depressive symptoms which may guide interventions for healthcare providers.</td>
<td>“No multicollinearity was observed with predictors but caution of results should be taken due to predominant self-reported findings suggest firm conclusion may not be ascertained from this study” (p. 125)</td>
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<td>Maguire et al., (2017)</td>
<td>Aimed to investigate the predictors of FOR in head and neck cancer (HNC) caregivers, examining the role of caregiver stressors, social support, and loneliness.</td>
<td>Participants found from nine university hospital ethics committees in Ireland between March and December 2013. Total Sample: n = 180 caregiver/survivor dyads.</td>
<td>Cross-sectional design Caregiver characteristics and care-related stressors questionnaire. FOR was assessed by the Worry of Cancer Scale based on a 5-point measure to assess FOR in survivors.</td>
<td>Higher caregiver FOR was associated with -greater time spent caring (p &lt; .001) -lower survivor QOL (p &lt; .001) -higher caregiver loneliness (p &lt; .001) -survivor surgery (p &lt; .001). Other significant correlations with FCR in the study: -Caregiver gender (p &lt; .05) -Time since diagnosis (p &lt; .05) -chemotherapy (p &lt; .05)</td>
<td>Younger age has consistently been shown to increase the level of FOR in both survivors and caregivers.</td>
<td>The caregiver and survivor questionnaire took place a year apart, in which time the survivor’s health may have changed.</td>
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<td>Mellon, S. (2002)</td>
<td>Explore the meaning of the illness to the family and family quality of life for survivors and family members and to describe similarities and differences between survivors and family members meaning of the illness.</td>
<td>A stratified, random sample of 123 family dyads was obtained through a SEER database. Total sample: n = 246. Inclusion criteria: - Cancer survivor - 1-5 years of diagnosis - Completed primary treatment ≥ 1 year - Stage I – III - No recurrence - Not terminal - Not currently receiving treatment</td>
<td>Cross-sectional qualitative descriptive design. Two open-ended questions were asked: How would you describe the meaning of the cancer illness to your family? How do you think the cancer illness has affected your family QOL?</td>
<td>Meaning of Illness and Family QOL. Going on after cancer, concern for cancer in family, worry of cancer coming back, taking care of health. Survivors and family members have similar worry of the cancer coming back. Survivors stated, “When I get a pain, I worry whether they got all the cancer.” (p. 1121) Family members stated, “Now, I’m still scared – It’s really scaring me. I’m still worried about it coming back.” (p. 1121)</td>
<td>Finding a positive meaning to a cancer diagnosis can improve QOL and reduce FCR. FCR is a chronic stressor for. Nurses can encourage survivors and families to openly express FCR and assist them in putting those fears into perspective. Further research is needed on family survivorship to explore the relationships between meaning and QOL and coping strategies.</td>
<td>Worry about cancer returning is one of the five major themes in the similarities between survivors and family members. Patients and family members stated they had increased FCR when going to doctor appointments, increased pain, or problems with blood pressure. Results pertain only to survivors who never had a recurrence.</td>
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| Mellon & Northhouse, (2001)      | Examine what factors are critical and how they may affect the entire family unit’s quality of life during the long-term survivor phase. | Recruited in the Southeastern lower peninsula of Michigan from the National Cancer Institute’s SEER Cancer Registry Data  
In home face-to-face interviews.  
Total Sample: \( n = 123 \) family dyads | Quantitative Study  
Fear of Recurrence Questionnaire (FRQ) | Caregivers FOR was a significant predictor to quality of life \( (p < 0.01) \).  
The survivors FOR was significantly related to the Family Meaning of Cancer Illness \( (p > 0.001) \). | Survivors and caregivers will need continual interventions to keep FOR manageable.  
Health care providers need to assess long-term survivors for FOR stressors. | FOR has a significant impact on survivors and their caregivers. | Level IV |
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<td>Mellon, Kershaw, Northouse, &amp; Freeman-Gibb, (2007)</td>
<td>Identify factors associated with fear of recurrence in a population-based sample and determine if survivors and family caregivers influenced one another’s fear of recurrence.</td>
<td>A population-based sample identified from the Metropolitan Detroit Cancer Surveillance System (MDCSS). A sample was randomly selected from the registry of patients that was stratified by race and cancer site. Eligibility criteria: -survivors were 1-5 years post-diagnosis -cancer state of I-III -age 50-70 years at time of diagnosis.</td>
<td>Quantitative secondary analysis Fear of recurrence measured using the FOR Questionnaire (Northouse, 1981). Caregivers had a modified version</td>
<td>Survivors and caregivers who reported more family stressors and less meaning associated with the illness had increased FOR ($p &gt; 0.01$). Neither family hardiness nor social support related to FOR (both $p &gt; 0.05$). Dyads comprised of older survivors with younger caregivers had more FOR ($p &lt; 0.05$) Caregivers had significantly more FOR than survivors ($p &lt; .01$). Time since diagnosis was not statistically significant with FOR.</td>
<td>Both the survivor and the caregiver need to feel supported as they affect one another. Survivors with younger caregivers and caregivers with younger survivors both experienced more FOR. As one family member’s FOR increased so did the other members. Self-reports of health and well-being are not the most reliable.</td>
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<td>Mosher et al., (2017)</td>
<td>Identify key challenges for caregiver coping with spouse diagnosed with advanced colorectal cancer.</td>
<td>Patient and caregiver dyads from a Midwestern United States academic hospital. Individuals with advanced colorectal cancer (n = 24) Primary caregivers (n = 24)</td>
<td>Qualitative Variables: Fear of recurrence Thematic coding was analyzed by two separate authors and reconciled coding. Atlas software was used for thematic analysis.</td>
<td>Theme of emotionally processing initial diagnosis or recurrence. 17 of 24 dyads stated similar feelings of despair, impatience, shock, or trauma with recurrence. Theme of an uncertain future. One of the greatest challenges was dealing with decline and worsening prognosis.</td>
<td>Caregivers described the emotional toll of caregiving as their greatest challenge. The aspects of the caregiver’s emotional toll centered on suffering of the patient, recurrence diagnosis, and patient’s physical decline. Study only accounted for Stage IV cancer patients who were English speaking and Caucasian. Further studies need to look at racial and gender challenges associated with recurrence.</td>
<td>Study findings suggest caregiver experience greatest challenge with caring or colorectal cancer patients is emotional.</td>
<td>Level VI</td>
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<td>Study Design/Major Variables/and Instruments</td>
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<td>Northouse et al., (2002)</td>
<td>Evaluate the FOCUS program a family-based program of care for women with recurrent breast cancer and their family caregivers.</td>
<td>Performed in the Midwest region of the United States. Eligibility Criteria: -Recurrence or progression of breast cancer -Age 21 or older -Life expectancy of at least six months -Had a family member willing to participate in the study. 73 Survivors and caregivers in the intervention group 71 Survivors and caregivers in the control group</td>
<td>Longitudinal RCT Optimistic Attitude -practicing optimistic thinking -sharing fear and negative thoughts -maintaining hope -staying hopeful in the face of death</td>
<td>Caregivers don’t want to burden survivors by discussing caregivers’ fears.</td>
<td>The program was shown to promote family communication about the illness. Caregivers also need to be assessed for FOR.</td>
<td>Addresses both the patient and the family member’s emotions with recurrent cancer.</td>
<td>Level II</td>
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<td>Northouse, Laten, &amp; Reddy (1995)</td>
<td>Determine if differences existed in survivors and caregivers’ level of adjustment, support, symptom distress, hopelessness, and uncertainty following recurrent breast cancer.</td>
<td>Eligibility criteria: -women who had a first recurrence of their breast cancer -between 1 month and 3 years after recurrence -married or living with a male partner. Total Sample: 81 women and 74 husbands agreed to participate</td>
<td>Quantitative correlational study Hopelessness: Beck Hopelessness Scale (HS) Uncertainty: the Mishel Uncertainty in Illness Scale (MUIS) Social Support: A modified version of the Social Support Questionnaire (SSQ). Symptom Distress: The Symptom Distress Scale</td>
<td>Women who thought the recurrent phase of cancer was the most stressful were experiencing significantly more symptom distress than women who thought the initial phase was the most stressful ($p &lt; 0.05$). No significant relationship was found between the length of time that husbands knew about their wives’ recurrence and husbands scores on adjustment measures. 39% of husbands said that the time of recurrence as the most distressing. 36.1% of husbands said they were very surprised the cancer recurred and 48.6% were somewhat surprised</td>
<td>Healthcare providers need to find a way to identify couples at greater risk of poorer adjustment to recurrent illness. Hopelessness is a factor that places both the survivor and husband as risk of more adjustment difficulties during cancer recurrence.</td>
<td>Study highlighted the differences in patients’ and spouses’ perceptions of the illness. Husbands were only somewhat surprised that recurrence occurred while the Survivors were very surprised. Significant differences in levels of uncertainty between husbands and survivors.</td>
<td>Level VI</td>
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<td>Ozga et al., (2015)</td>
<td>Identify associated factors of fear of recurrence in ovarian cancer patients.</td>
<td>15 articles were included in study.</td>
<td>Systematic Review</td>
<td>FCR measures varied among studies with results ranging from 22% - 80%.</td>
<td>Varied results were related to different measurement tools to assess FCR.</td>
<td>Study suggests inadequate demographic and cultural diversity within FCR literature.</td>
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<td>Variables: Fear of cancer recurrence.</td>
<td>FCR was reported with 56% in early stage disease and 48% in advances stages.</td>
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<td>Study suggests further research of current FCR assessment tools.</td>
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<td>Instruments: Disease trajectory Measurement of Fear of Cancer Recurrence.</td>
<td>Survivors reported thought of recurrence monthly (28%), at least weekly (24.5%) and at least daily (12%).</td>
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<td>Study suggests further longitudinal studies are needed to capture FCR survivorship.</td>
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<td>Themes identified in qualitative research.</td>
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<td>-Recurrence and death are their greatest fears.</td>
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<td>-Women described fear of recurrence as being denied a future.</td>
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<td>-FCR was often heightened by follow-up visits and end of treatment.</td>
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<td>Petricone-Westwood and Lebel (2016)</td>
<td>“The aim of this scoping review was to gain an understanding of the current state of knowledge on friends and family, or caregivers, of patients diagnosed with ovarian cancer, at any point in the disease trajectory” (p. 186).</td>
<td>19 articles reviewed.</td>
<td>Scoping review variables: Fear of recurrence with spousal caregivers. Gender differences with caregiving experience. Cancer recurrence on spousal caregivers</td>
<td>Literature reviewed found men were likely to have high anxiety, distress, and fewer unmet needs during caregiving journey than ovarian cancer survivor. Literature review suggested younger aged caregivers had healthier behavior changes but decreased adjustment to cancer trajectory. Literature reviewed suggested recurrence improved communication between spouse and patient decrease intrusive thoughts among caregivers. Literature reviewed suggested physical wellbeing was normal at diagnosis but deteriorated after recurrence in caregivers. Authors found limited peer reviewed studies on the caregiver of ovarian cancer patients. Patient’s psychological wellbeing affected the caregiver more than physical wellbeing. Spiritual and social wellbeing influenced the spouse’s caregiving ability. Study suggests caregivers often felt excluded from care teams which healthcare providers regardless of their discipline should be mindful of the caregiver.</td>
<td>“The scoping method does not include quality assessments of studies, as its purpose is to examine the state of the literature mindful of this when interpreting the results together” (p. 191)</td>
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| Ponto, 2008      | “… utilize a family systems framework and results from a pilot study of husbands of women with ovarian cancer to 1) analyze predictors of adjustment and growth in women with recurrent ovarian cancer, and 2) to describe relationships among demographic, illness, appraisal, and dyad resource variables and adjustment and growth in recurrent ovarian cancer survivors and spouses” (p. 4-5) | Recruited from the National Ovarian Cancer Coalition (NOCC) and other advocacy groups  
Setting: Home self-report mailed or online questionnaire  
Total Sample: n = 60 couple dyads | Descriptive, Correlational, Cross Sectional Study  
Fear of Recurrence Questionnaire  
Mishel’s Uncertainty in Illness Scale | “Poorer survivor adjustment was correlated with lower spouse age ($r = -0.465$, $p < 0.05$), higher spouse uncertainty ($r = 0.393$, $p < 0.05$), and fear of recurrence ($r = 0.596$, $p < 0.01$)” (p. 134)  
Both survivor and spouse reported:  
- More negative meaning  
- Poorer adjustment | Spouses experience more FOR than survivors  
Survivors had more growth than spouse  
Spouses adjust better when their relationship is aggregable, positive, and harmonious (p. 141) | Dissertation                                                                                                                                               | Level IV                                                                                                           |
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| Ponto & Barton (2008) | Address the gap in the literature and guide further research and practice by describing the experience of ovarian cancer from the husband’s perspective. | Recruited from a healthcare institution in the Midwest and other advocacy groups Home telephone interviews Eligibility criteria: - 18 year of age - able to speak and read English - able to participate in a one-to-one telephone interview. Total Sample:  
  n = 11 husbands | Qualitative study Instruments:  
  - Data was collected through a one-time phone interview.  
  - Interviews were audio-taped  
  - Lasted about an hour.  
  - Audio-tapes were transcribed  
  - Reflective notes were written  
  An analysis was performed independently by two nurse researches. | Themes found in data:  
  - Emotional devastation of the initial diagnosis.  
  - A new focus/priority in life.  
  - Changes in marital relationship. Some positive and some negative.  
  - His response by her response  
  - Others sharing in the burden of providing support to the survivor  
  - Importance of having family members to lean on.  
  - Acknowledged importance in addressing husband’s psychological needs. | Social support plays an important role in spouses  
  The initial diagnosis is “shocking” and devastating for the spouse  
  Diagnosis causes spouse to reprioritize his life.  
  A loss of equality is noted as the relationships change emotionally and physically | Many men discussed positive aspects of the disease which was surprising.  
  Many men also stated they wish they had some psychological support at the beginning of the diagnosis.  
  Telephone interviews limited the evaluation of non-verbal communication. | Level VI |
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<td>Ponto, Ellington, Mellon, &amp; Beck (2010)</td>
<td>“…to analyze predictors of adjustment and growth in women who had experienced recurrent ovarian cancer” (p. 357)</td>
<td>Survivors were recruited through the National Ovarian Cancer Coalition (NOCC) and other advocacy groups</td>
<td>Quantitative, cross sectional research design</td>
<td>Women had more negative appraisal of meaning of illness compared to other cancer populations without recurrence.</td>
<td>Significant predictors of adjustment included:</td>
<td>Helpful in predicting level of adjustment in women with recurrent ovarian cancer.</td>
<td>Level IV</td>
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<td>Setting: Home self-report mailed or online questionnaire</td>
<td>Illness characteristics</td>
<td>“Lower age and fewer years in the relationship were associated with poorer adjustment” (p. 360)</td>
<td>- Age</td>
<td>Younger age correlated with poorer adjustment</td>
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<td>Eligibility criteria:</td>
<td>Meaning: the survivors appraised the meaning of their cancer experience using the Constructed Meaning Scale</td>
<td>“Negative meaning was associated with poorer adjustment” (p. 360)</td>
<td>- Years in the relationship</td>
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<td>-women diagnosed with recurrent ovarian cancer</td>
<td>PAIS-SR was used to measure their adjustment to illness.</td>
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<td>- Symptom distress</td>
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<td>-21 years or older</td>
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<td>- Performance status</td>
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<td>-able to speak and read English</td>
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<td>- Meaning of the illness</td>
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<td>-had a spouse or partner willing to participate.</td>
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<td>Total Sample: n = 60 women with recurrent ovarian cancer</td>
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<td>Roland et al., (2013)</td>
<td>“Identify and comprehensively present the psychosocial needs of ovarian cancer survivors, including young survivors &lt; 45 years of age” (p. 2408)</td>
<td>28 articles met inclusion criteria for psychological domains within ovarian cancer. Domains identified: -Quality of life -Support and relationships -Self-image and sexual functioning -Psychological distress and functioning -Fear of recurrence and death. -Personal growth and coping</td>
<td>Literature review Variables: -Fear of recurrence with ovarian cancer survivors. -Ovarian cancer diagnosis -Age -Stage of Disease -Psychological</td>
<td>Review suggested greatest period of distress is at time of diagnosis with associated feelings of fear, uncertainty, and loss of control. Anxiety was reported with stage III and IV with increase time since diagnosis and depression scores were decreased. FCR scores increased with changes in physical symptoms, decrease functional ability, and depression scores. Literature suggests ovarian cancer survivors experience FCR years after diagnosis and was associated with decreased quality of life and emotional distress. Age was significantly associated with FCR and death.</td>
<td>Greatest needs identified with ovarian cancer survivors were physical complications which affected all psychological domains. Review results identify valid ovarian cancer measures to provide comparisons amongst studies and generalizability. Review suggests fear of cancer recurrence impacts ovarian cancer survivors with long term psychological outcomes.</td>
<td>Authors acknowledged studies included in review used non-validated questionnaires, homogenous study samples, cross-sectional study designs which may impact results of review. Due to improved treatment outcomes and diagnostic testing ovarian cancer survivors are living longer which presents challenging psychological impacts on survivors.</td>
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<td>Shilling et al., (2017)</td>
<td>Explore the impact of long-term cancer survivorship on board aspects of life and wellbeing.</td>
<td>Patients with stage III or IV ovarian, lung, and melanoma cancers. Patient-caregiver dyads interviewed in their homes. Total Sample: n = 24 dyads</td>
<td>Qualitative Study Design: Open coding by two authors from transcripts to develop thematic framework. Themes and subthemes with greater than 2% disagreement between reviewers and where kappa was &lt; 0.4 were considered to have unacceptable reliability. Software NVivo 11 was used for data management.</td>
<td>Themes: Family Dynamics: concerns around recurrence which lead to inability of moving forward with life. Implication for the future: Changes in outlook and realigning priorities. Sub theme: participants taking stock of their lives, realizing what is important and maximizing time. Life on Hold: inability to plan long term and living “day by day”. Mortality and death: uncertainty impacts all aspects of dyads life behind this theme is the patients’ health and how long that can be maintained.</td>
<td>Difference in diagnosis affected dyads communication, adjustment to cancer journey, and sense of loss for the future. Age of dyads had different perspectives with uncertainty themes. Supports from family and friends helped dyads cope with uncertainty.</td>
<td>Lack of defined outcomes for patient health status impacted financial, retirement, and planning.</td>
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| Simard & Savard (2008) | Develop and empirically validate a multi-dimensional self-report scale for assessing the FCR, the Fear of Cancer Recurrence Inventory (FRCI) | Randomly selected French-Canadian patients treated for breast, prostate, lung, and colorectal cancer within the past 10 years. Total Sample: \( n = 1,704 \) survivors | Descriptive Research Study  
Concerns About Recurrence Scale (CARS)  
Fear of Recurrence Questionnaire (FRQ)  
Fear of Cancer Recurrence Inventory (FCRI) | There is a lack of definition and standardized assessment for FCR | Further research is needed to assess FCR as multi-dimensional | None | Level V |
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<td>Simard et al. (2013)</td>
<td>To provide a comprehensive overview of current scientific knowledge on FCR and to formulate recommendations for future research.</td>
<td>Search of Medline, CINAHL, PsycINFO, and AMED databases from 1996 through December 2011.</td>
<td>Systematic Review on quantitative studies. Data was extracted using a standardized coding sheet adapted from the PRISMA Statement. Quality of evidence for each outcome rated using the GRADE system (high quality, moderate, low quality).</td>
<td>22 longitudinal studies assessed FCR over time. 18 reported no change over the time periods examined. Eight showed that FCR decreases over time, and two showed an increase over time. Strong evidence observed about the relationship between FCR and age. Nine studies showed that younger survivors reported greater FOR than older survivors. Strong evidence (22 studies) suggest that cancer survivors with more physical symptoms experience greater FCR. Eight studies observed that depression and ten studies observed that anxiety were significantly correlated with FCR. Five studies found that caregivers FCR was greater than survivors FCR.</td>
<td>Findings confirm that FCR is one of the most commonly reported problems and one of the most prevalent areas of unmet needs among survivors. Further rigorous longitudinal studies are needed to confirm and assess the stability of FCR over time The proposal and evaluation of theoretical models of FCR is a priority. Strategies to assist caregivers with high FCR is an area in need of further attention and research.</td>
<td>No consensual definition of FCR or standard measure of FCR exists. One of the most consistently associated factors with FCR was younger age. It is not clear from the research why caregivers report higher FCR than survivors.</td>
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<td>Simonelli et al., (2017)</td>
<td>Review empirical data on FCR, present several theoretical frameworks, and psychosocial treatments addressing FCR.</td>
<td>Literature search in academic data bases with specific search terms relating to FCR.</td>
<td>Narrative review</td>
<td>Triggers associated with FCR are new or worsening symptoms, test procedures, anniversary of diagnosis, healthcare utilization, and cancer related media.</td>
<td>Evidence reviewed suggests prevalence of FCR is long term with cancer survival.</td>
<td>Literature reviewed found most studies included breast cancer survivor, white, and cross-sectional studies which findings may be hard to generalize to diverse populations.</td>
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<td>Variables:</td>
<td>FCR was not found to be proportional to prognosis and survival.</td>
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<td>Future research is needed to test theoretical frameworks to enhance interventions, clinical diagnosis, and variations of cancer types.</td>
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<td>Stephens, Westmas, Kim, Cannady, &amp; Stein, (2016)</td>
<td>Examine whether specific cancer-related problems were associated with the odds of relationship breakup following diagnosis and whether these relationships differed between male and female cancer survivors.</td>
<td>Population-based samples of survivors of six cancers identified through 14 state cancer registry databases. Inclusion criteria: Participants must be 18 or older at time of diagnosis, reside in the state from which they were sampled, and able to read/write English or Spanish. Physician consent for surveying participants was obtained. Total final sample n = 8651. 6,099 of these completed surveys. Up to 20 attempts were made to reach individuals by telephone.</td>
<td>Quantitative, Correlational, Cross-Sectional study Data was collected as part of the American Cancer Society’s Study of Cancer Survivors- II (SCS-II) at 2, 6, or 10 years after diagnosis. Socio-demographic variables were collected from registry records The Cancer Problems in Living Scale (CPILS) was used to assess physical and psychosocial problems. The Criticism and Withdrawal Subscale of the Partner Response to Cancer Inventory (PRCI) assess unsupportive behavior by others during treatment.</td>
<td>Chi-square analyses indicated that the rate of divorce was significantly greater for female survivors compared to male survivors (6.4% vs 2.9%, p &lt; .001). Longer time since diagnosis was associated with higher divorce rates (6.0% for the 10-year cohort vs 3.7% in the 2-year cohort). Male cancer survivors’ risk of divorce or separation was significantly associated with fear of cancer recurrence (OR = 1.32, p &lt; 0.001)</td>
<td>Could not establish whether the cancer-related problems reported preceded or followed relationship dissolution. The use of retrospective self-reports for cancer-related problems and partner’s negative reaction is a limitation.</td>
<td>Study does a nice job assessing cancer-related problems amongst spouses but only briefly addresses cancer recurrence. Men had greater odds of relationship breakup associated with fears of cancer recurrence. Possibly because men rely on spouse as primary source of emotional support.</td>
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<td>Thewes et al., (2012)</td>
<td>Identify all available fear of recurrence-specific questionnaire and subscales and critically appraise their properties.</td>
<td>36 manuscripts identified twenty various tools for measuring FCR</td>
<td>Systematic Literature Review FCR in cancer survivors Instrument assessment was complete by validity and reliability from authors who developed FCR assessment tools. Medical Outcomes Trust to assess merits of assessment tools.</td>
<td>Moderate correlations between CARS subscales and the Intrusive Thoughts ($r = 0.43–0.64$) subscales of the Impact of Event Scale (IES), and the Distress ($r = 0.38–0.54$) FCR Scale adapted from Fear of Developing Ovarian Cancer Questionnaire showed moderate test reliability across assessment intervals. FCR Questionnaire suitable for mixed cancer patients, good internal consistency, with survivors and caregivers. FCR Inventory showed the most promise with clinically significant cut off score for FCR Internal consistency and test-retest reliability ($r = 0.89$)</td>
<td>Common dimensions of FCR were assessed in assessment tools which included psychological or functional impact, intensity, and frequency of FCR. Study identified lack of clinical consensus of assessment tools for FCR. Most FCR assessment tools are discriminative measures and have no external criteria to test validation.</td>
<td>Assessment tools identified common elements of FCR: Triggers, severity, psychological distress, functional assessment, overall fear, impact on future, and worry of recurrence.</td>
<td>Level V</td>
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<td>Citation</td>
<td>Purpose/ Objectives</td>
<td>Study population/ Sample/ Setting</td>
<td>Study Design/ Major Variables/ and Instruments</td>
<td>Results</td>
<td>Implications</td>
<td>Comments</td>
<td>Level of Evidence</td>
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<td>Turner et al., (2011)</td>
<td>Describe health status, levels of anxiety, and depression, unmet supportive care needs and positive outcomes in the partners/family members of breast, prostate, and colorectal cancer survivors 5-16 years post-diagnosis.</td>
<td>Partners and caregivers were recruited through a linked study that included a sample of long-term survivors of cancer registries in the UK (Thames Valley and Yorkshire/North East England) Total Sample: n = 659 survivors n = 257 caregivers</td>
<td>Descriptive Study Cancer Survivor’s Partners Unmet Needs (CaS-PUN)</td>
<td>Agreement between couples was highest (≥ 50%) on the need for help to manage fears of recurrence 15.6% answered “yes” to the question “I need help to manage my concerns about the cancer coming back”</td>
<td>It is important for health care workers to find a way to identify couples at a high risk for FCR and provide additional interventions.</td>
<td>caregivers to long-term survivors with no signs of recurrence, generally have similar health status and levels of anxiety to that of the general population.</td>
<td>Level VI</td>
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<th>Citation</th>
<th>Purpose/Objectives</th>
<th>Study population/Sample/Setting</th>
<th>Study Design/Major Variables/and Instruments</th>
<th>Results</th>
<th>Implications</th>
<th>Comments</th>
<th>Level of Evidence</th>
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<td>Urbaniec, et al., (2011)</td>
<td>Provide information about the support needs of an at-risk population that may benefit from psychosocial intervention.</td>
<td>Participants were identified from the Gynecological Oncology clinics and database at the Royal Adelaide Hospital Cancer Centre in South Australia. Eligibility Criteria: - Gynecological cancer diagnosis at least one year earlier - Completed primary treatment - Older than 18 years - Read and write in English Exclusion Criteria: - Presence of prior diagnosis of psychiatric impairment - Previous Cancer diagnosis - Palliative care or relapse Total Sample: n = 45 cancer survivors</td>
<td>Quantitative, correlational, cross-sectional study Beck Depression Inventory-Second Edition (BDI-II) Spielberger State Anxiety Inventory (SAI) Cancer Survivors’ Unmet Needs Measure (CaSUN)</td>
<td>The mostly highly endorsed unmet need was FOR (26.7%) The strongest predictor of FOR was emotional well-being (p = .01).</td>
<td>Improved awareness of FOR may encourage the development and use of targeted interventions and assessments. Enhancing a women’s emotional well-being may assist in reducing their FOR.</td>
<td>N/A</td>
<td>Level IV</td>
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Study population/Sample/Setting | Sampling from Patient Reported Outcomes Following Initial treatment and long-term Evaluation of Survivorship registry. Mix population of survivors 10 years post diagnosis melanoma ($n = 469$), colorectal cancer ($n = 861$), endometrial cancer ($n = 688$), thyroid cancer ($n = 218$), Hodgkin ($n = 103$) and non-Hodgkin lymphoma ($n = 27$). Total Sample: $n = 2615$ survivors |
Results | Higher FCR reported with younger age ($\beta = 0.14$) female gender ($\beta = 0.12$). Characteristics: comorbid conditions, stage II disease, and scheduled appointments, time since diagnosis were associated with higher FCR ($p < .01$). Survivors who wanted more information during treatments reported higher FCR compared to survivors who were satisfied with information ($p < 0.001$). Years since diagnosis and gender were negatively associated with FCR ($p < 0.05$). |
Implications | Healthcare professional’s awareness of risk factors associated with higher FCR stage II disease, >2 years since diagnosis, female gender, and younger age. FCR can occur long after cancer diagnosis and was highest risk before 2 year but still experiencing FCR later than 10 years. Health-related quality of life and FCR was found to have small to moderated negative correlation and survivors reported good level of functioning. |
Comments | Cancer type when compared to FCR severity had little variance which suggest FCR is universal concern among cancer survivors. Limitation to this study is unable to compare disease free survivors, number or recurrences, and advanced disease effect on FCR. Limited to Stage I and II survivors |
Level of Evidence | Level VI |

**Type/Levels of Evidence.** Level I: Evidence from a systematic review or meta-analysis of all relevant RCTs (randomized controlled trial) or evidence-based clinical practice guidelines based on systematic reviews of RCTs or three or more RCTs of good quality that have similar results. Level II: Evidence obtained from at least one well-designed RCT (e.g. large multi-site RCT). Level III: Evidence obtained from well-designed controlled trials without randomization (i.e. quasi-experimental). Level IV: Evidence from well-designed case-control or cohort studies. Level V: Evidence from systematic reviews of descriptive and qualitative studies (meta-synthesis). Level VI: Evidence from a single descriptive or qualitative study. Level VII: Evidence from the opinion of authorities and/or reports of expert committees. (Ackley, Swan, Ladwig, & Tucker, 2008).
Appendix C

April 8, 2019

Winona State University graduate nursing students Brandon Crouley and Jennifer Skadan have my permission to use select data from my research study, “Adjustment and growth in women with recurrent ovarian cancer and their spouses” for their secondary analysis titled “FEAR OF RECURRENCE IN OVARIAN CANCER SURVIVORS AND THEIR SPOUSES”.

Only de-identified data pertaining to their study as outlined in their thesis proposal will be provided to them.

Sincerely,

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507-292-5127 (f)
Appendix D

DEMOGRAPHIC QUESTIONNAIRE

Meaning, Adjustment and Growth in Ovarian Cancer Survivors and Their Spouses
Demographic Profile – Survivors and Spouses

Thank you for being willing to complete this questionnaire. All responses will be kept strictly confidential.

Directions: Please answer all of these questions accurately. The information you provide will be used only for this research study and will not be seen by anyone outside the research team.

1. Today’s date: ____________/__________/__________
   month   day   year

2. Your date of birth: ____________/__________/__________
   month   day   year

3. Your gender (circle): (1) Male  (2) Female

4. Your ethnic background (select one):
   (1) Hispanic, Latino, or of Spanish Origin
   (2) Not Hispanic or Latino

5. Your racial background (select one or more):
   (1) Asian
   (2) Black or African American
   (3) Native Hawaiian or Other Pacific Islander
   (4) American Indian or Alaska Native
   (5) White

6. Your marital status:
   (1) Married  (2) Living together, not married

7. Length of time Married/living together:
   Number of years

8. Highest grade of school you completed:
   (1) 8th grade or less
   (2) Some high school
   (3) High school graduate
   (4) Technical school graduate
   (5) Some college
   (6) College graduate
   (7) Postgraduate/Professional

9. What best describes your employment status?
   (1) Full-time
   (2) Part-time
   (3) Unemployed
   (4) Retired
   (5) Full-time homemaker

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10. Are you a religious person? _____(1) Yes _____(2) No

11. What is your religion?
   _____ (1) Catholic
   _____ (2) Greek Orthodox
   _____ (3) Jewish
   _____ (4) Latter Day Saint
   _____ (5) Muslim
   _____ (6) Protestant
   _____ (7) Other __________________________
   _____ (8) None

12. How often do you attend religious services, meetings or activities?
   _____ (1) Never
   _____ (2) Once or twice a year
   _____ (3) Several times a year
   _____ (4) About once a month
   _____ (5) Two or three times a month
   _____ (6) Once a week
   _____ (7) More than once a week

13. How spiritual of a person would you describe yourself to be?
   _____ (1) Not at all spiritual
   _____ (2) Slightly spiritual
   _____ (3) Moderately spiritual
   _____ (4) Quite spiritual
   _____ (5) Very spiritual

14. What (if any) types of other health problems do you have? Check all that apply.
   _____ (1) Heart disease
   _____ (2) Diabetes
   _____ (3) Lung disease
   _____ (4) Arthritis
   _____ (5) Kidney disease
   _____ (6) Fatigue syndrome
   _____ (7) Hypertension
   _____ (8) Neuromuscular disease
   _____ (9) Other (please specify): __________________________
   _____ (10) None

15. How bothersome are these other health problems?
   _____ (1) Not applicable
   _____ (2) Not at all bothersome
   _____ (3) Slightly bothersome
   _____ (4) Moderately bothersome
   _____ (5) Quite bothersome
   _____ (6) Very bothersome

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16. What is your household income before taxes?
   (1) Under $10,000
   (2) $10,000-$19,999
   (3) $20,000-$29,999
   (4) $30,000-$39,999
   (5) $40,000-$49,999
   (6) $50,000-$59,999
   (7) $60,000-$79,999
   (8) $80,000-$99,999
   (9) $100,000 or more

17. How would you describe the adequacy of your current financial situation?
   (1) I have problems making ends meet.
   (2) My financial situation is comfortable.
   (3) My income is more than adequate to meet my needs.

18. Please circle only one number that best describes your current activity level.
   0 I have normal activity without symptoms.
   1 I have some symptoms, but I do not need to spend any extra time resting during the day.
   2 I need some time to rest (e.g., in bed), but it amounts to less than half of my normal daytime.
   3 I need to rest (e.g., in bed) for more than half of my normal daytime.
   4 I am unable to get out of bed.

19. How did you learn about this questionnaire?
   (1) I am a NOCC State Division Leader
   (2) I received it from a NOCC State Division Leader
   (3) I saw it on a website (please indicate which website)
   (4) I heard about it at a meeting (please indicate what group meeting)
   (5) I saw a flyer for the study (please indicate where the flyer was located)
   (6) Other, please describe