

A systematic review of ovarian cancer and fear of recurrence

MELISSA OZGA, DO,¹ CAROL AGHAJANIAN, MD,¹ SHANNON MYERS-VIRTUE, PSYD,²
GLYNNIS MCDONNELL, MA,^{1,3} SABRINA JHANWAR, PHD,¹ SHIRA HICHENBERG, MA,¹
AND ISABEL SULIMANOFF, MLS¹

¹Memorial Sloan Kettering Cancer Center, New York, New York

²Temple University and Rutgers Cancer Institute of New Jersey, New Brunswick, New Jersey

³St. John's University, Queens, New York

(RECEIVED November 7, 2014; ACCEPTED December 03, 2014)

ABSTRACT

Objective: To assess demographic, medical, and psychological factors that are associated with fear of recurrence (FCR) in ovarian cancer patients.

Method: We searched PubMed, EMBASE, Cochrane, CINAHL, and PsycINFO. For PubMed, a search using Medical Subject Headings (MeSH) was run, as well as a text-word search from 1990 to July of 2014. The search terms used consisted of ovarian terms, fear terms, and recurrence/progression themes. Title and abstract reviews were conducted by two independent reviewers to determine eligibility, and discrepancies were decided by a third reviewer. Full-text reviews of potentially eligible articles were conducted by the review team, which met regularly to ensure the reliability of eligibility ratings across all articles.

Results: A total of 15 articles met our inclusion criteria. Nine were quantitative studies that utilized a cross-sectional design, and the other six included three qualitative studies, two small intervention studies, and one study that utilized content analysis to explore written correspondence among ovarian cancer patients. FCR was reported as a significant concern for both older and younger women at both early and advanced stages. Women were distressed about recurrence at various times during their treatment and posttreatment. FCR was noted to be prevalent around cancer follow-up examinations. Many women reported not receiving adequate support for recurrence. FCR was also shown to be linked in some way to hopelessness, faith/spirituality, and posttraumatic stress disorder (PTSD). FCR was also linked to patients' anxiety about death and dying and uncertainty about the future of their medical health.

Significance of Results: This review demonstrates that FCR is prevalent in the ovarian cancer population. Moreover, cancer recurrence fears are not adequately assessed or treated. More information is needed on the factors that may be related to women's fears about recurrence of ovarian cancer. In addition, a validated measure of FCR among ovarian cancer patients as well as a treatment intervention are needed.

KEYWORDS: Ovarian cancer, Fear of recurrence, FCR, Recurrence/progression

INTRODUCTION

The American Cancer Society estimates that 21,980 women will be newly diagnosed with ovarian cancer

in the United States during 2014. Ovarian cancer has the highest mortality rate of the gynecological cancers (National Cancer Institute, 2013). It is also the fifth leading cause of cancer death among women in the United States (Seigel, 2014). The majority of women are diagnosed at an advanced stage. While survival rates vary depending on stage of diagnosis, the five-year relative survival rate for all stages is

Address correspondence and reprint requests to: Melissa Ozga, Memorial Sloan Kettering Cancer Center, Department of Psychiatry and Behavioral Sciences, 641 Lexington Avenue, 7th Floor, New York, New York 10022. E-Mail: ozgam@mskcc.org

44% (American Cancer Society, 2014). The disease course for ovarian cancer is often difficult. Initial treatments often include surgery and chemotherapy, which may cause significant physical, psychological, and social side effects (Fitch, 2010). Women who undergo successful initial treatment then require additional follow-up care to monitor for recurrence. Follow-up care generally includes ongoing physical examinations, CT scans, and blood tests (e.g., for Ca-125).¹ It is estimated that between 70 and 75% of women diagnosed with ovarian cancer will experience a recurrence (Armstrong et al., 2006; Sugimoto & Thomas 1998). Therefore, the fear of cancer recurrence (FCR) is commonly reported among ovarian cancer patients (Shinn et al., 2009; Steginga & Dunn, 1997; Wenzel et al., 2002). While FCR has been recognized as a common challenge for ovarian cancer patients, there has to date not been a comprehensive summary of the research on FCR in this population.

Cancer Recurrence

Cancer recurrence has been defined as the return of cancer after completing treatment and having a length of time during which the cancer has not been redetected (American Cancer Society, 2014). The period in which no cancer is detected is typically referred to by physicians as “no evidence of disease” (NED) or “in remission.” Recurrence after a period of remission differs from cancer progression, which is when an existing cancer spreads or worsens. It can be difficult to differentiate between recurrence and progression, especially when there is only a short time period between completion of treatment without evidence of disease and a return of the cancer, because there is no specific timeline with which to define a true remission. A recurrence or progression of the cancer, in turn, will lead to more workups and treatments, and will most likely evoke many emotions and questions.

Fear of Cancer Recurrence

While there is not a universal definition of the fear of cancer recurrence, it is often defined as “fear that the cancer will return or progress in the same place or a different part of the body” (Simard et al., 2010; 2013; Vickberg, 2003). FCR has been recognized as a common concern among cancer patients (Baker et al., 2005). Indeed, FCR has received growing attention in research with adult cancer survivors. There have been several literature reviews on FCR (Crist & Grunfeld, 2013; Koch et al. 2013; Lee-Jones et al.,

1997), including a systematic review that provided an overview of quantitative research conducted over the past 20 years on FCR among adult cancer survivors of various cancer diagnoses (Simard et al., 2013). The authors concluded that cancer survivors consider FCR to be one of their greatest concerns and that many survivors’ psychosocial needs are not met when it comes to FCR, suggesting that it is an important area for future research.

There are limitations to the existing FCR research, including: a lack of well-validated measures of FCR (Simard et al., 2013; Thewes et al., 2012); a dearth of longitudinal studies (Simard et al., 2013); and the fact that the majority of studies focus on breast cancer patients (Lee-Jones et al. 1997). Indeed, a recent review found that 42 of the 130 studies on FCR focused specifically on breast cancer (Simard et al., 2013). Therefore, current research on FCR may not be generalizable to individuals with other types of cancer. Another 37 of the studies reported in the review included a mixed sample of cancer sites (Simard et al., 2013). This is also problematic because there are significant differences between recurrence rates for different types of cancer, which may influence the degree of FCR.

Fear of Cancer Recurrence and Ovarian Cancer

The natural tendency of ovarian cancer is recurrence and remission (American Cancer Society, 2014). The most common histopathological type of ovarian cancer is epithelial, accounting for 90% of cases (McCorckle et al., 2003). Approximately 80% of patients diagnosed with ovarian epithelial cancer will relapse after standard first-line treatment, which includes platinum- and taxane-based chemotherapy (National Cancer Institute, 2014). Given the disease course, prognosis, and recurrence rates associated with ovarian cancer (National Cancer Institute, 2014; American Cancer Society, 2014), FCR may be a particularly important area to understand when working with this population. Fear of recurrence has been identified as an ovarian cancer-specific symptom and a patient-reported outcome that is prevalent and severe. In all cancer types, worry and anxiety are prevalent. However, in ovarian cancer, fear of recurrence or fear of progression reflects the high likelihood that the cancer will recur. Additionally, the frequent follow-up testing that is standard after treatment for ovarian cancer may elevate FCR (Donovan et al., 2014). Many ovarian cancer patients identify Ca-125 levels with their disease status (Hamilton, 1999), which can be distressing. Indeed, there is evidence that anxiety when getting Ca-125 testing is common (Mirabeau-Beale et al., 2009),

¹Ca-125 is a protein found more in ovarian cancer cells than in other cells. It is a blood test used to monitor those who have ovarian cancer. The test is usually performed every three months during chemotherapy treatment and after treatment has ended.

and preoccupation with Ca-125 is associated with increased symptoms of depression and anxiety (Parker et al., 2006).

There has been increased attention given to the importance of quality of life and psychological well-being among ovarian cancer patients (McCorkle et al. 2003). Some studies have suggested that, while many ovarian cancer survivors report few unmet physical needs, they do report significant unmet psychological needs (Matulonis et al., 2008). Therefore, there is a need to better understand factors that may impact psychological well-being in this population, such as FCR. The literature on psychological adjustment among ovarian cancer survivors has suggested that FCR is an important issue that many women face (Hamilton, 1999). It is a commonly reported concern of ovarian cancer survivors (Matulonis et al., 2008). Researchers suggest similar levels of FCR for early- and advanced-stage ovarian cancer patients (Mirabeau-Beale et al., 2009), indicating its prevalence across various stages of the disease.

Overall, the evidence suggests that FCR is an important issue among ovarian cancer patients. However, there has not been a synthesis of the research on this topic. There is a need to better understand FCR among ovarian cancer patients. This information will guide further research and aid in the development of interventions aimed at assisting ovarian cancer patients coping with FCR. The purposes of this systematic review were (1) to identify research studies that have explored FCR among ovarian cancer patients; (2) to characterize FCR in this population in terms of prevalence and specific concerns; (3) to identify the demographic, medical, and psychological factors associated with FCR; and (4) to discuss the implications for treatment interventions and clinical practice.

METHODS

Comprehensive literature searches were conducted in five databases for English-language references between 1990 and July of 2014: PubMed, EMBASE, Cochrane, CINAHL, and PsycINFO. For PubMed, a search using medical subject headings (MeSH) was run, as well as a text-word search. For EMBASE, a search using Emtree (EMBASE vocabulary) terms was run, as well as a text-word search. For Cochrane, a search using MeSH terms was run, as well as a text-word search. For CINAHL, a search using CINAHL vocabulary terms was run, as well as a text-word search. For PsycINFO, a search using PsycINFO vocabulary terms was run, as well as a text-word search. The search strategy had three components, which were linked together using the AND operator: (1) ovarian terms, (2) fear terms, and (3) recurrence/

Table 1. Total figures on July 22, 2014 after records were added to the EndNote library

All references	1,635
PubMed	380
Embase	851
Cochrane	299
CINAHL	71
PsycINFO	34

progression terms. Table 1 contains the complete keyword search strategy and Table 2 contains the complete MeSH search strategy.

All search results were combined in a bibliographic management tool (EndNote), and duplicates were eliminated using the capabilities of EndNote. Any duplicates missed by the software were eliminated manually. Title and abstract reviews were conducted by two independent reviewers to determine eligibility, and discrepancies were decided by a third reviewer. Full-text reviews of potentially eligible articles were conducted by the review team, which met regularly to ensure the reliability of eligibility ratings across all articles. There were 431 duplicates removed.

RESULTS

A total of 15 articles met our inclusion criteria. Nine were quantitative studies that utilized a cross-sectional design. Of those nine, three utilized the same larger database to conduct separate analyses on specific subgroups of ovarian cancer patients based on age. Three of the other quantitative studies utilized a larger database to conduct separate analyses on specific subgroups of ovarian cancer patients based on stage of diagnosis. All other quantitative studies utilized separate samples. The remaining six studies consisted of three qualitative studies, including interviews with ovarian cancer patients, two small intervention studies that did not target FCR specifically, but reported ovarian cancer patients' FCR in findings, and one study that utilized content analysis to explore written correspondence among ovarian cancer patients. The majority of

Table 2. Total figures on July 23, 2014 after duplications were removed

All references	1,204
PubMed	360
Embase	540
Cochrane	282
CINAHL	14
PsycINFO	8

studies relied upon open-ended questions to glean information about FCR. One study utilized the Fear of Relapse/Recurrence Scale. Table 3 provides information specific to the samples, procedures, measures, and FCR findings identified in each of these studies.

Characterization of FCR Among Ovarian Cancer Patients

The methods of assessing FCR varied widely across studies, resulting in rates ranging from 22 (Wenzel et al., 2002) to 80% (Cesario et al., 2010) of ovarian cancer patients reporting FCR. Among the survey-based studies, approximately half of ovarian cancer patients reported ever experiencing FCR and slightly less than half reported that they did not receive adequate help to cope with FCR. For example, one large study ($N = 315$) conducted by Fitch and colleagues (1999) found that 54% of Canadian women with ovarian cancer reported FCR and 43% reported inadequate help in coping with this fear. Substudies from this survey divided the sample into older (>60 years) and younger women (<45 years). Among older women ($n = 146$), 43% reported FCR since diagnosis, 22% reported FCR within the past month, and 37% reported receiving adequate support to manage this fear (Fitch et al., 2001). Among younger women ($n = 39$), 64% reported FCR since diagnosis, 46% reported FCR in the past month, and 18% reported receiving adequate help for this problem (Fitch et al., 2000). A second cross-sectional survey by Fitch and Steele (2010) found that FCR was the top-reported unmet need among women with ovarian cancer, with 78% ($n = 50$) listing it as an unmet need.

Kornblith and colleagues (2010) administered the Fear of Relapse/Recurrence Scale (Greenberg et al., 1997) and reported a mean score of 2.5 among women diagnosed with advanced ovarian cancer at least three years previously who were currently relapse-free ($N = 42$). The mean score indicated uncertainty about greater FCR. However, the majority of women agreed or strongly agreed with statements regarding FCR (66.7%). In similar studies, FCR was reported in 56% of early-stage ovarian cancer survivors (Matulonis et al., 2008; Mirabeau-Beale et al., 2009) and in 48% of advanced-stage cancer survivors. Among long-term, early-stage ovarian cancer survivors (>5 years), the prevalence of FCR was slightly lower, with 22% reporting (Wenzel et al., 2002). Cox and colleagues (2008) found that 33% of women who participated in a pilot study of nurse-led, phone-based follow-up care ($N = 52$) discussed FCR during their calls with the nurse.

In terms of specific recurrence concerns, many studies identified concerns related to health and the future, as well as evidence that these concerns

were significantly challenging for women. For example, Kornblith and colleagues (2010) found that 63.4% of the women they surveyed reported uncertainty to strong agreement with the statement that they would experience a relapse within 5 years, 54.8% reported worrying about their health, and 40.5% reported feeling unsure about the future (40.5%). Stewart and colleagues (2001) assessed views about recurrence among relapse-free ovarian cancer survivors ($N = 200$). Some 45% of these women believed their risk of recurrence was less than average, 28.5% believed their risk to be average, 23% perceived above-average risk, and 3.5% stated they could not rate their risk. In terms of time spent thinking about recurrence, 35% reported hardly ever thinking about the possibility of recurrence, 28% thought of it at least monthly, 24.5% at least weekly, and 12% at least daily. In terms of specific fears, 53% were afraid of what their futures held for them, and 12% were very afraid of dying of ovarian cancer. Similarly, Wenzel and colleagues (2002) found that 10% of long-term ovarian cancer survivors reported that FCR or death was one of their greatest problems during treatment, and 14% indicated that it was currently their greatest challenge after all this time.

The qualitative studies all noted FCR as a predominant theme that emerged among ovarian cancer patients. For example, one online qualitative survey of women diagnosed with ovarian cancer ($N = 360$) found that approximately 80% expressed worry about recurrence at some point. Women described recurrence as being a denial of a future. The most common response to a question about worry in all age groups was a single-word response: "recurrence" (Cesario et al., 2010). Qualitative interviews with ovarian cancer patients yielded four themes, two of which focused on recurrence: waiting for recurrence and facing the diagnosis of recurrence. Women who had experienced recurrence ($n = 11$) reported feeling shock and devastation, despite awareness of the statistics regarding the prevalence of ovarian cancer recurrence (Howell et al., 2003). Reb (2007) conducted interviews with women diagnosed with stage III or IV ovarian cancer within the past years, who had completed an initial course of chemotherapy, and had no evidence of recurrence ($N = 20$), and they reported significant fear and anxiety related to recurrence. Negative communications with their health-care providers about these topics was associated with greater anxiety and less hopefulness. Several women reported recurrence and death as their greatest fears. Content analysis performed on women's correspondence with the founding editor of *Conversations! The International Newsletter for Those Fighting Ovarian Cancer* found that for women in remission, letters about stress and anxiety were more

Table 3. Information specific to the sample, procedures, measures, and FCR findings identified in each of the studies

Author Team	Sample	Method	Instrument/Measures	Fear of Recurrence Findings
Cesario et al. (2010)	N=360 women diagnosed with ovarian cancer	Qualitative One-time interview Qualitative analysis of narrative data from interview	Online interview Interview included questions about worries related to ovarian cancer	Approximately 80% of the women in the study expressed worry about recurrence at some point during the interview
Cox et al. (2008)	N=52 women who had completed treatment for ovarian cancer, stages I–IV	Pilot intervention study One group pretest–posttest design	FACT–O Satisfaction Experience with Follow-Up Care Questionnaire	One-third of women discussed fear of recurrence
Fitch et al. (1999)	N=315 women diagnosed with ovarian cancer, stages I–IV	Quantitative Cross-sectional One-time survey	Survey designed by researchers	Fear of recurrence reported by 54% of women
Fitch (2000)	N=39 women diagnosed with ovarian cancer; age <45 years.	Quantitative Cross-sectional; Reanalyzed subsample of Fitch et al. (1999)	Survey designed by researchers described in Fitch et al. (1999)	Fear of recurrence reported by 65% of women, and only 18% reported receiving adequate help
Fitch (2001)	N=146 women diagnosed with ovarian cancer; age >61 years	Quantitative Cross-sectional; Reanalyzed subsample of Fitch et al. (1999)	Survey designed by researchers described in Fitch et al. (1999)	Fear of recurrence reported by 45% of women
Fitch and Steele (2010)	N=50 diagnosed with ovarian cancer; included both women who had completed treatment and those still in treatment	Quantitative Cross-sectional One-time survey	Supportive Care Needs Survey (adapted by researchers)	Most common psychological needs were fear of recurrence (78%) and fear of cancer spreading (70%)
Ferrell et al. (2003)	21,806 pieces of correspondence from ovarian cancer newsletter	Nonhuman subjects design; content analysis of archived correspondence	No measures administered	Four themes: diagnosis, treatment, remission, and recurrence. Two themes among women with recurrent disease: coping with recurrence and distress over recurrence. Total of 62 letters included strategies to cope with recurrence and 23 about distress related to recurrence
Howell et al. (2003)	N=18 women who had experienced a recurrence of ovarian cancer	Qualitative One-time telephone interview	Interviewing to explore the perspectives of women living with ovarian cancer and experience with recurrence	Four themes emerged from the Interviews: waiting for recurrence, facing the diagnosis of recurrence, managing treatment-related concerns, and attempting to regain control

Continued

Table 3. *Continued*

Author Team	Sample	Method	Instrument/Measures	Fear of Recurrence Findings
Kornblith et al. (2010)	<i>N</i> =42 women diagnosed with stage III or IV ovarian cancer; >3 years from diagnosis without recurrence; majority Caucasian (90%)	Quantitative Cross-sectional One-time survey	Impact of Cancer Scale MHI-17; FACT-NTX (neurotoxicity); FACT-Sp (spirituality) Beck Hopelessness Scale; Fear of Relapse/Recurrence (five-item scale); PCL-C; MOS-Social Support Survey; Survey of sexual problems related to cancer	Mean score on Fear of Relapse/Recurrence was 2.5, which corresponded to “uncertain” about statements related to fears of recurrence; 63.4% reported they were not certain-to-strongly agree with statement that they would have a relapse in 5 years. Greater fear of recurrence was related to lower scores on spirituality, greater negative impact of cancer, lower positive well-being (MHI), and more PTSD symptoms
Matulonis et al. (2008)	<i>N</i> =58 ovarian cancer survivors diagnosed with stage I or II disease	Quantitative Cross-sectional One-time survey	Same measures in Kornblith et al. (2010)	61% reported anxiety when tested for CA-125; 56% reported fear of cancer recurring
Mirabeau-Beale et al. (2009)	<i>N</i> =100 ovarian cancer survivors; diagnosed with early stage ovarian cancer (<i>N</i> = 58) and advanced stage ovarian cancer (<i>N</i> = 42)	Quantitative Cross-sectional One-time survey	Same measures in Kornblith et al. (2010)	Fear of recurrence was prevalent in both survivor groups; 56% of early stage and 48% of advanced stage were afraid of the cancer recurring
Reb (2007)	<i>N</i> =20 women diagnosed with stage III or IV ovarian cancer; women had completed treatment and no evidence of recurrence; majority Caucasian (85%)	Qualitative One-time interview	Personal data form Interview guide that included open-ended questions about women’s experiences of hope	Women reported fears related to uncertainty and the possibility of early death. Facing the death threat emerged as women’s main concern, and the basic social process or core variable in dealing with the concern was transforming the death sentence; women reported significant distress and fears of recurrence at various time points.
Stewart et al. (2001)	<i>N</i> =200 women in remission from ovarian cancer for >2 years; majority Caucasian (87%)	Cross-sectional One-time survey	Questionnaire designed by study team: “To what did ovarian cancer survivors attribute the cause and lack of recurrence of their ovarian cancer?” “How did they perceive their personal risk of recurrence?” “How often did they think about recurrence?” “What would they report as their current health behaviors?”	45% of women believed their risk of recurrence was less than average, 28.5% average, 23% above average, and 3.5% did not know their risk; 35% of women reported hardly ever thinking about the possibility of recurrence, 28% thought of it at least monthly, 24.5% at least weekly, and 12% at least daily; 62.5% reported high to extreme anxiety at cancer checkups, 53% were afraid of what their futures held for them. 12% were very afraid of dying of ovarian cancer

Continued

Table 3. Continued

Author Team	Sample	Method	Instrument/Measures	Fear of Recurrence Findings
Walker et al., 2010	N=8 women diagnosed with advanced ovarian cancer	Intervention study Qualitative analysis	Semistructured interviews	Patients found it troubling when other group members experienced recurrences, but they took comfort in knowing that the group would be there to support them if they experienced recurrence. They thought facing these emotions was part of the process of coping with their illness
Wenzel (2002)	N=49 early-stage ovarian cancer survivors (>5years); majority Caucasian (90%)	Quantitative Cross-sectional One-time survey	Quality of Life of Cancer Survivorship (QoL-CS); Impact of Events Scale (IES-R)	22% reported fear of recurrence; 10% said that at the time of treatment fear of recurrence or death was among their greatest problems; 14% said fear of recurrence was presently their greatest challenge

common than letters celebrating survival (Ferrell et al., 2003). Similar to previously mentioned findings, women reported that fears of recurrence dominated their lives due to an awareness that recurrent ovarian cancer is common and indicates a poorer prognosis. For those who experienced a recurrence, letters focused on the distress caused by recurrence and the need to accept ovarian cancer as a chronic condition.

Factors Associated with FCR Among Ovarian Cancer Patients

Few studies specifically explored the demographic, medical, or psychological factors associated with FCR. Qualitative studies found that FCR was often heightened during follow-up appointments and at the end of active treatment (Cesario et al., 2010; Ferrell et al., 2003; Reb, 2007). In written correspondence, women indicated that ending active treatment triggered new fears and anxieties because they were now not actively fighting the disease (Ferrell et al., 2003). Similarly, in qualitative interviews women stated that they found the end of treatment to be distressing because they felt they were no longer under the protection of the treatment (Reb, 2007). Women also reported feeling anxiety about recurrence prior to follow-up appointments (Reb, 2007). Stewart and colleagues (2001) found that 62.5% reported high to extreme anxiety at cancer checkups, and Mirabeau-Beale and colleagues (2009) found that 50% were anxious when tested for Ca-125. There is some evidence that greater FCR is associated with less favorable psychosocial outcomes. For example, greater FCR correlated with lower scores on spirituality, greater negative impact of cancer, lower positive well-being, and more symptoms of posttraumatic stress disorder (Kornblith et al., 2010; Matulonis et al., 2008).

DISCUSSION

We carried out a systematic review of the literature in order to understand how women with ovarian cancer are affected by FCR. Our findings showed strong evidence that FCR is a problem among this population and that research in this area is lacking.

General Trends and Unmet Needs

There were several general trends found in the literature. Most notably, FCR is a significant concern among women diagnosed with ovarian cancer. FCR is reported by women across various ages and stages of disease. It is reported by women during treatment, after treatment has ended, and when faced with a recurrence of ovarian cancer. Factors that appeared to be associated with the reported FCR were cancer

follow-up examinations and tests (e.g., for Ca-125). Another notable trend was that many women reported not receiving adequate support in regard to FCR. Some developed their own strategies for coping with distress around recurrence, but this may not be true for all women diagnosed with ovarian cancer. The lack of adequate support regarding FCR is further concerning in light of the trend indicating that FCR is associated with such psychosocial outcomes as hopelessness, loss of faith/spirituality, PTSD, anxiety about death and dying, and uncertainty about one's future medical health.

While there were several trends noted in the literature, there were also limitations in the extant literature. First, it is not clear whether the current literature represents an adequate breadth of cultural and demographic diversity. Much of the literature was based on English- or French-speaking women, and the samples were majority Caucasian. Given this information, it is inconclusive whether the findings in these studies can be generalized to more diverse samples. Second, much of the literature focused on women who had survived two or more years after diagnosis. As ovarian cancer is a diagnosis with a poor prognosis and is often rapidly fatal, many women may be excluded in these samples. Furthermore, the literature may not be adequately capturing FCR during the period following diagnosis or initially after completing treatment. Third, there is a lack of consistent use of a valid FCR measure. The majority of studies utilized open-ended questions to assess FCR or focused on general psychosocial issues rather than specifically assessing FCR. Therefore, conclusions about the prevalence and severity of FCR in this population cannot be made. Fourth, the majority of studies did not explore the impact of FCR on a woman's quality of life or psychosocial functioning. Finally, the literature does not provide sufficient information on assessment and treatment of FCR among women with ovarian cancer. It is not clear how, or if, medical providers are assessing FCR among patients. It is also unclear what type of support is provided or available to women experiencing FCR. Moreover, it is unclear what type of support would be most effective.

Future Directions

This review demonstrates that FCR is prevalent in the ovarian cancer population and that it is often not adequately addressed or treated. The review also highlights significant limitations in the research on FCR among ovarian cancer patients. These general trends and limitations suggest important areas for future research and practice. There is a need for further research on FCR in this population, particularly among more diverse samples and among

women who are more recently diagnosed. We also recommend longitudinal research that can examine the trajectory of FCR over time, the relationship between FCR and psychosocial outcomes, and the factors that play a role in the maintenance of FCR. There is also a need for better assessment of FCR in this population, for both research and clinical purposes. A validated measure of FCR for ovarian cancer patients is needed to better understand FCR in this population. This would allow for more conclusive information on its prevalence. Additionally, it is suggested that assessment not only include the presence of FCR, but also its severity. It is important to differentiate FCR that is normal and expected from a level of FCR that may be having a significant impact on a woman's overall functioning. There are existent measures of FCR that have been utilized with broad cancer populations that may be adapted for use in this population. For example, the Concern about Recurrence Scale (CARS) has been validated among breast cancer patients (Vickberg, 2003). The CARS assesses overall fears, as well as including subscales that assess FCR in specific domains of worry (e.g., health, death, womanhood). There are additional measures of FCR that have demonstrated promising psychometric properties in other cancer populations that may inform assessment of FCR among ovarian cancer patients, such as the Fear of Relapse/Recurrence Scale (Greenberg et al., 1997), the Fear of Recurrence Questionnaire (Northouse, 1981), and the Fear of Cancer Recurrence Inventory (Simard et al., 2013).

In addition to the need for validated measures for research purposes, there is a need for clinical assessment of FCR by providers. Since FCR is a significant concern in this population, it may be important for providers to assess FCR in order to provide adequate support or to refer patients to further support services. Brief measures, such as the overall fear index of the CARS (which consists of four items) or the five-item Fear of Relapse/Recurrence Scale, may be considered. Alternately, providers may consider a brief one-question assessment of FCR, similar to the Distress Thermometer (National Comprehensive Cancer Network, 2007), which is often used in oncological settings. Further research is needed in the assessment of FCR in this population in order to identify those at risk and refer to the appropriate treatment.

Finally, given the reported FCR and the lack of adequate support reported in existing studies, there is a need for the development and implementation of interventions that address FCR among ovarian cancer patients. Treatment interventions aimed at ovarian cancer-specific FCR do not currently exist. However, there are existing interventions that have been applied across broad cancer populations that may inform

intervention among this population. For example, Humphris and Ozakinci (2008) developed a structured psychological intervention to address fears of recurrence among head and neck cancer patients. The intervention, which included cognitive-behavioral therapy techniques aimed at helping patients adjust to fears, showed initial promise and acceptability. Another intervention developed by Butow and colleagues (2013) utilized mindfulness-based techniques and metacognitive therapy techniques to help patients change the way they regulate and respond to FCR. Herschbach and colleagues (2010) evaluated two types of group therapy—cognitive-behavioral and supportive-expressive therapy—aimed at reducing fear of progression among individuals with various cancer diagnoses. Fear of progression decreased in both intervention groups compared to a control group, suggesting that these therapeutic techniques might be beneficial in addressing FCR specifically among ovarian cancer patients. Indeed, there is evidence that interventions that include cognitive-behavioral techniques—cognitive restructuring, teaching coping skills to manage emotional reactions, and behavioral tasks—have led to improved general psychological functioning among gynecological cancer patients (Manne et al., 2007). Therefore, these techniques may be incorporated into interventions designed to specifically target FCR among ovarian cancer patients.

In conclusion, this systematic review has highlighted the relevance of FCR among ovarian cancer patients, as well as the need for further research and clinical recommendations in this area. Future efforts should focus on the assessment of FCR in this population and the development of appropriate interventions. The development of a validated scale to assess FCR would enable quantitative analysis, which could be utilized by various physicians and psychosocial providers who, in turn, could make appropriate referrals for treatment and interventions. Interventions that specifically target FCR in the ovarian cancer population currently constitute an undeveloped area. Further research aimed at development of an assessment tool/intervention and accurate timing of implementing these constructs may allow us to identify and treat woman with ovarian cancer most at risk for FCR and those most disabled by these fears. Decreasing cancer recurrence fears in this population may lead to better adherence to cancer surveillance and improved quality of life.

REFERENCES

- American Cancer Society (2014). *When cancer doesn't go away*. Available from <http://www.cancer.org/treatment/survivorshipduringandaftertreatment/when-cancer-doesnt-go-away>.
- Armstrong, D., Bundy, B., Wenzel, L., et al. (2006). Intraperitoneal cisplatin and paclitaxel in ovarian cancer. *The New England Journal of Medicine*, *354*, 34–43.
- Baker, F., Denniston, M., Smith, T., et al. (2005). Adult cancer survivors: How are they faring? *Cancer*, *104*(11 Suppl.), 2565–2576.
- Butow, P.N., Bell, M.L., Smith, A.B., et al. (2013). Conquer fear: Protocol of a randomised controlled trial of a psychological intervention to reduce fear of cancer recurrence. *BMC Cancer*, *13*, 201. Available from <http://www.biomedcentral.com/1471-2407/13/201>.
- Cesario, S.K., Nelson, L.S., Broxson, A., et al. (2010). Sword of Damocles cutting through the life stages of women with ovarian cancer. *Oncology Nursing Forum*, *37*(5), 609–617.
- Cox, A., Bull, E., Cockle-Hearne, J., et al. (2008). Nurse-led telephone follow-up in ovarian cancer: A psychosocial perspective. *European Journal of Oncology Nursing*, *12*(5), 412–417.
- Crist, J.V. & Grunfeld, E.A. (2013). Factors reported to influence fear of recurrence in cancer patients: A systematic review. *Psycho-Oncology*, *22*(5), 978–986.
- Donovan, K.A., Mitchell, S.A., Dueck, A.C., et al. (2014). Recommended patient-reported core set of symptoms and quality-of-life domains to measure in ovarian cancer treatment trials. *Journal of the National Cancer Institute*, *106*(7), 1–8.
- Ferrell, B., Smith, S.L., Cullinane, C.A., et al. (2003). Psychological well-being and quality of life in ovarian cancer survivors. *Cancer*, *98*(5), 1061–1071.
- Fitch, M.I. (2010). Gynecologic cancer. In *Psycho-Oncology*. J.C. Holland et al. (eds.), pp. 167–171. New York: Oxford University Press.
- Fitch, M.I. & Steele, R. (2010). Identifying supportive care needs of women with ovarian cancer. *The Canadian Oncology Nursing Journal*, *20*(2), 66–74.
- Fitch, M.I., Gray, R.E., DePetrillo, D., et al. (1999). Canadian women's perspectives on ovarian cancer. *Cancer Prevention and Control*, *3*(1), 52–60.
- Fitch, M., Gray, R.E. & Franssen, E. (2000). Perspectives on living with ovarian cancer: Young women's views. *The Canadian Oncology Nursing Journal*, *10*(3), 101–108.
- Fitch, M.I., Gray, R.E. & Franssen, E. (2001). Perspectives on living with ovarian cancer: Older women's views. *Oncology Nursing Forum*, *28*(9), 1433–1442.
- Hamilton, A.B. (1999). Psychological aspects of ovarian cancer. *Cancer Investigation*, *17*(5), 335–341.
- Howell, D., Fitch, M.I. & Deane, K.A. (2003). Women's experiences with recurrent ovarian cancer. *Cancer Nursing*, *26*(1), 10–17.
- Greenberg, D.B., Kornblith, A.B., Herndon, J.E., et al. (1997). Quality of life for adult leukemia survivors treated on clinical trials of Cancer and Leukemia Group B during the period 1971–1988: Predictors for later psychological distress. *Cancer*, *80*(10), 1936–1944.
- Herschbach, P., Book, K., Dinkel, A., et al. (2010). Evaluation of two group therapies to reduce fear of progression in cancer patients. *Supportive Care in Cancer*, *18*(4), 471–479.
- Humphris, G. & Ozakinci, G. (2008). The AFTER intervention: A structured psychological approach to reduce fears of recurrence in patients with head and neck cancer. *British Journal of Health Psychology*, *13*(2), 223–230.
- Koch, L., Jansen, L., Brenner, H., et al. (2013). Fear of recurrence and disease progression in long term

- (≥ 5 years) cancer survivors: A systematic review of quantitative studies. *Psycho-Oncology*, 22(1), 1–11.
- Kornblith, A.B., Mirabeau-Beale, K., Lee, H., et al. (2010). Long-term adjustment of survivors of ovarian cancer treated for advanced-stage disease. *Journal of Psychosocial Oncology*, 28(5):451–469.
- Lee-Jones, C., Humphris, G., Dixon, R., et al. (1997). Fear of cancer recurrence: A literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. *Psycho-Oncology*, 6(2), 95–105.
- Manne, S.L., Rubin, S., Edelson, M., et al. (2007). Coping and communication-enhancing intervention versus supportive counseling for women diagnosed with gynecological cancers. *Journal of Clinical and Consulting Psychology*, 75(4), 615.
- Matulonis, U.A., Kornblith, A., Lee, H., et al. (2008). Long-term adjustment of early-stage ovarian cancer survivors. *International Journal of Gynecological Cancer*, 18(6), 1183–1193.
- McCorkle, R., Pasacreta, J. & Tang, S.T. (2003). The silent killer: Psychological issues in ovarian cancer. *Holistic Nursing Practice*, 17(6), 300–308.
- Mirabeau-Beale, K.L., Kornblith, A.B., Penson, R.T., et al. (2009). Comparison of the quality of life of early and advanced stage ovarian cancer survivors. *Gynecologic Oncology*, 114(2), 353–359.
- National Cancer Institute (2013). A snapshot of ovarian cancer. Available from <http://www.cancer.gov/research-andfunding/snapshots/ovarian>.
- National Cancer Institute (2014). Recurrent or persistent ovarian epithelial cancer treatment. Available from <http://www.cancer.gov/cancertopics/pdq/treatment/ovarianepithelial/HealthProfessional/page6>.
- National Comprehensive Cancer Network (2007). *NCCN clinical practice guidelines in oncology: Distress management, version 1*. Available from http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf.
- Northouse, L.L. (1981). Mastectomy patients and the fear of cancer recurrence. *Cancer Nursing*, 4(3), 213–220.
- Parker, P.A., Andrzej, K., Basen-Engquist, K., et al. (2006). The associations between knowledge, CA125 preoccupation, and distress in women with epithelial ovarian cancer. *Gynecologic Oncology*, 100(3), 495–500.
- Reb, A.M. (2007). Transforming the death sentence: Elements of hope in women with advanced ovarian cancer. *Oncology Nursing Forum*, 34(6), E70–E81.
- Seigel, R., Ma, J., Zou, Z., et al. (2014). Cancer statistics, 2014. *CA: A Cancer Journal for Clinicians*, 64(1), 9–29.
- Shinn, E.H., Carmack Taylor, C.L., Kilgore, K., et al. (2009). Associations with worry about dying and hopelessness in ambulatory ovarian cancer patients. *Palliative & Supportive Care*, 7(3), 299–306.
- Simard, S., Savard, J. & Ivers, H. (2010). Fear of cancer recurrence: Specific profiles and nature of intrusive thoughts. *Journal of Cancer Survivorship*, 4(4), 361–371.
- Simard, S., Thewes, B., Humphris, G., et al. (2013). Fear of cancer recurrence in adult cancer survivors: A systematic review of quantitative studies. *Journal of Cancer Survivorship*, 7, 300–322.
- Steginga, S.K. & Dunn, J. (1997). Women's experiences following treatment for gynecological cancer. *Oncology Nursing Forum*, 24, 403–408.
- Stewart, D.E., Duff, S., Wong, F., et al. (2001). The views of ovarian cancer survivors on its cause, prevention, and recurrence. *Medscape Women's Health*, 6(5), 5.
- Sugimoto, A. & Thomas, G. (1998). Early-stage ovarian carcinoma. In *Cancer in Women*. J. Kavanah et al. (eds.). Malden: Blackwell Science.
- Thewes, B., Butow, P., Zachariae, R., et al. (2012). Fear of cancer recurrence: A systematic literature review of self-report measures. *Psycho-Oncology*, 21(6), 571–587.
- Vickberg, S.M.J. (2003). The Concerns About Recurrence Scale (CARS): A systematic measure of women's fears about the possibility of breast cancer recurrence. *Annals of Behavioral Medicine*, 25(1), 16–24.
- Walker, L.M., Bischoff, T.F. & Robinson, J.W. (2010). Supportive expressive group therapy for women with advanced ovarian cancer. *International Journal of Group Psychotherapy*, 60(3), 407–427.
- Wenzel, L.B., Donnelly, J.P., Fowler, J.M., et al. (2002). Resilience, reflection, and residual stress in ovarian cancer survivorship: A gynecologic oncology group study. *Psycho-Oncology*, 11, 142–153.