Caregiving for patients diagnosed with ovarian cancer: An examination of distress and relationships with healthcare providers using attachment theory.

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General Abstract

This thesis focuses on describing and investigating the experiences of caregivers of individuals with ovarian cancer. Caregivers are an essential part of cancer care, and yet they are not formally recognized as such. The special focus on these caregivers stems from the recognition that ovarian cancer is unique from more commonly studied diseases, with a poor prognosis and frequent recurrences. This thesis sought to study this understudied population. The thesis begins with a scoping review of existing literature that specifically investigated this population. From this study, it was confirmed that few studies had focused on this population, however the mapped literature suggested that these caregivers experienced significant compromises to their quality of life. Some preliminary studies identified a theme that the caregiving experience was influenced by the relationships with healthcare providers.

This theme informed the second study of the thesis, that was a cross-sectional, correlational study that sought to recruit partner-caregivers of patients with ovarian cancer, a sample mostly of male-caregivers. This study sought to explore multiple facets of the caregiving experience as part of cancer care using the Cancer Caregiving Tasks, Consequences and Needs Questionnaire, measuring caregiver distress using the Hospital Anxiety and Depression Scale, and collecting sociodemographic and proxy-reports of the patient's medical information. A total of 82 partner-caregivers were recruited for the study, and our sample were mostly men, White, affluent and highly educated. Most of their partners were diagnosed with stage III or IV disease, and were treated with both surgery and chemotherapy. This study's analysis found that caregiving workload, lacking information from healthcare providers, problems with the quality of information and communication with healthcare providers, lacking time for social relations

due to caregiving, and needing more help from healthcare providers correlated with distress outcomes.

The third investigation sought to further explore these relationships by measuring attachment insecurity, as assessed by a short, modified version of Experiences in Close Relationships Scale. Using the same sample data, hierarchical regression analyses were used to test whether general attachment avoidance or attachment anxiety moderated the relationship between the caregiving experiences and distress outcomes. These analyses revealed that attachment anxiety contributed to a portion of the variance in distress, however the experiences with the healthcare team explained a large portion of the variance of distress. Attachment anxiety was found to play a minor role moderating the relationship between needing more help from healthcare providers and anxiety, and attachment avoidance contributed a very small, moderating role between lack of time for social relations and distress. Together, these studies have demonstrated that caregivers of patients with ovarian cancer are understudied, however they experience significant levels of depression and anxiety. Their distress is highly affected by their reported experiences as part of the cancer care team, regardless of their predisposition to distress through attachment insecurity.

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Content of Thesis and Author Contributions

This thesis includes a general introduction to relevant literature, three studies written as journal manuscripts, and a general conclusion. The first study entitled "Being a Caregiver to Patients with Ovarian Cancer: A Scoping Review of the Literature," was published in the journal *Gynecology Oncology*: Petricone-Westwood, D., & Lebel, S. (2016). Being a caregiver to patients with ovarian cancer: A scoping review of the literature. *Gynecologic Oncology, 143*(1), 184-192. The second study entitled "What do Partners of Patients with Ovarian Cancer Need from the Healthcare System? An Examination of Caregiving Experiences in the Healthcare Setting and Reported Distress" has been published in the journal *Supportive Care in Cancer*: Petricone-Westwood, D., Hales, S., Galica, J., Stragapede, E., Lebel, S. (2020). What do partners of patients with ovarian cancer need from the healthcare system? An examination of caregiving experiences in the healthcare setting and reported distress. Advanced online publication in *Supportive Care in Cancer*. The third study entitled "An Investigation of the Moderating Effect of Attachment on Distress among Partners of Ovarian Cancer Patients and their Relationship with the Cancer Care Providers" is currently being revised for submission to *Health Psychology*.

The thesis author, Danielle Petricone-Westwood, is the primary author on all studies and participated in all components of the three studies. I was responsible for conceptualizing the studies, under the guidance of Dr. Sophie Lebel. For Study 1, I conducted the literature searches, screened articles, and extracted data. I conceptualized the literature and wrote the manuscript. For Studies 2 and 3, I established an agreement with Ovarian Cancer Canada to advertise our study nationally, and contacted support centres across Canada to circulate advertisements. I prepared and submitted all three ethics applications required for our multi-site study and prepared all study materials. I screened and contacted all participants, and pre-screened all

patient charts in the gynecology oncology clinics from the Princess Margaret Cancer Centre, and actively recruited in clinic at the Kingston General Hospital with the support of clinic staff. I collected and managed data, conducted analyses and wrote the manuscripts.

My thesis supervisor, Dr. Sophie Lebel, oversaw all three projects and provided guidance throughout. Dr. Lebel additionally co-screened articles for relevance in the first study. She identified and recruited co-authors for Studies 2 and 3. Dr. Lebel provided guidance in choosing measures, data analysis and interpretation, the writing of all three manuscripts, and edited the content. Dr. Lebel's internal University of Ottawa research funded this study.

Dr. Sarah Hales is a staff psychiatrist from the Department of Supportive Care at the Princess Margaret Cancer Centre at the University Health Network. Dr. Hales was the Primary Investigator at the Princess Margaret and engaged their gynecology oncology's surgical oncology team to allow recruitment from their clinics. Dr. Hales provided guidance in submitting the Research Ethics Board application, and edited the manuscripts of Studies 2 and 3.

Dr. Jacqueline Galica is a professor at the School of Nursing at Queen's University. She was the Primary Investigator for this project at Queen's, and engaged the gynecology oncology team to support our recruitment efforts. She provided guidance for the Queen's University Research Ethics Board application. Dr. Galica made edits to the manuscripts of Studies 2 and 3.

Elisa Stragapede was an undergraduate student who used data to conduct her Honours thesis with Dr. Sophie Lebel. Ms. Stragapede assisted with data entry and management. Ms. Stragapede edited the manuscript for Studies 2 and 3.

General Introduction

Ovarian Cancer

Cancer is the leading cause of death in Canada, and it is estimated that 1 in 2 Canadians will have developed cancer at some point in their life (Canadian Cancer Statistics Advisory Committee on Cancer Statistics, 2019). A quarter of Canadians will die from cancer, and prognosis varies widely, with five year survival rates ranging from 98% for thyroid, 93% for prostate, and 88% for breast cancers, to 8% for pancreatic, 15% for esophageal, and 19% for lung and liver cancers. The five and ten-year predicted survival rates for Canadians with ovarian cancer are of 45% and 36%, respectively (Canadian Cancer Statistics Advisory Committee on Cancer Statistics, 2019). The difficulty detecting early symptoms of disease, and a lack of screening technology has led to approximately 75% of ovarian cancer diagnoses occurring at Stage III or IV (Jelovac & Armstrong, 2011), meaning curable treatments are no longer viable.

Ovarian cancer represented only 2.8% of the new cancer diagnoses among Canadian females in 2019, but is still the 5th leading cause of death among Canadian females (Canadian Cancer Statistics Advisory Committee on Cancer Statistics, 2019). Despite research efforts, there have not been any effective strategies for screening the general population for ovarian cancer (Lheureux et al., 2019). Prior to diagnosis, affected individuals experience persistent, non-specific symptoms, such as back, pelvic, or abdominal pain, abdominal distention, bloating, changes in bowel habits, fatigue, frequent urination, early satiety, nausea, and vomiting (Lheureux et al., 2019; Torre et al., 2018). These non-specific symptoms are often overlooked by healthcare providers (HCP) and patients (Goff et al., 2004). The average and median age of diagnosis is of 63 years (Jayson, Kohn, Kitchener, & Ledermann, 2014; National Cancer Institute, 2018).

The late diagnosis of ovarian cancer separates it from many other types of cancers. The advanced disease often implies that it has metastasized widely throughout the abdomen. There is an expectation that there will be several recurrences throughout the disease trajectory even if the disease is surgically removed in the first line of treatment (Jayson et al., 2014). Multiple recurrences means several rounds of chemotherapy, yielding high burden from side effects including pain, fatigue, peripheral neuropathy, alopecia, anorexia, sexual health concerns, and nausea (Trivers et al., 2013). In most cases, the first recurrence occurs within 18 months of diagnosis, and the time between recurrences becomes progressively shorter as the disease becomes more advanced (Jayson et al., 2014). Overtime, ovarian cancer will become resistant to platinum and other chemotherapeutic agents, requiring new agents until the disease finally becomes chemoresistant. Once this occurs, the disease no longer responds to treatment, which often results in a fatal bowel obstruction (Jayson et al., 2014). When the disease becomes platinum resistant, the median survival time for patients is one year (Jayson et al., 2014). A review found that 62% of individuals with ovarian cancer had used some form of complementary therapy, despite lack of scientific evidence, in hopes of finding a cure or symptom relief, and to achieve a greater sense of control over their disease (Trivers et al., 2013).

When considering the frequency and number of different anticancer interventions that can be offered to the patients, oncology teams must evaluate patient quality of life (Lheureux et al., 2019), including their psychological health and wellbeing (Jayson et al., 2014). Compromises to quality of life, and psychological concerns such as depression, mental morbidity, sexual health concerns, and fear of cancer recurrence are well documented in the literature on individuals with ovarian cancer (Ahmed-Lecheheb & Joly, 2016; Roland et al., 2013). This literature suggests that patients experience extensive distress (Norton et al., 2004; Roland et al., 2013), with

particularly high reported levels of anxiety and depression (Ahmed-Lecheheb & Joly, 2016; Bodurka-Bevers et al., 2000; Norton et al., 2004; Roland et al., 2013).

The aggressive nature of ovarian cancer has caused patients to feel isolated from other patients who have more common or prevalent cancer diagnoses (Roland et al., 2013). Patients have endorsed feeling surprised by their diagnoses as they had no prior knowledge of ovarian cancer. They reported feeling that ovarian cancer was under-recognized and under-studied in medical research, which led to resentment as they had not known which signs to look for when they first exhibited symptoms. Patients have reported frustration related to a lack of information specific to ovarian cancer, particularly in comparison to breast cancer (Trivers et al., 2013), and the seemingly disproportionately low resources devoted for ovarian cancer compared to more prevalent diseases (Power et al., 2008). The patient's relationship with HCP, and their trust in these providers seem to coincide with reports of lacking information (Trivers et al., 2013). Additionally, patients' appraisals of the quality of communication with HCP has been found to influence wellbeing and quality of life (Trivers et al., 2013). As the disease is often diagnosed at a late stage, conversations and decisions regarding curative versus palliative care must occur, but patients may not be willing to engage in this transition early on (Trivers et al., 2013). Unfortunately, one investigation found that half of patients with ovarian cancer receive aggressive treatments in the last month of life, and only had palliative care consults in the last month and a half before death, which are predictors of poorer quality of life and increased medical costs (Brown et al., 2014).

When studied among a sample of patients with different gynecological cancers, patients with ovarian cancer reported significantly higher levels of anxiety and depression symptoms (Norton et al., 2004). Patients with ovarian cancer also report higher cancer-related distress in

comparison to patients with breast cancer (Norton et al., 2004). In a qualitative exploration of their experiences, individuals with ovarian cancer have expressed a lot of fear and distress as they waited for a recurrence after learning about survival statistics and recurrence rates at time of their diagnosis. This fear did not however alleviate the devastation they experienced once there was a recurrence (Howell et al., 2003). Importantly, patients felt that after recurrence occurred, there was a change in the relationship with their HCP. They felt they had to advocate more for themselves and find more information about treatment options. This change in the relationship gave them a sense of hopelessness because of the recurrence and the new attitudes perceived from HCP (Howell et al., 2003). Additionally, they reported that the time between recurrences was so brief that they did not get reprieve from treatments. This made it difficult to face new treatments after having gone through others: despite the many treatments they had undergone, the cancer still returned (Howell et al., 2003).

This qualitative research depicts the unrelenting nature of the disease and its exhausting experience for patients. The patients, however, are not the only ones affected by the disease; their loves ones also are heavily involved in the informal care for the patients. The friends and family of these patients may experience similar frustration with the healthcare team and face similar adversities throughout the disease trajectory. Moreover, in the last six months of life, there is a lack of safe treatment options for complications or symptoms, such as pleural effusion, ascites, and bowel or bladder obstruction (Herrinton et al., 2007), meaning the responsibility of support and care may fall to the patient's friends and family, also known as the caregivers (Hartnett et al., 2016).

Caregivers

Caregivers are an Essential Part of the Healthcare System

Health systems are beginning to recognize the importance of caregivers in the maintenance of patient care and the healthcare system in general, particularly with the increase in home care and outpatient treatment protocols. Caregivers are studied in various populations, for example, the aging population (e.g. Ringer et al., 2017), dementia (e.g. McCabe et al., 2016), developmental disabilities (e.g. Scherer et al., 2019), cancer populations (e.g. Geng et al., 2018), amyotrophic lateral sclerosis (de Wit et al., 2018), and general palliative care (e.g. Kavalieratos et al., 2016). A Canadian report has estimated that caregivers provide up to 80% of the patient's care (Fast et al., 2002), and thus ensure the chronic illnesses of their loved ones are managed. Although the literature in caregiving encompasses many chronic illnesses, caregiving in cancer merits specific attention due to the acute and intense nature of cancer treatment and its iatrogenic effects (Kim et al., 2019).

Both the Canadian Cancer Society and American Cancer Society describe caregivers as essential to patient care (American Cancer Society, 2019b; Canadian Cancer Society, 2020). As cancer care is now mostly provided outpatient settings, caregivers are an extension of the cancer care team, and are tasked with providing complex medical support that traditionally was done by HCP (Northouse & McCorkle, 2015). Treatment advances have resulted in patients living longer with their diseases, meaning caregivers have played an increasingly important role over longer periods of time (Golant & Haskins, 2008). Caregivers are not trained in their role, nor are they paid for their work, yet they often are considered a lifeline for their loved one with cancer (American Cancer Society, 2020). Seventy-three percent of patients report receiving some type of caregiving from their loved ones on a daily basis (Golant & Haskins, 2008). In addition to medical tasks, caregivers provide different forms of care such as emotional support, transportation, meal preparation, performing household chores, providing financial support and

managing finances (Golant & Haskins, 2008), among others. Despite their fundamental role, caregivers of individuals with cancer are not formally recognized by the healthcare system, which lacks a standardized integration of monitoring and addressing caregiver physical and mental health concerns (Kent et al., 2016).

Consequences of Caregiving

Many caregivers find meaning and purpose in their caregiving roles, and believe it brings them closer to the patient (Revenson et al., 2016; Stenberg et al., 2010), but their necessity to ensure loved ones get adequate care is not without significant compromises to their mental health. Indeed, caregiver burden is an umbrella term employed to describe the multidimensional consequences and effects of this responsibility on the caregiver. While the definition of caregiver burden is debated, the construct encompasses both subjective and objective detrimental effects of caregiving on physical, psychological, social and financial wellbeing (Bastawrous, 2013; Zarit et al., 1986). Caregivers are referred to as “hidden” or “invisible” patients because of the compromises of their own health, quality of life and wellbeing (Brodaty & Donkin, 2009; Kent et al., 2016; Revenson et al., 2016; Stenberg et al., 2010). Caregivers typically prioritize the patient’s health over their own and are unable to adequately cater to their own health needs (Revenson et al., 2016). Caregivers often feel pulled in many directions with care responsibilities, familial responsibilities, limited time for social supports, work and financial responsibilities (Revenson et al., 2016; Stenberg et al., 2010).

Psychosocial Consequences of Caregiving in Cancer

Psychosocial research has investigated the experiences of caregivers of patients with cancer throughout the cancer trajectory over the last couple decades (Pitceathly & Maguire, 2003; Stenberg et al., 2010). Caregiver research was identified as a high priority for cancer care

research among psychosocial oncology experts in 2011 (Rankin et al., 2011). As a result, extensive literature now supports that caregivers experience significant burden and compromises to their quality of life (Stenberg et al., 2010). Investigations on caregiver burden and experiences of caregivers often focus on two predominant components of the caregiving experience: 1) caregiver distress (e.g. Geng et al., 2018; Mitchell et al., 2013; Nissen, 2016) and 2) unmet caregiving needs (e.g. Beesley et al., 2018; Lambert et al., 2018; Lund et al., 2015).

Caregiver Distress. The Cancer Journey Advisory Group of the Canadian Partnership Against Cancer's Pan-Canadian Practice Guidelines describe distress as encompassing unpleasant emotional experiences and can include symptoms of depression, anxiety disorders, cancer-related distress, fear of cancer recurrence, and stress disorders. Distress can range in severity from common, anticipated adjustment to cancer, to clinical levels which may meet criteria for a mental disorder (Howell et al., 2009). For the purposes of this research, our studies have evaluated distress by measuring symptoms of depression and anxiety, however literature on distress may encompass any or all of the aforementioned symptoms.

A recent meta-analysis found that among caregivers in cancer, the prevalence of depression was of 42% and of 47% for anxiety (Geng et al., 2018). These numbers are higher than what is reported in Ontario on the general caregiving population where prevalence rates of distress were at 26% (Health Quality Ontario, 2018). Caregivers endorsed distress levels that are comparable to or higher than patients' endorsements, particularly as the patient approaches end-of-life (Bowman et al., 2009), as well as comparable levels of unmet needs (Bowman et al., 2009).

Unmet Caregiving Needs. Unmet needs are defined as "a difficulty for which assistance was either insufficient or not received" (Mao et al., 2008, p. 118), that is considered both

important and unsatisfied (Soothill et al., 2001) or unmet according to the individual (Taylor & Currow, 2003). Systematic reviews on caregivers in cancer have identified multiple common unmet needs to include physical, psychological, financial, lifestyle-related, social, spiritual, and informational domains (Lambert et al., 2012; Wang et al., 2018). Unmet needs research is often conducted using composite measures to describe frequency and pervasiveness of unmet needs, however unmet needs are not necessarily predictive of caregiver distress (Lambert et al., 2018). As such, research on unmet needs may benefit from being conducted in conjunction with quality of life or caregiver burden outcomes in order to understand the impact on caregiver wellbeing.

Limitations of Generalizability of Caregiving Literature

Many caregiving reviews have not specified differences across the disease trajectory, studying only a "snapshot" in time, and thus cannot comment on the different problems for patients and caregivers that arise or fluctuate over time (Revenson et al., 2016; Stenberg et al., 2010). There is evidence that caregivers of patients with curable disease steadily improve, however in progressively debilitating illnesses, their distress increases overtime (Revenson et al., 2016). In cancer caregiving research in cancer, the most common disease populations studied in caregiving are breast, gastrointestinal, prostate, colon and lung cancers (Stenberg et al., 2010). Caregiver researchers have commented that there are gaps of knowledge in terms of disease-specific problems and burdens (Revenson et al., 2016). This means that when a disease has certain unique characteristics, such as the frequency of recurrences across the ovarian cancer disease trajectory, limited disease-specific research implies that we cannot assume these caregivers have the same experiences as others. In addition to disease-specific concerns, there are gender-specific limitations in caregiver research. In the pooled sample in a recent meta-

analysis on caregivers, only 31% were men (Geng et al., 2018). These limitations suggest that little is known about partner-caregivers in ovarian cancer.

Male Caregivers

The following section uses the terms “men” and “male” interchangeably to include literature on individuals who were assigned male at birth or identify as men, who may be cis- or transgendered. The literature reviewed is assumed to be mostly based on cis-gendered men. As ovarian cancer is a disease of the female reproductive organs, it is presumed that a large portion of partner-caregivers are men. Intervention studies on caregivers, however, primarily consist of females (Kent et al., 2016), and there is less information in general on male caregiver’s psychological outcomes and unmet needs (Lambert et al., 2012).

Research on male caregivers yield similar findings as in the general caregiving literature. For example, male spouse-caregivers prioritize their sick partners and thus have difficulty managing their own health (Hand et al., 2019; V. Lopez et al., 2012), and all caregiving and domestic tasks (V. Lopez et al., 2012). Male caregivers report fearing the uncertainty of cancer and fearing their partners may die (V. Lopez et al., 2012). Women are described as more vulnerable to caregiver distress (Kim et al., 2006) and physical health compromise (M. Pinquart & Sorensen, 2006), but a meta-analysis comparing gender differences in caregivers found that there were only minor differences between genders (M. Pinquart & Sorensen, 2006). Their analyses found effect sizes of gender to be small to very small, accounting for only for 1-2.8% of variance in the outcomes (M. Pinquart & Sorensen, 2006). Interestingly, in controlling for social support and intensity of stress, gender differences in depression and physical health were eliminated, suggesting an important role for social considerations (M. Pinquart & Sorensen, 2006), and the context in which caregivers provide support.

Despite these minimal differences between male and female caregivers, males may be less supported than their female counterparts. Men are known to underreport their distress, are less likely to ask for support (O'Brien, Fahr, et al., 2005; Smith et al., 2018) and HCP tend to underestimate their distress (Smith et al., 2018). Male caregivers of patients with breast and gynecological cancer report believing few people understood the female-body diseases, making it difficult to find support (V. Lopez et al., 2012). Male caregivers report difficulty expressing and naming their emotions and knowing who to turn to for support (V. Lopez et al., 2012). They also report higher caregiver stress than female caregivers when patients reported lower psychosocial functioning (Kim et al., 2006), and have unmet needs related to knowing how to comfort and support the patient (Hand et al., 2019). Given patients with ovarian cancer are vulnerable to significant psychological distress, these male spouse-caregivers may experience more stress than the general cancer caregiving population. Their distress however may be overlooked by HCP.

Relationships with Healthcare Providers

The relationship between HCP and caregivers has increasingly been recognized as a contributing factor to the caregiving experience (Hand et al., 2018, 2019; Higginson & Evans, 2010; Lund et al., 2015). Caregivers of patients with advanced cancer want more support from HCP in coping with current and anticipated difficult emotions around advanced disease, and their caregiver-patient roles. Caregivers tend to minimize or deny their struggles due to shame or guilt around their feelings, and believe that they have to prioritize the patient (Nissim et al., 2017), but also report needing more help from the cancer care team with decision making, financial management, and stress (Mazanec et al., 2018).

A qualitative investigation found that current and bereaved caregivers in advanced cancer hoped for more support in the face of uncertainty of illness and disease progression (Nissim et al., 2017). They wanted more information on death and dying, and on palliative care and its benefits (Nissim et al., 2017). Indeed, information needs are the most frequently cited unmet needs by caregivers (Wang et al., 2018). When crises occur, caregivers resort to catering to these needs themselves, and research information on diagnosis, treatment, side effects and home care (Stenberg et al., 2010). Caregivers of individuals with gynecological cancers have echoed this need for HCP to provide high quality of communication and better access to information on the gynecological disease, tests and care (Hand et al., 2018, 2019; Mazanec et al., 2018).

Theories on Caregiver Coping

Two theories have been highlighted by Revenson and colleagues (2016) in their book on the general caregiving population; the *wear and tear hypothesis* and the *adaptation hypothesis*. The *wear and tear hypothesis* (Bass & Bowman, 1990; Townsend et al., 1989) posits that overtime, the depletion of resources for the caregiver results in poorer outcomes for the caregiver, as they become more vulnerable to deleterious effects. In Bass and Bowman's (1990) test of this theory, they found that the appraisal of caregiving challenges predicted more difficulty in bereavement. This theory has aligned with caregiving literature, suggesting that the general caregiving population experiences "wear and tear" overtime and that stress becomes exacerbated as their time as caregivers increases. This is contrasted with the *adaptation hypothesis,* which posits that caregivers adapt and adjust to their roles overtime. The *adaptation hypothesis* (Helson, 1964, as cited by Lawton, Moss, Hoffman, & Perkinson, 2000) posits that most caregiving stress and burden occurs when caregiving demands begin, however as the caregiver adapts and becomes familiar with tasks, they become less stressed and burdened.

Most of the literature on caregivers in general has supported the *adaptation hypothesis*, when the analyses have controlled for the psychosocial resources and "objective" demands (Revenson et al., 2016). It has been cautioned, though, that for methodological reasons, the *adaptation hypothesis* may have been biased by longitudinal attrition, as participants yielding poorer outcomes are less likely to continue in studies (Revenson et al., 2016). This theory also has considered caregivers of patients who have curable disease, long-term disability, or are progressive over many years such as dementia, and other forms of caregiving. Caregivers in cancer, however, when studied independently report higher psychological morbidity as illness becomes more advanced or as patients become palliative (Pitceathly & Maguire, 2003).

The discrepancy in psychological morbidity across caregivers likely can be influenced by external factors, such as the nature of the illness, information needs, and others. There likely is also influence from internal factors and traits, such as caregivers' personal histories, coping mechanisms and reactions to stress. As their stressors pertain to interpersonal relationships and the need for caregivers to both care for the patient and work with the healthcare team, theories related to coping mechanisms through relationships may help us to better understand caregiver reactions to stressors. One such theory is attachment theory. Attachment orientations may play an important role in understanding caregiver outcomes, as they pertain to these intrapersonal traits.

Attachment Theory

Attachment theory (Bowlby, 1969) posits that across the lifespan, humans form close bonds to important people in their lives, from whom they develop relationship expectations. Initially studied in children-parent relationships, *attachment* determines how a child responds to stressors in the environment using their parental figure, or *attachment figure* (Ainsworth et al.,

1987; Bowlby, 1969). In response to a threat, children will seek physical proximity and security to their attachment figure. When the threat is gone, they cease security-seeking behaviours, thus allowing the child to engage in other important life tasks such as exploring their environment (Bowlby, 1969). Hazan and Shaver (1990) noted that, similarly to children, when adults are confronted with a threatening situation their attachment needs for security are activated (Hazan & Shaver, 1990). These can be accessed through either actual proximity to a loved one, or emotion regulation strategies and self-soothing developed in healthy early childhood experiences (Mikulincer & Shaver, 2016b). If they successfully gain perceived proximity to the attachment figure, their stress is relieved and they feel secure, however if not, they engage in alternative emotion regulation strategies which lead to maladaptive coping, or greater distress (Mikulincer & Shaver, 2016a). Attachment thus is recognized as an important determinant of interpersonal relationships and emotion regulation (Mikulincer & Shaver, 2016a), and predicts psychopathology and distress (Mikulincer & Shaver, 2016b) including in cancer (Hinnen et al., 2016).

Throughout an individual's attachment experiences, core cognitive-emotional mental representations, or *internal working models*, are formed with two primary components: a representation of themselves and of significant others (i.e. parents, close friends, romantic partners; Bowlby, 1969; Mikulincer & Shaver, 2016). These working models permit individuals to anticipate responses, plan for the future, and use these models for decision-making surrounding attachment-related events (Bowlby, 1969; Cassidy & Shaver, 2016; Mikulincer & Shaver, 2016b). Bartholomew (1990) proposed the use of internal working models to describe attachment styles, using a continuum of their Model *of Self* and their *Model of Others*. Bartholomew believed this would allow for nuances in attachment patterns (Bartholomew,

1990). A positive Model of Self would mean feeling competent, and worthy of attention and love, versus a negative model where they perceive themselves as being unworthy of love, lack confidence in themselves, and are vulnerable to distress. A positive Model of Others would reflect perceiving attachment figures as reliable and trustworthy, and a negative model would lack this perception of others being dependable. These two dimensions therefore combine to make four possible styles of attachment: secure (positive on both dimensions), dismissing avoidant (low Model of Others, high Model of Self), preoccupied (low Model of Self, high Model of Others), and fearful avoidant (high on both dimensions; Bartholomew, 1990). Securely attached individuals tend to have a positive sense of self, have good self-efficacy, and feel worthy of care (Bowlby, 1969; Johnson & Brubacher, 2016; Mikulincer & Shaver, 2016b).

Attachment Patterns

From these internal working models, two orthogonal dimensions of attachment have been proposed: *attachment avoidance* and *attachment anxiety* (Brennan et al., 1998). *Attachment avoidance* describes an individual's comfort with closeness and intimacy in relationships, and how much they allow themselves to be dependent on significant others. People high in attachment avoidance tend to prefer independence, are uncomfortable being close with others, and will deactivate their attachment needs when faced with distress or insecurity. Individuals high in attachment avoidance tend to regulate their emotions through suppression, which includes denial of negative affect or avoidance of the source of emotional stress, and suppressing of physiological arousal (F. G. Lopez et al., 2001). *Attachment anxiety* pertains to how much an individual needs to feel close to loved ones and protected. High levels of attachment anxiety relate to worries about being abandoned by or underappreciated by their attachment figures, and are highly invested in relationships (Feeney, 2016; Mikulincer & Shaver, 2016b). Individuals

high in attachment anxiety use hyperactivating proximity seeking-strategies when distressed. They employ reactive coping, with strong emotional responses, impulsivity and an exaggerated appraisal of the stressor (F. G. Lopez et al., 2001). In contrast, individuals with attachment security, i.e. low levels of both attachment avoidance and attachment anxiety, tend to use appropriate emotion regulation strategies when faced with a stressor, including problem solving, accurate appraisals of the problem, and will mobilize support from their environment to effectively reduce the stressful impact of the situation (Mikulincer & Shaver, 2016c). Of note, adult attachment can be measured as relating to a specific or all romantic partners (romantic attachment), or towards relationships in general (general attachment; Mikulincer & Shaver, 2016d).

Brennan, Clark and Shaver (1998) conducted a large factor analysis study employing all existing self-report attachment measures at the time, and created two 18-item subscales measuring attachment avoidance and attachment anxiety (Brennan et al., 1998). This scale, the Experiences in Close Relationships Scale (ECR) has been widely used to measure these two dimensions of different forms of attachment insecurity as continuous scores. The ECR can be modified to pertain to a particular relationship (e.g. a romantic partner), to one's romantic relationships in general, or to one's overall attachment tendencies in various relationships (Mikulincer & Shaver, 2016d).

Attachment and Social Support

Attachment avoidance and anxiety have been studied in many contexts, including how it can apply to social interactions, appraisals of social support, and caregiving. Mikulincer and Shaver (2009) have outlined the importance of accessible social support from an attachment perspective in order to maintain mental health. Support-seeking behaviours, such as those in

attachment behaviours, and support-providing, such as caregiving from attachment figures, are related. Insecurely attached individuals are more likely to perceive social support from their attachment figures as being less available or that they are less responsive, in comparison to their secure counterparts (Mikulincer & Shaver, 2009).

Attachment theorists have discussed *caregiving* in the context of provision of care to a loved one, such as a child or a romantic partner, with the goal of reducing their suffering, protecting them from harm, and fostering their capacity to grow and develop (Mikulincer & Shaver, 2016b). The purpose of caregiving, from an attachment perspective, is to provide the close other protection and support from danger, which then allows them to explore their environment and meet other needs (Bowlby, 1969). This definition and study of caregiving includes provision of support and care in daily life as stressors or concerns may arise (Carnelley et al., 1996). This definition is a slight distinction from our previous discussion of caregiving related to the provision of support to a loved one affected by chronic illness, in providing practical, emotional, and physical support in the aim of managing the illness. Nonetheless, behaviours and difficulties related to spouse-caregiving in cancer has been found to relate to both romantic attachment insecurity to the partner, and gender (Kim & Carver, 2007). Male spouse-caregivers with romantic attachment avoidance, as measured by the Measure of Attachment Quality, have been reported to provide less frequent emotional care, whereas romantic attachment anxiety was related to less frequent medical care (Kim & Carver, 2007). Regardless of gender, romantic attachment security has been linked to comfort in the provision of practical care, and less perceptions of the caregiving role as burdensome (Kim & Carver, 2007).

Attachment in Patients Related to Healthcare Providers

It is important to highlight that working models may change throughout one's life after experiencing different relationships and adjusting to new experiences and in different contexts (Johnson & Brubacher, 2016; Mikulincer & Shaver, 2016b), and that attachment can involve romantic attachment to a partner or general attachment in across different relationships. This demonstrates the relevance of studying dimensions of general attachment in the context of illness, where it poses a threat to an individual's security and wellbeing. Attachment theorists have posited that when someone is categorized as having a secure attachment in general, they are resilient in times of distress, adverse events, and illness, as they seek out the support and help they need to overcome the adversity (Cassidy & Shaver, 2016; Hooper et al., 2012). This is partly explained by general attachment insecurity that can influence how a patient perceives and interacts with their HCP, which can influence both their relationship with the HCP (R. C. Miller, 2008). General attachment styles in patients can influence their adherence to treatment (Feeney, 2000), and thus their health outcomes (Hooper et al., 2012). Indeed, patients categorized as having general secure attachment have been related to both a stronger alliance between patients with cancer and their physicians, as well as better perceived support from the physicians (Palmer Kelly et al., 2019). Patients categorized as having general insecure attachment however was related to less trust and poorer satisfaction with the physician (Palmer Kelly et al., 2019).

In a sample of patients with diabetes studied by Ciechanowski and colleagues (2004), general attachment style was significantly related to patient-healthcare provider relationships, where having a general attachment security style was related to better patient-healthcare provider collaboration in care. Additionally, better ratings of the patient-healthcare provider relationship was associated with better treatment adherence, and the HCP relationship mediated the relationship between general attachment style and treatment adherence (Ciechanowski et al.,

2004). This research highlights how a patient's general attachment styles can influence the relationship with their HCP, which may also apply to caregivers of individuals with advanced cancer.

Attachment in Advanced Cancer

The study of attachment theory in health is particularly important in advanced cancer, because of how threatening and challenging the disease is both physically and psychologically. Attachment has previously been studied in advanced cancer settings (Hinnen et al., 2016; Hunter et al., 2006; Lo et al., 2009; Tan et al., 2005), as the disease poses a major threat to security with the possibility, and even anticipation of loss. As discussed previously, when patients are diagnosed with ovarian cancer, their prognosis is poor and they are often prescribed an aggressive treatment regimen, implying that attachment systems are activated while individuals cope with the stressor (Simpson & Rholes, 2012). Romantic attachment insecurity has been linked to distress (Simpson & Rholes, 2012) and negative affect amongst patients with cancer, which was mediated by lower perceived emotional support (Hunter et al., 2006).

Hinnen (2016) hypothesized different distress trajectories by applying Bartholomew (1990)'s four attachment styles to four distinct trajectories of distress identified by a large longitudinal study of breast cancer patients (Henselmans et al., 2010). Among individuals with cancer with secure general attachment, distress is heightened at initial diagnosis and when the disease worsens, such as at a time of recurrence or progression. This is followed by a gradual return to near-baseline levels of mental health (Hinnen et al., 2016). Comparatively, a patient with a dismissing general attachment style may demonstrate low levels of distress until the stress or illness becomes too demanding to be suppressed, resulting in a significant increase in distress (Hinnen et al., 2016). Preoccupied general attachment styles may result in a sudden surge of

distress at the time of diagnosis, that perpetuates across treatment due to the hyperactivation and inability to downregulate emotions. Finally the fearful-avoidant general attachment style would expect chronically elevated distress, which may be independent of the disease trajectory (Hinnen et al., 2016).

Attachment in Caregivers

A meta-analysis by Nissen (2016) evaluated the correlations between levels of self-reported general and romantic attachment insecurity levels and styles, social support, and depression and anxiety outcomes, in samples of both patients and caregivers of patients with cancer. Higher levels of attachment anxiety were associated with higher levels of depressive symptoms, finding no statistically significant differences between patient and caregiver data. Higher levels of attachment avoidance were also associated with depressive symptoms, although this association was smaller. Higher attachment anxiety and avoidance were associated with lower perceived social support among both patients and caregivers. This review further reported (only among caregivers) an association between both higher attachment anxiety and attachment avoidance with anxiety symptoms, highlighting the importance of evaluating both depression and anxiety symptoms (Nissen, 2016).

Consistent with the general population, general attachment insecurity in cancer caregivers is positively correlated with symptoms of depression and anxiety, and negatively correlated with perceived social support (Nissen, 2016). Vogel and Wei (2005) suggest that higher levels of romantic attachment avoidance may prevent someone from seeking support because of their negative working model of others. The interacting nature of attachment insecurity, social support seeking and provision, and distress outcomes has been investigated in the context of social support from friends and family, or in the general public. It has yet to be established, however, if

perceived support from HCP is influenced by general attachment insecurity in similar ways. As previously described, HCP play an important role in terms of making patients feel secure as they depend heavily on the healthcare team, which may also apply to caregivers.

As described earlier, the experiences caregivers have with the healthcare team may contribute to their distress and may be related to their general attachment. In qualitative investigations, caregivers of patients at the end of life have reported negative experiences of the healthcare team as they often did not allow them to ask questions or did not listen to the caregivers' concerns (Jo et al., 2007). Caregivers need a sense of security in order to be able cope with caregiving at the end of life. This sense of security requires three elements: that caregivers have friends and family to support them, that they have access to treatment and disease information as needed, and that the healthcare system is available to support them. If caregivers feel that the healthcare team is trustworthy and will respond when needed, they are better able to cope with the illness and more confident in their roles (Stajduhar et al., 2008). This theme reflects the *secure-base script,* proposed by attachment theory researchers, which describes the distress-managing cognitive models of individuals with secure romantic attachment when faced with a threat: "If I encounter an obstacle and/or become distressed, I can approach a relationship partner for help; he or she is likely to be available and supportive; I will experience relief and comfort as a result of proximity to this person; I can then return to other activities" (Mikulincer, Shaver, Sapir-Lavid, & Avihou-Kanza, 2009, p.616). In accordance with the secure-base script, this qualitative data suggests that caregivers may need to know that the healthcare team will be available and can respond to their needs related to caregiving. In summary, caregivers of ovarian cancer patients require further investigation to understand their experiences. Given the existing

caregiver literature, it is possible that their distress is influenced by unmet needs related to the healthcare team, which in turn may be affected by their levels of general attachment insecurity.

The Current Research

Although there has been a targeted focus on cancer caregivers, there is a dearth of literature focused solely on the experience of caregivers of patients with ovarian cancer. Due to the unique nature of ovarian cancer, their caregivers merit specific exploration as their experiences may differ from the general oncology caregiving population. The focus of this doctoral program of research is thus to begin to describe the experience of ovarian cancer caregivers (OCC) and to investigate their distress. Based on the preliminary existing literature, it is speculated that they have a unique and arduous caregiving experience both in practical and emotional ways, related to the frequency of recurrence, the changing treatments as the disease progresses, and the psychological and physical distress experienced by patients.

Study 1: Being a Caregiver to Patients with Ovarian Cancer: A Scoping Review of the Literature.

Study 1 sought to systematically identify existing literature on ovarian cancer caregivers in order to describe the state of the literature. We thus conducted a scoping review for the purposes of mapping existing literature and to identify important gaps on the ovarian cancer caregiving experience throughout the disease trajectory. We chose the scoping method to allow for the inclusion of all types of literature describing ovarian cancer caregivers. With this method, both peer-reviewed journals and other sources of literature are considered in order to describe the breadth and depth of available literature (Levac et al., 2010). This study was published in the journal *Gynecologic Oncology* (Petricone-Westwood & Lebel, 2016).

Study 2: What do Partners of Patients with Ovarian Cancer Need from the Healthcare System? An Examination of Caregiving experiences in the Healthcare Setting and Reported Distress.

Among the identified themes of our review, relationships with HCP was identified as important to the caregivers, and seemed to have an influence on their wellbeing. There were however few studies that had quantitatively evaluated this important component of the caregiving experience. This is notable, as cancer care as an institution relies heavily on caregivers in order to ensure that patients receive adequate care.

Study 2 was thus designed as an exploratory, quantitative investigation of the relationship between ovarian cancer caregiver distress and their experiences with the cancer care institution and HCP. While several studies have cited the importance of interactions with the healthcare team and unmet needs, it was unclear which components of the relationships with the healthcare team correlated with symptoms of depression and anxiety. This was hypothesized to be particularly important in ovarian cancer, where frequent recurrences and changes in treatment means a high dependence on HCP for meeting informational, physical and psychosocial needs. This study focused on partners-caregivers, as partners most often fill the role of caregiver, and because most partners were men, who are underrepresented in the literature.

This study was developed as a cross-sectional study that sought to recruit partner-caregivers of patients with ovarian cancer. Participants were recruited through advertisements by the organization, Ovarian Cancer Canada, and through support groups in Calgary, Alberta and Ottawa, Ontario. Participants were additionally recruited through two gynecology oncology clinics at the Cancer Centre of Southeastern Ontario at the Kingston General Hospital, and at the Princess Margaret Cancer Centre of the University Health Network in Toronto. These studies

were approved by the Research Ethics Boards of the University of Ottawa, the University Health Network, and Queen's University. This study was published in the journal *Supportive Care in Cancer* (Petricone-Westwood et al., 2020).

Study 3: An Investigation of the Moderating Effect of Attachment in Distress among Partners of Ovarian Cancer Patients and their Relationship with the Patients' Healthcare Providers

Study 3 sought to build on the findings of study two, which narrowed our focus to specific characteristics of the caregiving tasks and relationships with HCP that were correlated with higher scores of depression and anxiety. As many of these factors pertained to support from the cancer care team, this study sought to explore whether general attachment insecurity among ovarian cancer partner-caregivers may contribute to caregiver distress in the context of their support from the healthcare team. We hypothesized that higher levels of general attachment insecurity would predict higher levels of depression and anxiety symptoms, and that both general attachment anxiety and general attachment avoidance would significantly moderate the relationship between experiences with the healthcare team and symptoms of depression and anxiety. Multiple hierarchical regression analyses were conducted to test these hypotheses and provide explained variance. Collectively, these studies have described how the caregiving experiences that can contribute to distress, and identified predispositions to distress through general attachment insecurity among this understudied population. This study is currently being revised for submission to the journal *Health Psychology*.

Being a Caregiver to Patients with Ovarian Cancer: A Scoping Review of the Literature.

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Abstract

Objective: Ovarian cancer differs from many other cancer diagnoses due to its late diagnosis and high rates and frequencies of recurrences. The physical and psychosocial wellbeing of patients are well documented in the literature, however limited research exists specifically on their friends and family, or caregivers. The goal of this review was to examine the state of the literature on ovarian cancer caregivers. ***Method:*** A scoping review was conducted on any articles describing caregivers of patients with ovarian cancer. Databases were searched systematically using key terms related to ovarian cancer and caregiving. Both authors screened articles for eligibility. Grey literature was also consulted. ***Results:*** 19 articles were identified after screening: nine quantitative, five qualitative, two mixed-methods, two case studies and a personal account. Quantitative studies were conducted over different time-points in the disease trajectory, whereas qualitative studies and the personal account spanned the whole trajectory. Collectively, the studies suggested that the experience of being a caregiver to patients with ovarian cancer changes overtime, as the first year post-diagnosis shows little compromise in wellbeing and quality of life, which then steadily declines throughout the rest of the disease trajectory. Studies commented on quality of life, distress, needs, social wellbeing, spirituality, relationships with healthcare providers, relationships with patients, physical health and financial wellbeing. ***Conclusions:*** This scoping review of the literature demonstrates little peer-reviewed evidence on the experiences and quality-of-life of caregivers in ovarian cancer. This population experiences physical and psychosocial challenges that merit exploration, to subsequently aid in designing interventions.

Keywords: ovarian cancer, oncology caregivers, scoping review, family, gynecology, psychosocial oncology

Being a caregiver to patients with ovarian cancer: A scoping review of the literature.

In 2009, ovarian cancer was the fifth leading cause of female cancer deaths among Canadians (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2014), despite representing only 2.9% of the 93,600 new Canadian female cancer diagnoses in 2014 (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2014). Ovarian cancer is referred to as the "silent killer," as it was historically thought not to have any presenting symptoms before the disease was advanced. Initial symptoms however are now known to be non-gynecological symptoms, such as for example back pain and bloating, meaning they are often overlooked by patients and healthcare providers (Goff et al., 2004). Due to the lack of screening methods and nonspecific early symptoms, approximately 75% of patients are diagnosed with advanced disease (Jelovac & Armstrong, 2011). Even once the disease is treated, there is a high rate of recurrence and prognosis is poor; ovarian cancer represents the leading cause of deaths among women with gynecological cancer (Jelovac & Armstrong, 2011).

In addition to being perceived as a "silent killer," ovarian cancer is characterized by an expectation that there will be several recurrences, which is unlike many other types of cancer. Most patients with advanced disease will develop a first recurrence within 18 months of their diagnoses, followed by several other recurrences which have progressively shorter intervals of time being disease-free (Jayson et al., 2014). Treatment regimens change based on the time lapses between interventions, as the cancer becomes resistant to platinum and other agents. After several rounds of treatments, the disease becomes chemo-resistant and often leads to bowel obstruction, causing death (Jayson et al., 2014). 50% of patients with FIGO stage III ovarian cancer will live longer than 5 years after diagnosis, and the median survival rate for patients with

recurrent ovarian cancer is of 3 years. Once the cancer becomes platinum resistant, median survival time is of 1 year (Jayson et al., 2014).

In the treatment of ovarian cancer, oncology teams must find a balance between reintroducing chemotherapeutic agents against the quality of life of patients and their psychological wellbeing (Jayson et al., 2014). To date, the psychological needs and concerns of individuals diagnosed with ovarian cancer are well documented (Roland et al., 2013). As do most patients diagnosed with any cancer, this population of patients experiences high levels of distress (Norton et al., 2004; Roland et al., 2013), particularly in levels of depression and anxiety (Bodurka-Bevers et al., 2000; Norton et al., 2004; Roland et al., 2013). The literature however further supports the unique experience of ovarian cancer, particularly through these patients feeling socially isolated due to the more uncommon but aggressive nature of their illness, as opposed to other more common diagnoses (Roland et al., 2013), such as other gynecological or breast cancers. Additionally, they were found to have significantly higher symptoms of depression when compared to samples of women with other gynecological cancers, and had higher levels of distress related to their cancer and treatments compared to a sample of breast cancer patients (Norton et al., 2004). Among patients with ovarian cancer, younger patients and patients with advanced or recurrent disease tend to be the most psychologically distressed (Norton et al., 2004; Roland et al., 2013).

In recent years, psychosocial oncology researchers have begun to focus on the experiences of the family and friends of patients with cancer and their quality of life throughout the cancer trajectory (Pitceathly & Maguire, 2003; Stenberg et al., 2010). These friends and family members are referred to as caregivers, as they are responsible for caring for and supporting patients outside the healthcare team. Caregivers are often identified by researchers

through the patients or healthcare team who volunteer them, or are contacted through cancer registries where they are listed in a patient's file (e.g. as a spouse). These studies and reviews have identified different predictors and correlates to caregiver psychological distress (Pitceathly & Maguire, 2003; Stenberg et al., 2010), allowing for a better understanding of their experiences and clinical implications. Distress and unmet needs in caregivers have been found to be comparable to, and in certain times even higher than those of patients, especially in end-of-life (Bowman et al., 2009). Caregivers report higher psychological morbidity as illness becomes more advanced or as the focus of patients' care becomes palliative instead of curative (Pitceathly & Maguire, 2003).

Despite the growing literature on caregivers, few studies have focused independently on the caregivers of patients with ovarian cancer. As the literature suggests higher disease psychological morbidity in patients, as well as the overwhelming evidence that cancer affects caregivers, the caregiving in ovarian cancer experience merits exploration. In order to obtain insight on the current state of the literature, we have conducted a scoping review, as this method allows us to consider all forms of literature portraying caregivers of patients with ovarian cancer. The scoping method allows for researchers to examine peer-reviewed journal articles and other forms of literature, to then collect and present data on the population and provide insight on the breadth and depth of literature available to date (Levac et al., 2010). Unpublished literature is considered in order to inform and guide future studies that will employ proper scientific methods. Scoping reviews differ from systematic reviews primarily as systematic reviews tend to have a narrow focus and research question, often restricting inclusion criteria to specific research designs. In contrast, scoping reviews cover broader topics and thus include various study designs (Arksey & O'Malley, 2005). The focused research questions of systematic reviews require

included studies to be assessed for their quality in order to evaluate the answers to their questions. The broad nature of scoping review questions means that quality of studies is not assessed (Arksey & O'Malley, 2005). 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.

Method

Database Search

We conducted our search systematically in order to exhaust the literature published on caregivers of patients with ovarian cancer. Any friends or family members of patients diagnosed with ovarian cancer were considered caregivers for the purposes of our literature search. Arksey and O'Malley (2005)'s scoping method of was employed. The following databases were used through the OVID interface on November 19th, 2014: 1) PsycINFO, 2) PubMED, 3) CINAHL, and 4) Web of Science. The concepts searched pertained to ovarian cancer, and family or caregivers. Our keyword formula for databases resembled the following: (ovar* AND (cancer OR oncology OR "cancer journey" OR "health behavio*" OR palliat* OR neoplasm OR malignan*)) AND (husband* OR spous* OR caregiv* OR famil* OR "family cancer care" OR "familial-professional relationship*" OR bereave*).

Our search aims were to determine all literature focused on this population, and thus inclusion criteria were limited to: 1) caregivers of patients diagnosed with ovarian cancer at any stage; 2) caregivers over 18 years of age; 3) published peer-reviewed studies; 4) dissertations; 5) conference abstracts; 6) case studies; 7) articles written in English, French, or Italian. Excluded studies included: 1) pediatric studies; 2) articles focused on caregivers of patients diagnosed with non-ovarian cancers; 3) review articles; and 4) articles published before 1990. Of note, in studies

where caregivers of patients with ovarian cancer were a subsample (where the sample included various disease sites, or both patients and caregivers), studies were only included if they reported specific results on caregivers of patients with ovarian cancer.

Filtering of the Literature

After conducting our search, all articles were pulled into Reference Manager (version 12) and duplicates were removed. A total of 927 articles remained. Authors (SL and DPW) individually screened articles by title and abstract using inclusion and exclusion criteria. Kept articles were compared and discrepancies were discussed and agreed upon before proceeding. 32 articles were kept following the first phase and were pulled for phase two. 4 pieces of literature could not be found despite efforts to retrieve them. Of the remaining 28 articles, one author (DPW) read through articles to determine eligibility. Any articles that no longer met inclusion criteria were removed from the database, leaving 16 articles from the database searches. Reference lists of pulled articles were consulted to find any additional papers, and grey literature was searched for using a Canadian government information search engine from the University of Ottawa, and the Canadian Health Research Collection database. Stakeholders in the field were contacted for any unpublished literature they may give families. No additional articles were found in these final manual stages. One additional article was found from a database email notification from a database (Plotti et al., 2014). Two additional unpublished abstracts were identified following the meeting of one author (DPW) with an author on these abstracts (Fitch et al., 2013; Sapsford et al., 2013). These were added to the review giving a final total of 19 articles (see Figure 1).

Data Extraction

The standardized data spreadsheet used for charting data collected the following information from articles when available: 1) details of publication, including methods and samples; 2) caregiver participant demographics; 3) diagnostic or prognostic information on patients at time of recruitment and data collection; and 4) types of data provided by the literature, including quantitative outcomes, qualitative themes, and personal opinions.

Results

Scope of the Literature

19 studies were identified and pulled after searching through the literature. Among these, nine studies were quantitative, five were qualitative, two applied a mixed-method, two were case studies, and one was a personal account. Four were abstracts from conference proceedings (Fitch et al., 2013; Plotti et al., 2014; Ponto, 2010; Ponto et al., 2009). Sample sizes tended to be low for all types of studies, with some exceptions. See Table 1 for information on these studies. Seven of these studies were published from the same three samples: one was a sample of bereaved family caregivers (Fitch et al., 2013; Sapsford et al., 2013), another was of husbands of patients who have had a recurrence (Ponto, 2010; Ponto et al., 2009), and another sample was pulled from a quality of life substudy of a large longitudinal Australian ovarian cancer study (Beesley et al., 2011; Butow et al., 2014; Price et al., 2010).

Disease Trajectory Time Periods

Quantitative studies were conducted at different time points in the disease trajectory, including one to three years post-diagnosis (Awadalla et al., 2007; Frost et al., 2012; Koldjeski et al., 2007; Le et al., 2004; Price et al., 2010), the last year before the patient died (Butow et al., 2014), and important time periods such as throughout chemotherapy treatment (Le et al., 2004), or after recurrence of the ovarian cancer (Ponto, 2010; Ponto et al., 2009). Qualitative studies

and the personal account reflected the whole disease experience after the patient had either finished treatment (Gates, 1993; Ponto, 2010; Ponto et al., 2009; Ponto & Barton, 2008), or died (Fitch et al., 2013; Sapsford et al., 2013; Tarraza & Ellerkmann, 1999).

Main Findings

To present the findings from the identified studies, we have arranged the main study outcomes, correlates and themes into five different categories: socio-demographic findings, psychosocial findings, physical findings, findings related to relationships with healthcare providers and the medical team, and other.

Quality of Findings

These findings are of varying sample sizes (see Table 1) and scientific rigour. Among the published journal articles with quantitative outcomes, all instruments were either already validated or validated in the study. Validated instruments were used to measure depression and anxiety outcomes (Beesley et al., 2011; Butow et al., 2014; Price et al., 2010), social support (Butow et al., 2014; Price et al., 2010), optimism (Butow et al., 2014; Price et al., 2010), quality of life (Arden-Close, Moss-Morris, Dennison, Bayne, & Gidron, 2010; Beesley et al., 2011; Butow et al., 2014; Frost et al., 2012; Price et al., 2010), intrusive thoughts (Arden-Close et al., 2010), caregiver burden (Frost et al., 2012), and family strengths and coping (Koldjeski et al., 2007). Measures of couple communication (Arden-Close et al., 2010) and caregiver quality of life (Awadalla et al., 2007) were validated in the study. Most published qualitative research showed methodological rigour generally consistent with the Critical Appraisal Skills Program Qualitative Research Checklist (Evans et al., 2015) as they explained with detail their entire method, including their recruitment and data collection, their data extraction, the analysis, and efforts to minimize bias. Three studies were transparent in their method (Ferrell et al., 2002;

Koldjeski et al., 2007; Ponto & Barton, 2008) and one study did not describe their method of analysis (Tarraza & Ellerkmann, 1999). Although the methods chosen seemed appropriate, most studies did not provide explicit justification for their choices. For example, family members were interviewed as a group to investigate how the family was coping as a unit (Koldjeski et al., 2007), whereas individual interviews were conducted with husbands to explore their personal experiences of caregiving (Ponto & Barton, 2008).

Demographic Information

Socio-Demographic Information of Samples

Socio-demographic information of the samples is summarised in Table 1. Demographic information was not available for three studies (Ferrell et al., 2002; Gates, 1993; McLean & Hales, 2010). Spouses represented a large majority of the caregivers, with seven studies including only spouses, and other studies either not specifying or having mostly spouses. The studies recruiting all caregivers had a range of 45% to 78% spouses, and other participants were children, siblings, mothers, or friends.

Socio-Demographic Findings. Within the identified studies, few of the main findings pertained to socio-demographic information, or found that they were not significant predictors. Age and gender were the only significant factors identified. Age of the caregivers yielded mixed results. Age influenced health behaviours as younger caregivers were found to exercise more but older caregivers ate more vegetables (Beesley et al., 2011), younger couples adjusted more poorly to the disease (Ponto, 2010; Ponto et al., 2009), and younger caregivers had higher levels of anxiety (Price et al., 2010). On the other hand, other studies found no significant relationship between age and quality of life (Butow et al., 2014) or depression scores (Price et al., 2010).

One study found differences between gender in terms of how distress predicted other psychological outcomes, as women caregivers had less distress as they showed higher optimism and social support than men caregivers across the last year before death. Women, however, had more distress and unmet needs than men as the patient neared the end of their lives (Butow et al., 2014).

Psychosocial Findings

Quality of Life

Six of the identified studies assessed the overall quality of life of caregivers (Awadalla et al., 2007; Butow et al., 2014; Frost et al., 2012; Koldjeski et al., 2007; Le et al., 2004; Price et al., 2010). Collectively, these studies suggest that caregiver quality of life tends to be high or improve from diagnosis to 12-18 months post-diagnosis (Frost et al., 2012; Koldjeski et al., 2007) or throughout first rounds of chemotherapy post-diagnosis (Le et al., 2004), but then continuously declines after this (Frost et al., 2012) to scores that are below the population norms for mental wellbeing in quality of life assessments as distress increases (Butow et al., 2014). More specific outcomes, such as mental, physical, social and spiritual wellbeing, will be discussed later in their respective categories.

Depression and Anxiety Outcomes

Data on caregiver depression and anxiety were reported in five of the identified studies (Awadalla et al., 2007; Butow et al., 2014; Frost et al., 2012; Koldjeski et al., 2007; Price et al., 2010). Similarly to the quality of life findings, depression and anxiety scores tended to be lower at the beginning of the disease trajectory (Frost et al., 2012; Koldjeski et al., 2007). Anxiety scores were higher than depression scores (Koldjeski et al., 2007), as was its prevalence (Price et al., 2010), and subclinical and clinical levels of anxiety and depression were both significantly

more prevalent in caregivers than community norms (Price et al., 2010). In terms of correlated variables, lower social support and lower optimism (Butow et al., 2014; Price et al., 2010) and a greater number of unmet needs were related to depression and anxiety scores (Butow et al., 2014). Additionally, qualitative papers alluded to distress, and described that distress was related to the devastation of the first diagnosis and disease (Ponto & Barton, 2008; Sapsford et al., 2013), overall coping with the disease, treatment, and its symptoms (Ferrell et al., 2002; Fitch et al., 2013; Gates, 1993).

Social Support

Six studies commented on the importance social support and wellbeing (Arden-Close et al., 2010; Butow et al., 2014; Ferrell et al., 2002; Frost et al., 2012; Koldjeski et al., 2007; Ponto & Barton, 2008). Social support was found to vary but decline from diagnosis to three years later (Frost et al., 2012), and was found to be consistent over the last year of life (Butow et al., 2014). Social support was one of the biggest unmet needs reported by caregivers at the beginning of the last year of life (Butow et al., 2014), and caregivers often report feeling socially isolated (Ferrell et al., 2002). Caregivers found comfort in reading letters of other caregivers as they felt they were not alone in their experiences (Ferrell et al., 2002), and many families reported social support (Ponto & Barton, 2008), rearranging family dynamics, and accepting help improved their wellbeing (Koldjeski et al., 2007). It was also important for caregivers to share the burden of caring with friends and family (Koldjeski et al., 2007; Ponto & Barton, 2008). An important unmet need was caregiver's inability to manage the topic of cancer in social settings near the patient's end of life (Butow et al., 2014). The only identified correlated variable to social wellbeing was with better couple communication between the patient and spouse (Arden-Close et al., 2010).

Spirituality

Seven studies reported on spirituality or related concepts such as maintaining hope and drawing meaning (Ferrell et al., 2002; Fitch et al., 2013; Frost et al., 2012; Gates, 1993; Koldjeski et al., 2007; Sapsford et al., 2013; Tarraza & Ellerkmann, 1999). Spirituality was reported as an important source of comfort and coping, including drawing positive meaning and purpose of the illness through faith (Ferrell et al., 2002), by maintaining hope despite the poor prognosis (Ferrell et al., 2002; Gates, 1993), and through seeking spiritual support through religious figures (Koldjeski et al., 2007). Qualitative spiritual comments from caregivers often reflected thoughts about the meaning of advancing symptoms and treatment (Ferrell et al., 2002; Fitch et al., 2013; Tarraza & Ellerkmann, 1999), transitioning to end-of-life and palliative care (Fitch et al., 2013), experiencing a loved one dying and end-of-life itself (Ferrell et al., 2002; Fitch et al., 2013).

Assessments of spiritual wellbeing found that caregiver hope was high in the first year post-diagnosis (Koldjeski et al., 2007), but that spiritual wellbeing diminished overtime, as finding purpose and comfort in oneself became more difficult (Frost et al., 2012). These findings reflected previously mentioned findings of the lower quality of life and distress following the first year post-diagnosis. Despite the importance of spirituality for support and coping, hopelessness (Ferrell et al., 2002) and helplessness (Gates, 1993; Tarraza & Ellerkmann, 1999) were described as sources of distress for participants. Additionally, caregivers experienced distress when the patient suffered from treatment side effects (Gates, 1993; Tarraza & Ellerkmann, 1999) and as the end of the patient's life approached (Frost et al., 2012; Sapsford et al., 2013). Higher spiritual wellbeing was associated with concentration, outlook and worry, fewer symptoms of insomnia, and the patient experiencing few symptoms (Frost et al., 2012).

Relationship to Patient

We excluded studies that combined patient and caregiver outcomes in order to obtain a clear representation of caregivers, but there were still some noteworthy findings from ten studies of the patient-caregiver dyads reflecting caregivers' experiences (Butow et al., 2014; Ferrell et al., 2002; Le et al., 2004; McLean & Hales, 2010; McLean & Nissim, 2007; Ponto, 2010; Ponto et al., 2009; Ponto & Barton, 2008; Price et al., 2010; Tarraza & Ellerkmann, 1999). The caregiver's wellbeing tended to be more related to patient psychological wellbeing, as opposed to the patients' physical wellbeing. In the last year before death, the most reported unmet needs were of reducing patient stress, fear of cancer spreading and the lack of recovery, and difficulty managing their own needs with those of the patients (Butow et al., 2014). Caregivers were often concerned for patient's psychological wellbeing (Ferrell et al., 2002; Ponto & Barton, 2008), and caregiver's wellbeing was often influenced by patient psychological, spiritual, and marital wellbeing (Le et al., 2004; Ponto, 2010; Ponto & Barton, 2008; Price et al., 2010). Caregiver quality of life however was not related with response to chemotherapy, symptom severity, or performance status (Le et al., 2004). Caregivers often alluded to the pain of watching the patient suffering (Ferrell et al., 2002; Gates, 1993; Ponto & Barton, 2008; Tarraza & Ellerkmann, 1999). In Tarraza's (1999) study of bereaved family members, watching the patient suffer was reported as the worst part of the experience. These findings together suggest that physical outcomes do not influence the caregiver's response, however witnessing the patient suffer in other ways is related to distress in the caregiver. The psychological wellbeing of patients seems to have a strong influence on caregiver distress.

Spousal relationships have been studied, and two case studies demonstrated some complicated dynamics between ovarian cancer patient and the caregiver (McLean & Hales,

2010; McLean & Nissim, 2007). Both positive and negative changes in the spousal relationship were found (Ponto & Barton, 2008), and spousal caregivers were found to have higher levels of depression than child caregivers (Price et al., 2010). After recurrence, better illness communication between patients and caregivers were associated with less intrusive thoughts in spousal caregivers (Arden-Close et al., 2010).

Physical Wellbeing Findings

Quality of Physical Health and Health Behaviours

Five of the identified studies commented on caregivers' physical health and wellbeing. Only one study evaluated health behaviours that met recommended health guidelines, and changes since diagnosis (Beesley et al., 2011). The range of caregivers who did not meet various positive health behaviours recommendations ranged from 10% to 80% of those surveyed, and there were more negative health behaviour changes since diagnosis than there were positive ones (Beesley et al., 2011). Variables related to negative health behaviours included less education, anxiety or depression, and the inability for either the caregiver or the patient to perform daily activities (Beesley et al., 2011). Similarly to other quality of life domains, physical wellbeing was found to be within normal ranges at diagnosis (Frost et al., 2012; Le et al., 2004), but then began to deteriorate after the first 18 months post-diagnosis (Frost et al., 2012). Within the last year before death, physical wellbeing was only significantly below the population norm at four to six months before death (Butow et al., 2014).

Reports of Health and Health Concerns

One study that did a content analysis on caregivers' letter submissions to an ovarian cancer newsletter found that caregivers often commented on the physical wellbeing of patients but rarely on their own (Ferrell et al., 2002). The authors suggested that caregivers may have a

lack of awareness of their own health, or a sense of guilt in describing their own health while the patient is so sick (Ferrell et al., 2002). Due to the genetic nature of the disease, some family members worried for themselves or for female family members potentially also developing the disease (Ferrell et al., 2002).

Caregiver Relationship with Healthcare Providers (HCP) and the Medical System

Acknowledgement by HCP

Seven studies had results on caregivers' relationship with the patient's HCP. Despite the family playing a central role in caring for the patient, there is little evidence of HCP making efforts to include family members and address their concerns (Koldjeski et al., 2007; Sapsford et al., 2013). Caregivers emphasized the importance of acknowledgment from the HCP and to be offered support themselves (Butow et al., 2014; Gates, 1993; Ponto & Barton, 2008). They also often felt anger and blame towards HCP for the late-stage diagnosis (Ferrell et al., 2002; Gates, 1993).

Treatment Education

In the last year of life, an important unmet need of the caregivers was acquiring prognostic information (Butow et al., 2014). Caregivers also sought alternative treatments and hoped for a cure despite having exhausted the standard treatments (Ferrell et al., 2002). They felt they were not educated enough about the disease (Ferrell et al., 2002) and sought information and education themselves (Koldjeski et al., 2007; Sapsford et al., 2013).

Palliative and Supportive Care

In two articles, caregivers commented on the importance of hospices and end-of-life care in terms of the relief it offers patients (Ferrell et al., 2002; Gates, 1993). American studies referred to this as hospice care. Caregivers reported positive experiences with hospice care, and

its importance for advanced disease care and for bereavement support (Ferrell et al., 2002). The hospice allowed caregivers the opportunities to grieve and come to terms with the approaching death of the patient (Gates, 1993).

Other findings

Financial Wellbeing

One abstract identified commented on the economic value of being a caregiver. They reported a mean cost of 10,981€ annually for Italian caregivers of patients with ovarian cancer (14,933.20 USD in June 2014; Plotti et al., 2014). This and another study reported that caregivers had to miss work as they cared for patients (Butow et al., 2014; Plotti et al., 2014). Caregivers endorsed having to rearrange their lives and priorities (Ponto & Barton, 2008), which likely influences their work lives. Once caregivers recognized that the patient was dying, they felt the need to be present 24 hours a day for care and support (Sapsford et al., 2013).

Needs Assessments

Only one study formally investigated the unmet needs of caregivers of patients with ovarian cancer (Butow et al., 2014). This investigated the last year of life, and reported that unmet needs were reported in 56% at one year before death, to 88% in the last 0-3 months (Butow et al., 2014). This study further demonstrated patterns of caregiver wellbeing declining overtime as the disease progressed.

Interventions

We did not identify intervention studies designed specifically for caregivers of patients with ovarian cancer, however the two identified case studies of a couple with ovarian cancer detailed the use of emotion focused therapy to treat couples in distress (McLean & Hales, 2010; McLean & Nissim, 2007). These studies commented on the importance of the relationship

dynamic that may be challenged by the roles of being a caregiver and care taker, and the importance of their relational and attachment histories (McLean & Hales, 2010; McLean & Nissim, 2007).

Discussion

The findings of this scoping exercise demonstrate that there is limited peer-reviewed scientific knowledge on the experiences of being a caregiver to patients with ovarian cancer. There is, however, evidence that our studied population has considerable threats to their psychosocial and physical wellbeing. Our review allowed us to gain some perspective on their experiences throughout the trajectory of the disease, although only 19 articles were identified.

Reviews of the literature on general caregiving populations have identified a lack of reviews that span the cancer disease trajectory (Revenson et al., 2016; Stenberg et al., 2010), and a need for disease-specific reviews that examine problems related to the disease and treatments (Stenberg et al., 2010). The literature examined has allowed us to begin to learn about caregivers' experiences across the trajectory of disease, from pre-diagnosis to after patient's death. These findings map out some important outcomes that future research should evaluate longitudinally within this cancer population. Specifically, our findings depict fairly stable to good wellbeing among caregivers within the first year post-diagnosis, followed by a steady decline as the patient continues to be sick and as the disease progresses. Caregivers seemed to be doing the most poorly in the last year before death. Collectively, these findings reflect ovarian cancer's aggressive nature, characterized by several consecutive important disease and treatment related events: surgery, chemotherapy, remissions, recurrences, palliative care and end-of-life.

Few correlations were found between the caregiver's wellbeing and disease-related events or patient's physical health, although the patient's mental health and wellbeing seemed to

play more of a predicting role. This was outlined especially in the longitudinal investigation by Le and colleagues (2004) that found caregiver's quality of life to be correlated with patient psychosocial variables and not physical or disease-related variables.

This review has identified caregivers' spirituality and social wellbeing to be important. These themes arose often and seemed to play a role in caregiver's overall wellbeing. Social networks of caregivers seemed to have influence on the quality of their experiences; other family members and friends are crucial for supporting these caregivers. The relationship with the medical team also was very important. Comments were both positive and negative, ranging from gratitude to the healthcare team but also disappointment, anger and frustration related to late diagnosis and limited treatment options. Caregivers often feel excluded by the healthcare team and feel they need to be better incorporated in decision-making.

Limitations

This review has some limitations that should be acknowledged. Firstly, there were four studies that we were unable to retrieve, so we were unable to consider them in our findings. It is also possible that our search formula omitted large scale studies that had a subgroup of caregivers of patients with ovarian cancer if their title, abstracts or keywords did not contain ovarian cancer-specific keywords. The scoping method does not include quality assessments of studies, as its purpose is to examine the state of the literature (Arksey & O'Malley, 2005), so we must be mindful of this when interpreting the results together. The lack of quality assessments and peer-revision in some studies implies that the highlighted results are tentative and require further study, however peer-reviewed published quantitative and qualitative literature seems to be of adequate quality. Many of the studies had both patients and caregivers, or had patients identify their caregivers, which may introduce bias to the samples examined. Participating

families also may have had a self-selection bias and may have been resilient, like for example in Koldjeski et al. (2007) where families were strong in communication, coping with unexpected events, spending time together, expressing appreciation for other members, committing to one another, and were high in spiritual wellness. These factors may limit the generalizability of studies, especially considering how aggressive and limiting ovarian cancer can be. Families of healthier patients or patients responding well to treatments may have been more inclined to participate.

Future Directions and Clinical Implications

In our review, we were unable to identify any interventions that have targeted caregivers of patients with ovarian cancer specifically, despite having identified many unmet needs in this population (Butow et al., 2014). Due to the limited research, more studies should be conducted in order to design such interventions. Our findings suggest caregivers experience less compromise in their physical health than their psychological health, so psychotherapeutic interventions may be beneficial. This may, however, be reflective of the lack of studies focused on caregiver's physical health. Of note, the general caregiving population has been found to experience various physical health compromise due to their role (Stenberg et al., 2010), suggesting it may be important to consider this further in the ovarian cancer caregiving population. There were also few studies reporting on depression or anxiety specifically, which should be explored in future studies. Due to the patterns of recurrence in ovarian cancer, research should examine more closely how the frequency of recurrences and changing treatments may influence caregiver wellbeing. This may reflect the identified pattern of quality of life declining after 18 months, which is the point by which most patients have their first recurrence (Jayson et al., 2014).

It is important for oncology teams, regardless of their discipline, to be mindful of the caregiver. If the patient has been in treatment for over a year, or if they have a prognosis of a year or less, clinicians should pay close attention to the caregivers and ask them about their own wellbeing and functioning. Additionally, if a patient with ovarian cancer reports being in distress or is suffering, caregivers may also need additional psychosocial supports as they are at an increased risk of being distressed themselves. Throughout the disease trajectory, healthcare providers can engage the patient's family by asking them about their experiences and wellbeing. Our findings suggest that some caregivers may lack adequate social supports, so demonstrating support, including them in care planning, and providing them with the information they need may be an important factor in helping to reduce their concerns and distress.

Clinicians working directly with caregivers of patients with ovarian cancer should be attentive to caregiver's overall quality of life, with particular attention to their spiritual wellbeing and to their social supports and resources as these have been identified as important for caregivers, especially late in the disease trajectory. Hospice care may additionally be beneficial not only to the patient with ovarian cancer, but to the caregiver as well, as it offers the social support and medical aid in caring that caregivers often feel overwhelmed by in the last months of life. Recent literature suggests that patients with advanced cancer are referred late in the disease trajectory to hospice and palliative care services (Wentlandt et al., 2012), which would therefore also delay the care and support caregivers typically receive from palliative care services. Between 1997 and 2007, one study found the average length of stay in inpatient hospices to be of approximately 10 days, with 20% of the patients with ovarian cancer studied being admitted in the last three days of life (Wright et al., 2014). Collectively, this evidence suggests it is important to further consider the repercussions of late referral in ovarian cancer for caregivers. The

philosophies of palliative care services in offering respite and support to caregivers thus can be highly beneficial to caregivers of patient with ovarian cancer if integrated earlier in the disease trajectory.

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Figure 1

Filtering Identified Articles

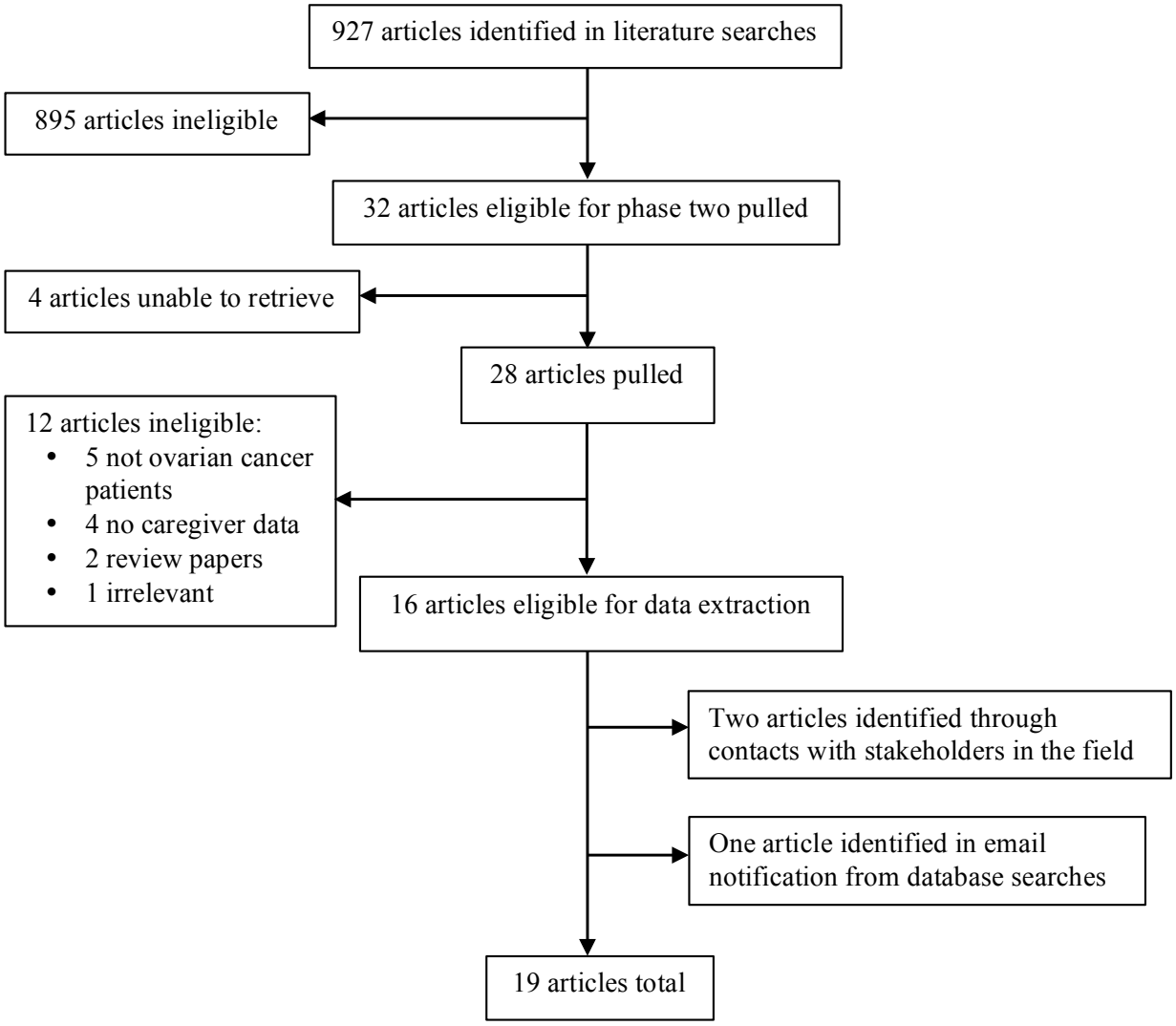

Table 1

Identified Literature

Authors & Year	Country	Type of literature & method	Disease period at recruitment & assessments	Size & demographics of OvCa CG sample	Relationship to PT	Content of results
Arden-Close et al. (2010)	UK	JA: Cross-sectional, QUANT scale validation. Administered to couples with OvCa. Substudy of an RCT.	< 5 years since last treatment. 65% advanced disease, 35% early stage. Follow ups: 3 & 6 mo	n=101. Mean age=57.8 (Range 34-79), 43% tertiary education, 32.6% a-level/technical qualification, 24.4% secondary education or lower	Partners	Couple communication and illness intrusiveness' influence on CG
Awadalla et al. (2007)	Sudan	JA: QUANT, cross-sectional questionnaire study, CG were proxies for PT QoL assessment	Outpatients seen for follow up, Dx >1 yr (mean 3.6[SD=5.2] yrs ago)	n=18. 14 (77.8%) male	Live with patient: 10 (55.6%) partners, 6 (33.3%) siblings, 1 (5.6%) parent	CG QoL compared to PT and other gynecological cancers
Beesley et al. (2011)	Australia	JA: QUANT questionnaire substudy of a longitudinal larger case-control study of PT, the Australian Ovarian Cancer Study. PT and CG completed QoL questionnaires 3 to 6 mo intervals for 2 yrs	Recruited 3-55 mo after Dx; median 19 mo. Invasive OvCa. PT: Dx 3.2 yrs earlier (range 1.5-6.0), 67% advanced disease (FIGO III-IV), 26% early (FIGO I-II), 7% unknown; 21% currently on chemo.	n=101. Mean age=58 yrs (range 22-84); 75% male, 72% spouses and 56% college or university educated (24% high school or less, 20% trade certificate, TAFE/college 22%, 35% university educated); marital status: 5% never married, 92% defacto/married, 2% separated/divorced, 1% widowed	71% partners, 21% children, 3% siblings, 5% other	Changes in physical health behaviours since PT Dx
Butow et al. (2014)	Australia	JA: See V. L. Beesley et al. (2011).	Recruited 3-55 mo after Dx with invasive OvCa (mean at baseline=31 mo since Dx), 51% on Tx. Data taken from last yr before death (baseline at 12 mo before death)	n=99 with at least one assessment in last yr of life, total of 203 assessments; mean age=59 yrs, 80% male, 78% married to PT, 37% employed, 63% lived in a major city	78% husbands, 16% children of PT, 6% in another relationship	CG QoL compared to population norms, and unmet needs assessment

Authors & Year	Country	Type of literature & method	Disease period at recruitment & assessments	Size & demographics of OvCa CG sample	Relationship to PT	Content of results
Ferrell et al. (2002)	USA	JA: Letters analysed for content: themes of letters were QUANT under subtypes and QUAL themes identified; ethnographic	Unspecified, many during Tx or survivorship phase & after PT death. Letters voluntarily sent to newsletter *"Conversations!: The international Newsletter for those Fighting Ovarian Cancer."*	n=1100 correspondences	Family CG	Correspondences written by CG about psychological, spiritual, social and physical experiences
Frost et al. (2012)	USA	JA: Longitudinal, descriptive study, QUANT questionnaires and QUAL open-ended questions and interview.	PT & CG recruited post-operatively and recently Dx, follow ups at 3, 7, 12, 18, 24 and 36 mo post-Dx. Partners could not participate if patient did not.	n=26. Mean=age 65.6[SD=12.94, 42-88], 54% unemployed; 56% protestant, 36% catholic, 7% other; 42% attended religious services 2-4 times per month.	Spouses/partners	CG QoL with large focus on spiritual wellbeing, and comparisons to PT QoL
Gates (1993)	USA	Personal account: Editor of the journal (American journal of hospice and palliative care) reports personal account of his mother having OvCa	From Dx through treatment	n=1. No demographic information	Son of PT	CG pain watching the PT suffer through disease; emphasis on importance of palliative care supports and interaction with health care team
Koldjeski et al. (2007)	USA	JA: Mixed-method longitudinal descriptive design for QUANT and QUAL data	Recruited from Dx and followed for a yr; assessments: 1-2 weeks after Dx, 6 & 12 weeks after Dx, 6 & 12 mo after Dx. Completed as a group by family members. PT: 17% stage I, 10% stage II, 56% stage III and 17% Stage IV (73% in late stage).	nf=18 families, nm=50 family members. 89% caucasian, 2% african american; 82% of members had education range of 12-16 yrs; 67% income >$25,000.	family members >18 yrs old; Spouses (45%) bore highest single burden followed by mothers, daughters & sisters (50%), then extended kin, friends & coworkers (5%)	Assessment of how families cope as CG

Authors & Year	Country	Type of literature & method	Disease period at recruitment & assessments	Size & demographics of OvCa CG sample	Relationship to PT	Content of results
Le et al. (2004)	Canada	JA: Prospective QUANT cohort of PT and CG	Recruited at the beginning of chemotherapy Tx for advanced or recurrent OvCa	Baseline n= 30 dyads; pre and post data for n=13 dyads as study terminated prematurely. 70% was first chemotherapy Tx, 30% second or more; mean age=57.43[SD=13.86, 29-8]; 28/30 were men, half working full-time; 30% spent 6-12 hours with PT; 57% spent >12 hours/day	CG identified expected to provide most support during Tx. 21 spouses, 1 daughter and 1 close friend	CG QoL compared to PT response to treatment and QoL
McLean & Nissim (2007)	Canada	JA: Two case studies of couples undergoing couples' emotion focused therapy presented in support of the new model of the intervention	6 mo after Dx of OvCa; ongoing Tx	n=1: age=44 yrs, married 12 yrs, no children	Spouse	CG-PT dyad interaction explored in therapy
McLean & Hales (2010)	Canada	JA: Case study of couple in intervention study of treatment developed for terminal cancer population	Two yrs after Dx – seen in palliative care & referred to psychosocial oncology	n=1. Husband, 30-year-old Caucasian man	Spouse	CG-PT dyad interaction explored in emotion focused therapy, with emphasis on psychosocial history's influence on current distress
Ponto & Barton (2008)	USA	JA: Semi-structured interviews were conducted by telephone with CG	Mean time since Dx=51.2 (range 10-15); 7 with no evidence of disease, 3 w/ known disease, 1 unknown; 5 Hx of recurrence, 5 no recurrence, 1 unknown; 3 currently in Tx, 8 not.	n=11 husbands, 5 recruited from advocacy organization and 6 from healthcare setting. All Caucasian and married an average of 36 years, majority employed with income of >$50,000.	Spouse/partner	CG experiences throughout the treatment trajectory; emphasis on social changes and needs

Authors & Year	Country	Type of literature & method	Disease period at recruitment & assessments	Size & demographics of OvCa CG sample	Relationship to PT	Content of results
Ponto (2010)	USA	AB: Cross-sectional, descriptive QUANT questionnaire study	Recurrent OvCa: 41% no known disease at time of study; 62.3% had 2 or more recurrences	n=32 married couples, mean age=63.9 (SD=8.9), over 50% college educated	Spouse/partner	CG psychological adjustment to disease, comparisons to PT adjustment and wellbeing
Ponto (2009)	USA	AB: Cross-sectional, descriptive QUANT questionnaire study	56% survivors had known disease or high/rising CA125, 40.6% ECOG 1.	See J. A. Ponto. (2010).	Spouse/partner	CG psychological wellbeing variables compared with PT
Price et al. (2010)	Australia	JA: See V. L. Beesley et al. (2011).	Recruited at Dx through major Tx centres & cancer registries. 70% PT Dx with stage III or IV. Dx on average 19 mo (range 3-56 mo) previously. 21% currently on Tx	CG: n=373 baseline assessments. Mean age=58 (range 20-86 yrs); 27.9% highschool only, 47.7% trade/technical, 24.4% university; 63.2% resided in a major city and 36.8% in remote areas	71.6% spouses, 18% children, 8.6% sibling/friend, 1.9% mother	CG levels of anxiety and depression compared to community norms
Tarraza & Ellerkmann (1999)	USA	JA: Questionnaires of 7 open-ended questions sent to families of deceased PT	PT deceased >1 yr ago; information documented at medical centre	n=32 questionnaires received	21 spouses, 7 daughters, 3 sisters, 1 brother.	CG reflections on their experience of OvCa after PT death
Plotti et al. (2014)	Italy	AB: QUANT data collection on demographic info, medical information and economic costs	Recruited within 4 weeks of Dx of advanced disease	n=90 CG, mean age=52.3	Not specified	Financial costs of being an OvCa CG
Fitch et al. (2013)	Canada	AB: QUAL in-depth interviews. Research question: what are experiences of and challenges these individuals face while caring for a family member with advanced OvCa	PT had died from the disease	n=13 family members or spouses	Family	CG experiences of the end-of-life of the PT and after death

Authors & Year	Country	Type of literature & method	Disease period at recruitment & assessments	Size & demographics of OvCa CG sample	Relationship to PT	Content of results
Sapsford et al. (2013)	Canada	AB: See Fitch M. I. et al. (2013)	PT had died from the disease	See Fitch M. I. et al. (2013)	Family	CG experiences of the disease trajectory, with emphasis on end-of-life of PT and after death

Note: AB=abstract; CG=caregiver; Dx=diagnosis; JA: journal article; mo=month; OvCa=ovarian cancer; QoL=quality of life; PT=patient; QUAL=qualitative method QUANT=quantitative method; SD=standard deviation; Tx=treatment; yr=year

What do Partners of Patients with Ovarian Cancer Need from the Healthcare System? An Examination of Caregiving Experiences in the Healthcare Setting and Reported Distress.

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Abstract

Purpose: Ovarian cancer is typically characterised by late-stage diagnoses, frequent recurrences, and treatment changes. Partner-caregivers of patients with ovarian cancer (CPOC) are thus heavily involved with cancer care and often are highly distressed. ***Methods:*** We explored the relationship with CPOC distress and caregiving experiences within the healthcare system and with the healthcare providers (HCP), using a cross-sectional questionnaire study. CPOC provided sociodemographic and patient medical information, and completed measures of consequences of caregiving and needs from HCP, and of depression and anxiety. We recruited through advertisements and two cancer centres. ***Results:*** *N*=82 CPOC provided complete questionnaires. Participants on average were 57.2 years old, English-speaking white men, and were partnered for 28.5 years. On average, patients were diagnosed at stage III, and treated with surgery and chemotherapy. Eight percent met clinical cut-offs for depression (23.2% in sub-clinical range), and 23.2% met clinical cut-offs for anxiety (20.7% in sub-clinical range). Depression and anxiety were significantly correlated with lacking time for social relationships, higher workload, lacking information, and needing more help from HCP. Only depression was correlated with problematic quality of information from HCP. ***Conclusions:*** CPOC distress is related to their caregiving roles within the cancer care system, and how HCP support them in their responsibilities, which may contribute to a lack of time to access their supports. Perceived involvement by the HCP has an important influence on CPOC distress. Higher demands of caregiving and insufficient support from the cancer care system may relate to increased distress. Our study supports the need for better integration of caregiver supports from within the healthcare system.

Keywords: cancer caregivers, caregiver distress, ovarian cancer, relationships with healthcare providers

What do Partners of Patients with Ovarian Cancer Need from the Healthcare System? An Examination of Caregiving Experiences in the Healthcare Setting and Reported Distress.

Ovarian Cancer

In 2019, ovarian cancer accounted for 5% of cancer deaths among women (American Cancer Society, 2019a), and its 5-year survival rate is 41% for stage III and 20% for stage IV (Torre et al., 2018). Seventy-five percent of ovarian cancers are diagnosed at an advanced stage due to a lack of effective early detection strategies (Jelovac & Armstrong, 2011). Treatments typically involve surgery, chemotherapy, and targeted drugs, often with a high risk of side effects (American Cancer Society, 2019a). As the disease progresses, treatments become limited and care increasingly becomes family members' responsibility (Herrinton et al., 2007). Research suggests that patients with ovarian cancer experience more distress than patients with other (Norton et al., 2004), and their caregivers also are highly distressed (Petricone-Westwood & Lebel, 2016; Price et al., 2010).

Caregiving for Survivors Across Disease Sites

Caregivers are heavily involved in the patient's disease management, assisting in treatment adherence, and providing emotional support (Badr & Krebs, 2013; Kent et al., 2016; Stenberg et al., 2010), typically providing 70 to 80% of patient care (Fast et al., 2002). Caregivers report prioritizing the patient's health and wellbeing over their own and struggling with self-care (Nissim et al., 2017; Revenson et al., 2016). They are equally and sometimes more distressed than patients (Braun et al., 2007; Price et al., 2010), and this distress may in part stem from unmet needs (Lambert et al., 2018). Caregivers in cancer frequently report concerns with their relationship with healthcare providers (HCP), including insufficient support in dealing with difficult feelings (Nissim et al., 2017). They report needing more help making cancer-related

decisions (Nissim et al., 2017), which is correlated with higher levels of depression and anxiety (Lambert et al., 2018).

A large sample of caregivers in cancer (*n*=590) was recently investigated to describe the caregiving experience in relation to the healthcare system (Lund et al., 2015). A third of caregivers reported poor inclusion in the patient's care, treatment and disease, and that HCP did not spend enough time providing them information. A third to half of caregivers identified that HCP infrequently showed interest in how the caregivers were feeling or whether they could handle the situation. The same proportion lacked information related to physical and psychological disease management, and did not know where to access support (Lund et al., 2015).

The significance of the caregiving role has been increasingly recognized; however, most research focuses on general cancer samples, or more prevalent tumour sites (e.g. breast and prostate; Badr & Krebs, 2013). As ovarian cancer is characterized by late diagnosis, multiple recurrences, and changes in treatment, their caregivers merit specific focus (Petricone-Westwood & Lebel, 2016). Additionally, many caregivers of patients with ovarian cancer (CPOC) are male-spouse caregivers, who are underrepresented in the literature (Kent et al., 2016).

Ovarian Cancer Caregivers

A scoping review on CPOC found that relationships with HCP influenced the caregiving experience (Petricone-Westwood & Lebel, 2016). CPOC reported needing more information from HCP throughout the disease trajectory (Stilos et al., 2018), and wanting more recognition and support from HCP (Stilos et al., 2018). CPOC have reported feeling abandoned by the cancer care team when they were not helped, and that they were passive in relation to CPOC needs (Stilos et al., 2018). CPOC often lack time to attend to all of their responsibilities and disrupted schedules due to their role (Hartnett et al., 2016; V. Lopez et al., 2012). This merits consideration

as CPOC have reported higher levels of depression and anxiety as compared to non-clinical community norms, and their distress increases over the disease trajectory (Butow et al., 2014).

Distress Related to Caregiving in the Healthcare System

North American cancer care is highly reliant on informal caregivers (American Cancer Society, 2019b; Canadian Cancer Society, 2020; Golant & Haskins, 2008), but it is unclear how the relationship between caregivers and cancer care may influence CPOC distress. Frequently rated unmet needs among caregivers are not always predictive of their distress (Lambert et al., 2018), and thus these correlations should be tested. Our objectives were thus to describe the CPOC experience of cancer care and to determine which experiences related to distress, which are defined as symptoms of depression and anxiety. To measure components of the caregiving experience, we used the Cancer Caregiving Tasks, Consequences and Needs Questionnaire (CaTCoN) which focuses on relationships with providers. It investigates the caregiver's perspective of their tasks, and any difficulties, consequences or unmet needs related to their caregiving within the cancer care system (Lund et al., 2012). It yields nine subscales: caregiving workload, lack of attention from HCPs around caregivers' wellbeing, lack of information from HCPs, lack of personal growth, lack of privacy during conversations with HCPs, lack of time for social relations, need for contact to other caregivers, need for help from HCPs, and problems with the quality of information and communication from HCPs (Lund et al., 2014).

We hypothesized that caregivers would experience high levels of depression and anxiety symptoms. We additionally hypothesized that depression and anxiety symptoms would be correlated with lacking information from the HCP (V. Lopez et al., 2012; Nissim et al., 2017; Stenberg et al., 2010; Stilos et al., 2018), lacking attention from HCP on caregiver wellbeing (Stilos et al., 2018), caregiver workload (Nissim et al., 2017; Stenberg et al., 2010), and lacking time for social relations (V. Lopez et al., 2012; Stenberg et al., 2010). The other CaTCoN

subscale were tested, but due to insufficient literature these correlational analyses were exploratory.

Methods

This analysis was part of a larger multicentre study investigating partner-caregivers of patients with ovarian cancer. The protocol for this study was approved by the Research Ethics Boards of the University of Ottawa (REB# H05-17-02), Queen's University (REB# NURS-455-18), and the University Health Network (UHN, REB# 18-5213), and is in compliance with the Canadian Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.

Recruitment

We conducted a cross-sectional, correlational investigation to include partners across the trajectory of ovarian cancer. We included partners of individuals diagnosed with all types and stages of ovarian cancer that had been treated or had reoccurred within 5 years. We included any person who was identified as a cohabitating romantic partner-caregiver (i.e. a spouse or common-law partner). Participants were required to be over 18 years of age and English- or French-speaking. We did not include partners if the patient had died as we sought to measure their experience during the caregiving period. Participants were offered an incentive of a $10 donation to Ovarian Cancer Canada or a $10 gift card to a coffee shop.

From October 2017 to August 2019, we recruited participants through advertisements in Ovarian Cancer Canada's regional and national newsletters, on their social media, and through a conference for patients and families. We circulated advertisements in cancer support centres across Canada, and in support groups in Kingston, Ontario and Calgary, Alberta. Interested participants contacted the primary author (DPW), who explained the study, determined eligibility, and sent them the questionnaire package after obtaining verbal informed consent.

When distributing the questionnaire packages, we included a copy of the consent form detailing information on the study and how we would use their information.

We introduced a second method of recruitment in January 2019. We recruited participants through two outpatient clinics. The first was the Gynecology Oncology clinic at the Cancer Centre of Southeastern Ontario (CCSEO) in Kingston, Ontario. CCSEO staff introduced the study to eligible partner-caregivers in their clinic. DPW also approached eligible participants while they attended clinic appointments with the patients. These participants provided verbal informed consent to DPW who reviewed and provided them with a copy of the consent form.

Additionally, we recruited in the Gynecology Oncology department of the Princess Margaret Cancer Centre at UHN in Toronto, Ontario. We screened surgical oncologists' clinic lists to identify individuals diagnosed with ovarian cancer who had a spouse or common-law partner mentioned in their charts. We screened a total of 929 charts and sent introductory letters to 129 patients who met our inclusion criteria. Introductory letters that were sent to patients explained the study and detailed the information that would be asked about their cancer. The letter asked patients to pass the information onto their partners if they were willing. The letter included an opt-out phone number and email contact if either patients or partners were not interested. We followed up with patients two weeks later if no one had responded to the letter. Interested participants read the consent form and provided consent by either accepting through the online form, or returning completed questionnaire packages.

Measures

We sent participants questionnaire packages through their choice of mailed paper packages or through emailed online Qualtrics surveying software. Participants from UHN were also provided a weblink they could type into a web browser.

Socio-Demographic and Medical Information

Participants provided sociodemographic information and their understanding of their partner's medical information, including the time of ovarian cancer diagnosis, treatments received, and stage of disease.

Caregiver Experiences with HCP

In order to evaluate the caregiver experience of the healthcare team, we used the CaTCoN (Lund et al., 2014). The majority of the 72 items include four response options to measure the degree to which each item applies from 0 (no problem/unmet need), 1 (slight problem/low degree of unmet needs), 2 (moderate problem/some degree of unmet needs), or 3 (highly problematic/highly unmet need), and all include a "don't know/not relevant" option, should it be irrelevant (e.g. needing time off work). A few items have Yes/No responses which are assigned a score of 0 (not a problem/not an unmet need) or 1 (problematic/unmet need), and endorsements of "yes" are followed by a similar 0 to 3 item to evaluate the severity of the unmet need or problem. All scores are transformed to range from 0 to 100 for analyses. This scale is interpreted through its 31 single items and nine separate subscales which we analyzed according to the author's instructions to determine an average score. Subscales were considered valid and attributed a score so long as half the subscale items were weightbearing (Lund et al., 2015). We report only on subscales in this study to limit type-1 error, given our inability to conduct multiple comparisons.

This tool is reported to have good psychometric properties, with high internal, convergent, and discriminant validity (Lund et al., 2014; Prue et al., 2015). Our calculated Cronbach's alphas on the CaTCoN subscales ranged from 0.66 to 0.88. The two-item subscale 'need for contact with other caregivers' had a poor Cronbach's alpha (-0.05), so we tested the inter-item correlation (Briggs & Cheek, 1986). The inter-item correlation was non-significant

(r=0.14, p=0.21, n=82). As only 12% of the sample endorsed this concern and as the subscale yielded inadequate psychometric properties, we removed it from our analyses.

Depression and Anxiety

The Hospital Anxiety and Depression Scale (HADS) was used to measure caregiver symptoms of depression and anxiety (Zigmond & Snaith, 1983). This scale has been used in several studies evaluating both patient and caregiver depression and anxiety outcomes (Mitchell et al., 2013). This self-report scale has 14-items that are equally divided into two subscales: anxiety (HADS-A) and depression (HADS-D) (Gough & Hudson, 2009; Zigmond & Snaith, 1983). The internal validity is statistically acceptable, as a good level of internal consistency was determined (HADS-A: Cronbach's α=0.85; HADS-D: Cronbach's α=0.84). Factor analyses support the two-factor structure of the HADS, and recent literature discourages the use of a total score (Lambert et al., 2011). We employed the established cut-off scores to describe distress, where 0 to 8 were considered non-clinical, 8 to 10 were considered sub-clinical and 11 to 21 were considered in the clinical range (Zigmond & Snaith, 1983).

Statistical Analyses

Only 1.43% of data was missing from participants, and therefore we used a simple imputation method for missing data. We checked the assumptions of our data to determine normality and correct for any skewness. We adjusted skewness for time since diagnosis, the HADS depression subscale, and the CaTCoN subscales lack of time for social relations, lack of privacy in discussions with healthcare providers, and needing more help from HCP.

We calculated descriptive statistics on all variables, and conducted correlational analyses, analyses of variance, or t-tests on all socio-demographic and medical variables, with the exception of gender (see table 1 for list of variables tested). Gender was excluded as we only had two women-participants. We then conducted bivariate, two-tailed correlational analyses to

determine the relationship between the CaTCoN and HADS subscale scores while controlling for any covariates. We employed a *p*-value of <0.05 for significance, and interpreted correlations according to Cohen (1988), where *r*-values of ±0.10 to ±0.29 indicated a small relationship, ±0.30 to ±0.49 indicated a moderate relationship and ±0.50 to ±1.00 indicated a strong relationship (Cohen, 1988).

Results

A total of *n*=82 participants returned questionnaires between October 2017 to August 2019. Twenty-two of the participants were recruited from advertisements, and 14 were from the CCSEO. At UHN, 54 partner-caregivers agreed to participate and were sent questionnaires, among which 46 completed the questionnaires. As 129 letters were sent, this indicates a participation rate of 35.7% for our active recruitment through UHN. We could not calculate recruitment rates for CCSEO and advertisements.

Our participants were on average 57.2 (*SD*=12.2) years old, mostly men (96.3%), mostly white (89.9%), English-speaking (91.5%), had a total household income of over $100,000 (52.5%) and had post-secondary or higher education (62.2%). One participant completed the questionnaire in French. Participants had been in their relationships with the patient for 28.5 (*SD*=14.8) years on average. Participants reported that their patient-partners had been diagnosed on average 20.8 (*SD*=28.5) months prior to completing the questionnaire. Most were diagnosed with stage III (53.9%) or stage IV (21.1%) ovarian cancer and had been treated with both surgery and chemotherapy (80.2%). Demographic information is described in Table 1.

Cancer Caregiving Tasks, Consequences and Needs

Table 2 provides further description of results on the CaTCoN subscales, including the percentage of the sample who endorsed any level of difficulty on each CaTCoN subscale (i.e. anything other than indicating all items as “no/not at all” or “don’t know/not relevant”), as well

as frequencies of subscale endorsement and mean scores. The subscales that were most frequently endorsed by our sample included caregiver workload (98%), problems with the quality and communication with HCP (95.1%), lack of information from the HCP (93.9%), lack of attention from the HCP around their wellbeing (87.8%), and lack of time for social relations (70.7%). Lack of privacy (53.6%) and needing help from HCP (36.6%) were less frequently endorsed. All caregivers reported some level of personal growth. To further describe caregivers' responses to subscales, we have reported the percentage of responses for the two most highly endorsed items within each subscale (Table 2).

Depression and Anxiety

Participants' average depression score was of 5.0 (*SD*=4.3; min=0.00, max=17.00), and 68.3% scored below the clinical range, 23.2% scored in the sub-clinical range, and 8.5% met the clinical cut-off for depression. The average anxiety score was of 7.1 (*SD*=4.2; min=0.00, max=18.00), 56.1% below the clinical range, 20.7% scored in the sub-clinical range, and 23.2% scored above the clinical range for anxiety.

Correlations

Sociodemographic Correlations

None of our sociodemographic or medical data were correlated with depression scores; however, age and recruitment method were significantly correlated with anxiety scores. Age was weakly negatively correlated with anxiety, as younger age was correlated with higher anxiety (r=-0.26; p=0.02). Using a two-tailed independent-sample t-test, we compared anxiety scores between participants of our recruitment strategies. Participants had significantly higher anxiety if they volunteered through advertisements compared to those who participated through active recruitment (M=8.9; SD=4.4, n=22 vs. M=6.45; SD=3.98, n=60; p=0.018). None of the other sociodemographic or medical variables were significantly correlated with anxiety.

Depression and Caregiving Experiences

Results of the correlations between depression and anxiety are listed in Table 3. Strong correlations were found between depression scores and lacking time for social relations (r=0.72; p<0.00), higher workload (r=0.56; p<0.00), higher lack of information from HCP (r=0.52; p<0.00). Moderate correlations were found between depression and needing more help from HCP (r=0.47; p=0.00). A weak correlation was found between depression and having problems with the quality of information and communication with HCP (r=0.26; p=0.02). Lacking attention from HCP around the caregiver's wellbeing, personal growth, and lacking privacy during conversations with HCP were not significantly correlated with depression.

Anxiety and Caregiving Experiences

We controlled for age and recruitment strategy as partial correlations with anxiety. A strong correlation was found between anxiety scores and lacking time for social relations (r=0.59; p<0.00). Moderate correlations were found between anxiety scores and needing more help from HCP (r=0.33; p=0.04), higher workload (r=0.37; p=0.00), and higher lack of information from HCP (r=0.31; p=0.01). Lacking privacy during conversation with HCP, lacking attention from HCP around the caregiver's wellbeing, having problems with the quality of information and communication with HCP and personal growth were not significantly correlated with anxiety.

Discussion

Our study sought to examine partner-caregivers of individuals with ovarian cancer and their experiences with cancer care, and how these experiences relate to symptoms of depression and anxiety. Our participants' depression scores (M=5.0; SD=4.3) and anxiety scores (M=7.1; SD=4.2), and combined clinical and subclinical prevalence rates were of 31.7% for depression and 43.9% for anxiety. These scores were above the average HADS scores identified in a large,

generalized sample of caregivers in cancer (*M*=3.80; *SD*=3.63 for depression; *M*=6.40; *SD*=4.5 for anxiety; Lambert et al., 2011). The prevalence was also higher as compared to another large sample of caregivers (*n*=444) where 15.1% of participants had sub-clinical or clinical levels of depression, and 35.8% had sub-clinical or clinical levels of anxiety, also using the HADS. These authors cited community norms of 11.4% for depression, and 33.2% for anxiety (Lambert et al., 2013).

Caregiving consequences subscales that were highly endorsed by participants included having a high workload, problems with the quality of information and communication with HCP, lack of information from HCP, lack of attention from HCP on the caregiver's wellbeing, and lack of time for social relations. Among these subscales, variables most highly correlated with both depression and anxiety were lacking of time for social relations, higher caregiving workload, and lacking information from HCP. Higher reports of problems with the quality of information and communication with HCP were correlated with depression only. Consistent with our results, CPOC studies on personal growth have found no relationship with distress (Camara et al., 2019).

Our study findings highlight important variables of the caregiving experience that may be contributing to caregiver distress. Specifically, CPOC may feel more distressed when they take on a high caregiving workload, when they believe they lack important information to adequately care for their sick partners, and when they lack time for their other relationships. This is consistent with Lazarus and Folkman's stress-coping theory (Lazarus & Folkman, 1984) that posits that coping with stressful circumstances depends on the perceived availability of resources believed to be necessary to meet the demands of the stressor. As such, caregivers will struggle to cope with their role, and will perceive it as stressful so long as the demands of caregiving outweigh the resources to provide care (Lund et al., 2012). CPOC's higher distress compared to

the general caregiving population may suggest a bigger discrepancy between the demands of care required from CPOC in outpatient treatment settings, and availability of systemic support.

Our study brings focus to ovarian cancer and men partner-caregivers, who are underrepresented in research (Kent et al., 2016), and we found them to be as distressed as the general caregiving population. HCP should consider this as men tend to avoid seeking help and minimize their symptoms (O'Brien, Hunt, et al., 2005), and clinicians tend to underestimate men's distress (Smith et al., 2018). Our study results also highlight socio-demographic considerations. Consistently with the literature, younger caregivers were more anxious than older caregivers. The minority of participants who responded to advertisements (n=22) reported significantly higher anxiety than those who participated through active recruitment (n=60). Advertisement-respondents came from across Canada, and some were from more remote areas (as disclosed by participants or inferred by DPW based on area codes). Future studies could evaluate whether anxiety increases with lack of closeness to cancer institutions, as compared to major cities with large cancer centres. It is also possible that Ovarian Cancer Canada's members may be unique, or have higher needs for support, thus increasing participation.

Limitations

We included any form of ovarian cancer in our study, including granulosa cell tumors and endometrioid adenocarcinoma of the ovary, which typically are diagnosed at earlier stages and in younger patients than serous ovarian cancers (Bouchard-Fortier et al., 2017). Our sample, however, was 75% stage III or IV with no significant differences between stages in our outcomes. Of note, we instructed participants to report their partner's medical information without consulting their partners to limit burden on the patients, and thus this information may contain error. We additionally did not collect current health status of patients (e.g. whether they were on active treatment, receiving curative or palliative treatments, had recurrences,

approaching end of life), which may have influenced caregiver's experiences of the healthcare team, as well as their distress. As the CaTCoN does not specify a recall period, it is unknown whether caregivers perhaps considered an intensive caregiving period, or reflected on their overall experiences in responding to items.

Another limitation to our sample's generalizability is that respondents were mostly of high income, white, English-speaking and highly educated, meaning many minority caregivers were not captured. This is noteworthy as among caregivers, lower income has been related to more distress and lower education has been found to relate to more unmet needs (Chambers et al., 2012). Racial minority caregivers have been found to provide more hours of care weekly and more caregiving tasks, and some non-white groups have been found to have more depression than white caregivers (Martin Pinquart & Sörensen, 2005). Systemic barriers to caregiver support in cancer care may disproportionately disadvantage less privileged caregivers (Chambers et al., 2012), for example if they cannot personally fund additional supports to help them in caring for the patient, or afford to be off work.

Our study collected subjective reports of caregiver needs, which limits our understanding of the situation, and our mostly men-participants may have underreported their needs. The homogenous sample may reflect barriers to caregiver recruitment. Our participants were both accessible through the patient, and could devote time to participation. It is plausible that the most distressed caregivers declined to participate, suggesting that our study likely underestimates OCC needs. The CaTCoN data is limited as the scale has not yet been validated in Canadian caregivers, and our data yielded poorer Cronbach's alpha scores on some subscales.

Future Directions

Future investigations should seek to examine directionality between caregiver distress and their needs. Investigations could collect multiple data sources to understand the healthcare

system's caregiver support (e.g. referrals, clinic attendance, and information from HCP or patients). Studies could investigate both environmental and personal qualities that increase caregiver distress when they perceive a lack of help from HCP. Environmental qualities include the context in which the caregiving occurs, such as availability of other supports (e.g. other family caregivers, homecare services). Internal qualities may include intrapsychic characteristics such as coping mechanisms and attachment styles. Attachment characteristics have been related to differences in caregiving experiences, particularly between men and women (Li et al., 2013). Such investigations may also help to identify caregiver support needs from HCP.

Our study highlights an understudied disease population, but neglects socio-economic, ethnic, and geographic minority caregivers. Creating networks of caregiver researchers may help with the accessibility to caregiver-participants and limit institutional barriers that are created when caregivers are not considered within the scope of the institution. Collaborative efforts could also improve minority representation in samples. Further, intentional efforts should be made to recruit and investigate specific minority populations, possibly in collaboration with community organizations or advocacy groups.

Clinical Implications

In an ideal scenario, CPOC would form a team alongside the patient's HCP: HCP provide professional care with the expectation that caregivers provide much of the rest of the care required for treatment to succeed. However, our study findings and the greater caregiver literature reflect a sentiment of inadequate collaboration from HCP in evaluating the caregiving workload and supporting the caregiver. CPOC may feel better supported by cancer care teams if they are given time to discuss their needs and ask questions. Distressed CPOC may also appraise their workloads as heavier, or be more sensitive to a lack of support from friends, family, and HCP.

Cancer care would likely benefit from formal integration of caregivers into all facets of care, and not only by psychosocial teams. Despite their essential role, CPOC are not formally recognized as part of cancer care, and our study suggests that this major chasm has a direct impact CPOC mental health. Standards of care to assess and address their needs at the outpatient-clinic level could strengthen the quality of caregiver care and research.

Declarations

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Conflict of Interest Statement: The authors confirm that there was no conflict of interest in the preparation of this manuscript.

Ethics Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the Research Ethics Board of the University of Ottawa (REB #: H05-17-02), Queen's University (REB #: NURS-455-18), and the University Health Network (UHN, REB #: 18-5213).

Consent to Participate: Informed consent was obtained from all participants in this study.

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Table 1

Demographic Variables of Participants and Medical Variables of Patient-Partners as Reported by the Participant

Characteristics	Mean (*SD*)
Age	57.2 (12.1)
Time since diagnosis (months)	20.8 (28.6)
Length of relationship with ovarian cancer patient (years)	28.5 (14.8)
Recruitment site	*n* (%)
Advertisements	22 (26.8)
Kingston General Hospital	14 (17.1)
Princess Margaret Cancer Centre	46 (56.1)
Gender	
Men	79 (97.5)
Women	2 (2.5)
Language	
English	75 (91.5)
French	1 (1.2)
Other	6 (7.3)
Education Level	
Some high school	3 (3.7)
High school diploma	10 (12.2)
Some post-secondary	18 (22.0)
Post-secondary degree	24 (29.3)
Some post-graduate	6 (7.3)
Post-graduate degree	21 (25.6)
Total household annual income	
Less than $20,000	0 (0)
$20,000-$40,000	6 (7.5)
$40,000-$60,000	9 (11.3)
$60,000-$80,000	13 (16.3)
$80,000-$100,000	10 (12.5)
Over $100,000	42 (52.5)
Race	
White	71 (89.9)
Other	8 (10.1)
Stage of ovarian cancer	
I	10 (13.2)
II	9 (11.8)
III	41 (53.9)
IV	16 (21.1)
Treatments	
Surgery	5 (6.2)
Chemotherapy	4 (4.9)
Surgery and Chemotherapy	65 (80.2)
Surgery, Radiation and Chemotherapy	7 (8.6)

Table 2

Cancer Caregiving Tasks, Consequences and Needs Questionnaire (CaTCoN) Subscales, Two Most Frequently Endorsed Items, and Descriptive Statistics

Subscale *Subscale items*[a]	*n* (%)	%	Mean (*SD*)[c]	α
Workload (5 items total)	81 (98.8)[b]		55.7 (20.5)	.69
To what extent have you had to provide practical help to the patient?				
A lot		36.6		
Some		35.4		
A little		23.2		
None		4.9		
Have you spent time transporting the patient?				
Yes, a lot		57.3		
Yes, some		25.6		
Yes, a little		11.0		
No, not at all		6.1		
Problems with the quality of information and communication with healthcare providers (7 items total)	78 (95.1)[b]		30.6 (21.1)	.88
Do you think enough time has been spent informing caregivers?				
To a high degree		18.3		
To some degree		36.6		
To a low degree		26.8		
Not at all		13.4		
Have you had to ask the health care professionals questions in order to get the information you have needed?				
Always/almost always		9.8		
Mostly		17.1		
Only sometimes		52.4		
Rarely/never		18.3		
Lack of information from healthcare providers (8 items total)	77 (93.9)[b]		38.3 (24.5)	.87
Have you as a caregiver lacked information about the best ways to help and support a person with cancer?				
To a high degree		11.0		
To some degree		36.6		
To a low degree		26.8		
Not at all		23.2		

Subscale *Subscale items*[a]	*n* (%)	%	Mean (*SD*)[c]	α
Have you as a caregiver lacked information about likely psychological reactions in a person with cancer?				
To a high degree		30.5		
To some degree		23.2		
To a low degree		23.2		
Not at all		19.5		
Lacking attention from healthcare providers around the caregiver's wellbeing (4 items total)	72 (87.8)[b]		51.8 (30.4)	.86
Have the health care professionals in the hospitals shown interest in whether you as a caregiver have been able to handle the situation?				
Always/almost always		18.3		
Mostly		23.2		
Only sometimes		18.3		
Rarely/never		34.1		
Have the health care professionals shown interest in how you have been feeling?				
Always/almost always		14.6		
Mostly		25.6		
Only sometimes		25.6		
Rarely/never		25.6		
Lack of time for social relations (2 items total)	58 (70.7)[b]		32.5 (30.5)	.83
Has the patient's cancer meant that you have not had enough time for (the rest of) your friends/acquaintances?				
Yes, a lot		12.2		
Yes, some		20.7		
Yes, a little		32.9		
No, not at all		32.9		
Has the patient's cancer meant that you have not had enough time for (the rest of) your family?				
Yes, a lot		8.5		
Yes, some		13.4		
Yes, a little		29.3		
No, not at all		46.3		
Lacking privacy during conversations with healthcare providers (2 items total)	44 (53.6)[b]		24.4 (29.8)	.66
Have the health care professionals' conversations with you (with or without the patient) taken place without being disturbed?				
Always/almost always		48.8		
Mostly		32.9		
Only sometimes		2.4		
Rarely/never		7.3		

Subscale *Subscale items*[a]	*n* (%)	%	Mean (*SD*)[c]	α
Have the health care professionals' conversations with you (with or without the patient) taken place out of the earshot of other patients and caregivers?				
Always/almost always		53.7		
Mostly		19.5		
Only sometimes		3.7		
Rarely/never		15.9		
Need help from healthcare providers (2 items total)	30 (36.6)[b]		12.8 (21.0)	.79
Have you needed help from health care professionals to find out the best way for you and the patient to handle the illness in practical terms?				
Responded yes, then asked "was need met?"		46.3		
To a high degree		17.1		
To some degree		23.2		
To a low degree		3.7		
Not at all		2.4		
Have you needed help from health care professionals to find out the best way for you and the patient to handle the illness emotionally?				
Responded yes, then asked "was need met?"		31.7		
To a high degree		4.9		
To some degree		15.9		
To a low degree		6.1		
Not at all		3.7		
Lack of personal growth (3 items total)	0 (0)[bd]		32.9 (25.1)	.77
Has the patient's cancer disease caused you to make positive changes?				
Yes, a lot		20.7		
Yes, some		37.8		
Yes, a little		28.0		
No, not at all		13.4		
Has the patient's cancer disease made you value your relationships with other people more?				
Yes, a lot		32.9		
Yes, some		31.7		
Yes, a little		26.8		
No, not at all		6.1		

[a]Two most highly endorsed items within each subscale
[b]Percentage of participants who endorsed any level of concern in this subscale, other than none/not at all
[c]CaTCoN scores were transformed on a scale of 0 to 100 to account for different item ratings
[d]All participants endorsed some form of personal growth

Table 3

Correlations between Caregiving Experiences with the Healthcare System and Depression and Anxiety Scores

	Depression			Anxiety[a]		
CaTCoN subscale	*r*	*p*	*n*[b]	*r*	*p*	*n*[b]
Caregiving workload	.56	.00	82	.37	.00	82
Lack of attention from HCP	.20	.08	78	.03	.80	78
Lack of information from HCP	.52	.00	82	.31	.01	82
Problems with quality of information from HCP	.26	.02	82	.16	.17	82
Lack of personal growth	-.06	.62	82	-.04	.70	82
Lack of time for social relations	.72	.00	81	.59	.00	81
Need help from HCP	*r*	.47			.33	
	p-value	.00			.04	
	n[b]	44			44	
Lacking privacy during conversations with HCP	*r*	.20			.15	
	p-value	.08			.22	
	n[b]	77			77	

Note. *r*=Pearson's correlations

[a]These scores were controlled for age and site

[b]*n*-values are reported as participants could respond "don't know/not relevant", in which case their scores were not considered, and bolded values indicate statistically significant correlations

An Investigation of the Moderating Effect of Attachment on Distress among Partners of Patients with Ovarian Cancer and their Relationship with the Cancer Care Providers.

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Abstract

Objective: Caregivers of patients with ovarian cancer experience distress related to difficulties with the cancer care system. Attachment insecurity is a well-known protector of distress, particularly as it relates to support from others. This study investigated whether general attachment insecurity moderated the relationship between caregiver depression and anxiety, and experiences with the patient's healthcare providers (HCP). ***Methods:*** Moderation analyses were used to evaluate the impact of attachment as part of a larger cross-sectional quantitative study of distress among caregivers of patients with ovarian cancer. Partners of patients with ovarian cancer were recruited through advertisements and two gynecology oncology outpatient clinics. ***Results*****:** *n*=82 participants completed the study. Participants were predominantly men, white, affluent and highly educated. Attachment anxiety correlated with both depression and anxiety, but attachment avoidance did not. Attachment anxiety explained a small portion of distress variance. Caregiver workload, lacking information from HCP, and lacking time for social relations due to caregiving explained a significant portion of the variance of depression. Lacking time for social relations explained a significant portion of the variance in anxiety. Attachment anxiety significantly moderated the relationship between needing more help from HCP and anxiety. Attachment avoidance significantly moderated the relationship between lacking time for social relations and both depression and anxiety. These moderating effects, however, only explained a small portion of the variance. ***Conclusions:*** Both attachment insecurity and caregiving experiences contribute to distress among caregivers of patients with ovarian cancer. Cancer care should work to recognize how caregiving responsibilities may affect caregivers' mental health.

Keywords: attachment, cancer caregivers, ovarian cancer, distress

An Investigation of the Moderating Effect of Attachment on Distress among Partners of Patients with Ovarian Cancer and their Relationship with the Cancer Care Providers.

In their lifetime, one in two Canadians will be diagnosed with cancer (Canadian Cancer Statistics Advisory Committee on Cancer Statistics, 2019), meaning a significant portion of Canadians will act as informal caregivers to these patients. It is well documented in the literature that caregivers in cancer experience significant distress (Geng et al., 2018), including symptoms of depression and anxiety, other compromises to their quality of life (Geng et al., 2018; K. D. Miller et al., 2019) and worsening of their health (V. Lopez et al., 2012). Caregivers in cancer often prioritize the health needs of their ill loved one over their own. As cancer care has advanced to outpatient treatment settings, the healthcare system has grown to depend on caregivers to support the patient and ensure treatment adherence (Golant & Haskins, 2008). Indeed, it is estimated that informal caregivers to people with chronic illnesses provide 70 to 80% of care that patients receive (Fast et al., 2002).

Efforts have been made to identify contributing factors to caregiver distress. A recent meta-analysis found prevalence rates for caregiver depression at 42%, and caregiver anxiety at 47%. They reported that among other factors, spouse-caregivers and avoidant caregivers were at greater risk of depression (Geng et al., 2018) as were younger caregivers (Geng et al., 2018; Mazanec et al., 2018). Investigations on the caregiving experience have found the relationship with healthcare providers (HCP) as important and influential for caregivers (Mazanec et al., 2018), including with decision making (Nissim et al., 2017). Caregivers often report a lack of information and resources (Hand et al., 2018; Mazanec et al., 2018; Stenberg et al., 2010), particularly related to their loved one's cancer, the provision of comfort and support, and how to maintain their own wellbeing (Hand et al., 2019).

Caregivers of patients with ovarian cancer are understudied, and face significant challenges as ovarian cancer is mostly diagnosed at a late stage, frequently recurs, and has a poor prognosis (Jayson et al., 2014; Jelovac & Armstrong, 2011). Partner-caregivers are often men, who are underrepresented in the caregiver literature (Kent et al., 2016). Their distress is often both underreported (O'Brien, Hunt, et al., 2005) and underestimated by HCP (Smith et al., 2018).

Our research team recently conducted a cross-sectional study of distress among partners of patients with ovarian cancer and different components of their relationship with HCP (Petricone-Westwood et al., 2020). This study sought to explore a breadth of factors contributing to caregiver distress as it pertains to their relationship with the healthcare team, and their experiences caregiving in the cancer care system. Symptoms of depression and anxiety were significantly correlated with lacking time for social relations due to caregiving, having a higher caregiving workload, lacking information from HCP, and needing more help from HCP. In addition, caregiver symptoms of depression were also correlated with having concerns about the quality of information and the quality of communication they had with HCP. Anxiety was correlated with being younger and having participated in the study by responding to advertisements circulated across Canada (Petricone-Westwood et al., 2020). These descriptive findings aid in understanding distress among caregivers of patients with ovarian cancer and have narrowed our focus on important factors related to the experiences of caregiving. A further exploration of the relationship between these variables was merited to elucidate how intrapersonal characteristics of caregivers may contribute to their distress.

Attachment is a highly studied construct that is well established in psychological literature and practice to influence emotion regulation, distress related to stressful events, and

mental health (Mikulincer & Shaver, 2016a). Attachment theory posits that when someone is faced with a threat, their reactions are conditioned through early relationships with parental or caregiving figures (Ainsworth et al., 1987; Bowlby, 1969). Attachment is commonly conceptualized as the intersection of two main working models: 1) the view of self (worthiness of love and care), and 2) the view of others (reliability and availability of others to provide care). These working models have been combined to create attachment *styles* (Bartholomew, 1990), however for the purposes of measurement, the working models can be conceptualized into two main *dimensions* of insecure attachment: 1) *attachment anxiety,* related to a negative view of self, including a fear of rejection and beliefs of being unworthy of care, and 2) *attachment avoidance,* related to a negative view of others, including an avoidance of dependence on others and of intimacy (Brennan et al., 1998; Feeney, 2016). Attachment can be measured as either romantic attachment, pertaining to romantic relationships, or general attachment oriented towards all relationships (Mikulincer & Shaver, 2016b).

Investigations have found that insecure attachment can result in a perceived lack of support from attachment figures and a perception that they are less responsive (Mikulincer & Shaver, 2009). Higher levels of general and romantic attachment anxiety and attachment avoidance have both been found to predict higher levels of depressive symptoms, anxiety, and a lower perceived social support among cancer caregivers (Nissen, 2016). Attachment needs are activated when there is the presence of a threat (Cassidy & Shaver, 2016), which has been widely studied in cancer (e.g. Kuscu et al., 2009; Lo et al., 2009; Nissen, 2016). HCP relationships with patients have been found to be influenced by the patient's attachment styles (Tan et al., 2005). As general attachment insecurity has an influence on perceived support and responsiveness,

general attachment insecurity among caregivers may increase distress through appraisal of the HCP as less supportive or dependable.

Objectives

Our study sought to investigate the role of general attachment insecurity on distress among caregivers of patients with ovarian cancer, and to determine whether this moderated the relationship between distress and experiences within the healthcare system. These five experiences were: 1) having a higher caregiving workload, 2) needing more help from HCP, 3) having problems with the quality of communication and information from HCP, 4) lacking information from HCP, and 5) lacking time for social relations as a result of caregiving. Our hypotheses were that among partner-caregivers of individuals with ovarian cancer:

1) Higher levels of attachment anxiety would be correlated with higher scores of depression and anxiety;
2) Higher levels of attachment avoidance would be correlated with higher scores of depression and anxiety;
3) Attachment anxiety levels would moderate the known relationships between the five variables of experiences with the healthcare system and HCP, and depression and anxiety. Specifically, higher levels of attachment anxiety would relate to a stronger relationship between experiences with the healthcare system and depression and anxiety.
4) Attachment avoidance levels would moderate the known relationships between the five variables of experiences with the healthcare system and HCP, and depression and anxiety. Specifically, higher levels of attachment avoidance would relate to a stronger

relationship between experiences with the healthcare system and depression and anxiety.

Methods

Study Design

This study's protocol was approved by the Research Ethics Boards (REB) of the University of Ottawa, Queen's University, and the University Health Network. This analysis was part of a larger cross-sectional, correlational study investigating partner-caregivers of patients with ovarian cancer and their relationships with HCP.

Participants

Partner-caregivers of individuals diagnosed with any stage of ovarian cancer were recruited. Participants were included if: 1) the patient had been diagnosed with, treated for, or had a recurrence of ovarian cancer within the last 5 years, 2) partner-caregivers were over 18 years of age, 3) they spoke and read in English or French, 4) they had met the healthcare team.

Study Setting

A thorough description of recruitment efforts is published elsewhere (Petricone-Westwood et al., 2020). Initial recruitment efforts involved the circulation of advertisements through Ovarian Cancer Canada, including through their national and regional newsletters, and through their social media (October 2017 to August 2019). Additional advertisements were posted in cancer survivorship centres across Canada, and through support groups in Kingston, Ontario and Calgary, Alberta. Active recruitment was conducted through gynecology oncology centres at the Princess Margaret Cancer Centre of the University Health Network in Toronto, Ontario (April 2019 to August 2019) and through Cancer Centre of Southeastern Ontario in

Kingston, Ontario (January 2019 to August 2019). Participants were approached through identified patients with ovarian cancer who consented to us contacting their partner-caregivers.

Questionnaires

Sociodemographic Variables

Sociodemographic variables were collected from participants and they were asked to provide their understanding of medical variables related to their partners' cancer. This included the date of diagnosis of their partner's ovarian cancer, stage of the ovarian cancer, and which treatments they had received for their ovarian cancer (i.e. surgery, chemotherapy, radiation, or combinations of these three).

Caregiving Experiences with HCP

The Cancer Caregiving Tasks, Consequences, and Needs Questionnaire **(**CaTCoN) was used to evaluate multiple facets of the caregiving experiences as part of the healthcare system. The scale measures consequences of caregiving experiences and factors related to relationships with the patient's HCP (Lund et al., 2014). For the purposes of this investigation, we utilized five of the nine subscales which were correlated with depression or anxiety in our previous analyses (Petricone-Westwood et al., 2020). They were 1) lack of time for social relations, 2) lack of information from HCP, 3) problems with the quality of information and communication from HCP, 4) needing more help from HCP, and 5) caregiver workload. Cronbach alpha's of these subscales ranged from 0.68 to 0.88. These subscales are interpreted separately (i.e. there is no total score). Subscale items are Likert-style items as well as yes/no items. Likert-style items are scored from 0 (not a concern nor unmet need) to 3 (high concern or unmet need). Yes/no items are scored either 0 (not a concern) or 1 (a concern). These items were transformed to be out of

100, and a mean score was attributed for each subscale. The authors recommend only scoring weight-bearing items, and subscale scores are continuous (Lund et al., 2014).

Depression and Anxiety

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used to measure symptoms of depression and anxiety. This 14-item scale yields two separate subscales, depression (HADS-D, 7 items) and anxiety (HADS-A, 7 items), and has been validated for use among caregivers of patients with cancer (Gough & Hudson, 2009; Lambert et al., 2011). The scale items are continuous and yield total subscale scores from 0 (no distress) to 21 (high distress). Established cut-offs for this scale are of 8 for sub-clinical distress, and 10 for clinical distress (Zigmond & Snaith, 1983). The Cronbach alpha for depression and anxiety in the sample was of 0.88 and 0.87, respectively.

Attachment Insecurity

A modified version of the Experiences in Close Relationships Scale (ECR-12; Lafontaine et al., 2016) was used to measure general attachment insecurity. This scale is a shortened version of the original 36-item Experiences in Close Relationships scale (ECR) questionnaire by Brennan, Clark, and Shaver (1998). The scale was developed to provide a continuous measure of its two subscales, attachment anxiety and attachment avoidance, as opposed to the categorical *styles* of attachment. It was originally validated to assess romantic attachment in romantic partnerships among undergraduate students, and has been validated in different populations and in different languages (Alonso-Arbiol et al., 2007; Wei et al., 2007). The ECR is one of the most frequently used tool for measuring insecure attachment (Lafontaine et al., 2016).

The ECR-12 scale has demonstrated strong psychometric properties in its romantic attachment version, including gender invariance and language invariance between English and

French (Lafontaine et al., 2016). Subscale scores are calculated through the mean Likert-item response, ranging from 1 (low/no insecure attachment) to 7 (high insecure attachment). Our scale was modified according to previously published instructions to encompass general attachment attitudes (Lo et al., 2009; Mikulincer & Shaver, 2016d), as opposed to the original questions prompting for the attachment relationship with romantic partners. For example, an item would state "I feel comfortable depending on romantic partners" which was modified to state "I feel comfortable depending on others." One item was improperly converted to the general prompt and was disregarded for the analysis, leaving a total of 11 items (item: "I tell my close relationship partners just about everything".

As this modified version of the ECR-12 has not been validated in this population, we conducted an exploratory factor analysis (EFA) using SPSS version 26. All attachment avoidance items adequately loaded onto the first factor. One item was removed from the attachment anxiety subscale due to inadequate fit and correlation with other items ("I worry a fair amount about losing others"). See footnote for the full factor analysis method and results.[1] The Cronbach alphas of our subscales were adequate (attachment anxiety: α=0.72, attachment avoidance: α=0.78).

[1] The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was of 0.64, and thus considered mediocre, however Bartlett's Test of Sphericity was rejected (p<0.01). The factor analysis could thus be interpreted despite the small sample. The 11-item EFA extracted three factors, using a criteria of an eigenvalue greater than 1 and by examining the scree plot (Tabachnick & Fidell, 2007). These three factors explained 59.54% of the variance. The avoidance subscale item loaded onto one factor, and the attachment anxiety items were divided into two sub-components of attachment anxiety: *fear of abandonment*, and *anger about separation* (Mikulincer & Shaver, 2016d). We conducted a confirmatory two-factor structure to determine which items adequately loaded onto each factor, using principle axis factoring. With this structure, 48.24% of the variance was explained by these two factors. According to Tabachnick and Fidell (2007), factor loadings of 0.32 are adequate for determining fit (0.32 are poor, 0.45 are fair, 0.55 are good, 0.63 are very good, and 0.71 are excellent). The coefficients for attachment avoidance were of 0.44, 0.50, 0.62, 0.83, and 0.88; thus all deemed adequate. The coefficients for attachment anxiety were of 0.40, 0.34, 0.79, 0.65, 0.63, and 0.44. The item "I worry a fair amount about losing others" yielded the nearly inadequate fit (0.34), and yielded a correlation lower than 0.3 with all other attachment anxiety items. This item was thus eliminated from the scale.

Analyses

Our data was entered into SPSS version 26 to conduct our analyses. Only 1.14% of our data were missing, so we conducted simple imputation for these missing data. We ran descriptive statistics on all sociodemographic, medical, predictor and outcome variables. Correlational analyses were conducted on all sociodemographic and medical variables to identify any confounding variables. Two-tailed independent-sample t-tests were used to compare any significantly differing sociodemographic categorical variables. We conducted Pearson correlational analyses to test for correlations between attachment variables, caregiving experiences subscales, and distress subscales.

Multiple hierarchical regression analyses were used to determine the explained variance of both attachment insecurity variables and variables related to caregiving experiences in cancer care on depression and anxiety. Identified sociodemographic and medical covariates were entered in the first block, and attachment avoidance and anxiety were entered in the second block. In the third and final block, we entered the five variables related to caregiving experiences: caregiver workload, needing more help from HCP, lack of information from HCP, problems with the quality of information and communication with HCP, and lack of time for social relations.

Multiple hierarchical regression analyses were also used to test for moderation and the explained variance of covariates, independent variables, and interaction effects of moderators. Attachment anxiety and attachment avoidance were separately tested as moderators between both outcome variables (depression or anxiety), and each CaTCoN subscale as the predictor variable. Any sociodemographic or medical variables that correlated with outcome variables were controlled for as covariates in the first step of the hierarchical regression.

Hayes and Rockwood (2017) argue that moderating variables do not have to be statistically related to independent variables, as per Baron and Kenny's (1986) initially proposed assumptions. Moderation models of attachment were deemed appropriate to test regardless of statistical significance of Pearson correlations between moderating variables and the predictor and outcome variables (Hayes & Rockwood, 2017). This resulted in multiple separate moderation analyses. We judged this to be best to test the hypotheses, as the subscales were not able to be combined into a single variables of distress nor of the caregiving experience. The two HADS subscales do not yield adequate psychometric properties for a total HADS score (Lambert et al., 2011), and our CaTCoN subscales were only correlated at a range of r=0.24 to 0.62, suggesting they could not be combined into one variable.

We employed a p-value of 0.05 to determine significance and confidence intervals of 95%. Given the small sample size, and the exploratory nature of this study, we did not modify our p-value with a Bonferroni correction due to the risk of Type II error. Pearson correlations were interpreted using Cohen (1992)'s method, where an r-value smaller than 0.29 was considered small, 0.30 to 0.49 were considered moderate, and 0.5 and over were considered strong (Cohen, 1992). When a significant interaction was found, we employed a simple slope analysis to assess the relationships between CaTCoN subscales and the distress outcome at: 1) low levels of attachment anxiety and avoidance (one *SD* below the mean), 2) average levels of attachment anxiety and avoidance (mean scores), and 3) high levels of attachment anxiety and avoidance (one *SD* above the mean).

Results

The sociodemographic and distress data is published elsewhere (Petricone-Westwood et al., 2020), but for adequate reporting we repeat them here. A total of 82 participants completed

the study. Participants were 97.5% men, with a mean age of 57.2 (*SD*=12.1) years of age. These participants were mostly white (89.9%), were English-speaking (91.5%), had a total household income over $100,000 (52.5%). Participants' highest level of education varied from high school diploma (12.2%), some post-secondary (22%), post-secondary degree (29.3%), some post-graduate (7.3%), or post-graduate degrees (25.6%). The average length of relationship with their partners with ovarian cancer was of 28.5 (*SD*=14.8) years. Their partners living with ovarian cancer were diagnosed on average 20.8 (*SD*=28.6) months prior to the study completion. Most partners were diagnosed at Stage III (53.9%) or IV (21.1%), and fewer at stage I (13.2%) or II (11.8%). A large majority of patient-partners were treated with both surgery and chemotherapy (80.2%). Most participants were recruited through active recruitment at the Princess Margaret Cancer Centre (56.1%), and Cancer Centre of Southeastern Ontario (17.1%), and a smaller portion responded to national advertisements (26.8%).

Correlations

Depression and Anxiety

Depression was not significantly correlated with any sociodemographic or medical variables, see Table 1. The mean depression score was of 5.0 (*SD*=4.3). In the sample, 8.5% had clinical levels of depression and 23.2% were sub-clinical. Depression was strongly correlated with caregiving workload ($r=0.56$, $p<0.001$), lack of time for social relations ($r=0.72$, $p<0.001$), lack of information from HCP ($r=0.52$, $p<0.001$); moderately correlated with needing help from HCP ($r=0.47$, $p<0.001$); and weakly correlated with problems with the quality of information from HCP ($r=0.26$, $p=0.02$), see Table 2 for all outcomes.

Participants' average anxiety score was 7.1 (*SD*=4.2). 23.2% of the sample were in the clinical range of anxiety, and 20.7% were sub-clinical. Anxiety was weakly negatively correlated

with age (r=-0.26, p=0.02), and higher anxiety was found among participants who responded to advertisements to participate, as opposed to those who were identified through active recruitment (M_{Adver}=8.9, SD_{Adver}=4.4, n_{Adver}=22 vs. M_{ActRec}=6.45, SD_{ActRec}=3.98, n_{ActRec}=60; p=0.018). In controlling for these variables, anxiety was strongly correlated with lacking time social relations (r=0.59, p<0.001), and moderately correlated with caregiving workload (r=0.37, p<0.001), lack of information from HCP (r=0.31, p=0.01), and needing help from HCP (r=0.33, p=0.04). Anxiety was not significantly correlated with having problems with the quality of communication and information from HCP (see Table 2), nor with other sociodemographic or medical variables (see Table 1).

Attachment

The mean item score for attachment avoidance was of 4.30 (SD=1.23, min=1.40, max=7.00) and for attachment anxiety was of 3.00 (SD=1.11, min=1.00, max=5.60). Cut-offs for elevated levels of attachment insecurity have been established for romantic attachment versions of the ECR-36 (Brassard et al., 2012). According to the suggested cut-offs of 2.5 (Brassard et al., 2012), 90.2% of the sample had clinically elevated attachment avoidance. The cut-off of 3.5 for attachment anxiety (Brassard et al., 2012) indicates that 34.1% of the sample reported clinically elevated attachment anxiety. Of note, these two subscales were not significantly correlated with one another (r=-0.11; p=0.35). Attachment anxiety was correlated with household income (ρ=-0.30, p=0.006), depression (r=0.28, p=0.01), anxiety (r=0.29, p=0.008). Attachment anxiety was significantly lower among participants whose partners had chemotherapy (t(79)=3.06, p=0.003; M_{Chemo}=2.90; SD=1.08, n=76 vs. $M_{NoChemo}$=4.40; SD=0.71, n=5). Attachment anxiety was not significantly correlated with any of the CaTCoN subscales. Attachment avoidance was not significantly correlated depression, anxiety, nor CaTCoN subscales.

Regression Analyses

Variance of Attachment, Caregiving Experiences as Predictors of Depression

Our linear regression model including attachment insecurity and all CaTCoN subscales on depression was significant overall and explained 65.1% of the variance in depression ($F(7,73)=19.44$, $p<0.001$, $R^2=0.65$), see Table 3. The first block of attachment insecurity variables significantly predicted 8.7% of the variance of depression. Among these two variables, only attachment anxiety significantly contributed to the model, whereas attachment avoidance did not significantly contribute to the model. The second block of variables related to the caregiving experience explained 56.4% variance. Of these five variables, reporting a lack of information from HCP, higher caregiver workload, and reporting a lack of time for social relations significantly contributed to the model. Needing more help from HCP and having problems with the quality of information and communication with HCP did not significantly contribute to depression.

Variance of Attachment, Caregiving Experiences as Predictors of Anxiety

Our linear regression model including attachment insecurity and all CaTCoN subscales on anxiety was significant overall and explained 49.8% of the variance in anxiety ($F(9,70)=7.73$, $p<0.001$, $R^2=0.50$), see Table 4. In the first block, our covariates explained 10.7% of the variance in anxiety. Recruitment type significantly contributed to the model, but age did not. In the second block, attachment insecurity variables significantly predicted an additional 10.9% of the variance of anxiety. Among these, attachment anxiety significantly contributed to the model, but attachment avoidance did not significantly contribute to the model. The third block of the caregiving experiences variables explained an additional 28.2% of the variance. Among these five variables, only having a lack of time for social relations due to caregiving significantly

contributed to the model. The other four variables did not significantly contribute to the model predicting anxiety.

Moderation Analyses with Attachment Anxiety

CaTCoN Subscales and HADS Depression

Attachment anxiety did not yield a moderating effect on the relationships the HADS depression subscale and needing help from HCP, lack of time for social relations, caregiver workload, problems with the quality of information and communication from HCP, and lacking information from HCP.

CaTCoN Subscales and HADS Anxiety

The overall model evaluating attachment anxiety as a moderator between needing more help from HCP and anxiety, while controlling for age and recruitment, was significant and explained 38.63% of the variance ($F(5,75)=9.44$, $p<0.001$, $R^2=0.39$). Covariates explained 11.6% of the variance in the model ($R^2=0.12$, $p=0.008$). Attachment anxiety yielded a main effect and explained 8.8% of the variance in anxiety ($\Delta R^2=0.09$, $p=0.005$), and needing help from HCP also demonstrated a main effect, explaining an additional 14.3% of the model ($\Delta R^2=0.14$, $p<0.001$). Attachment anxiety was found to moderate the relationship between needing more help from HCP and anxiety symptoms, but only explained 3.89% of the variance ($b=-0.04$, $t(75)=-2.18$, $p=0.032$, $\Delta R^2=0.04$). The relationship between anxiety and needing more help from HCP got stronger as attachment anxiety was lower. The effect was significant at low ($b=0.15$, $t(75)=4.37$, $p<0.001$), and moderate ($b=0.11$, $t(75)=4.55$, $p<0.001$), and high levels of attachment anxiety ($b=0.06$, $t(75)=2.05$, $p=0.044$) (see Figure 1). Attachment anxiety did not have a moderating effect on the relationship between the HADS anxiety subscale and the other CaTCoN subscales

(caregiver workload, lack of information from HCP, problems with the quality of information and communication between HCP, and lack of time for social relations).

Moderation Analyses with Attachment Avoidance

CaTCoN Subscales and Depression

The overall moderation model of lack of time for social relations predicting depression, as moderated by attachment avoidance, was significant. The model yielded a strong effect in explaining 56.25% of the variance of caregiver depression ($F(3,77)=33.00$, $p<0.001$, $R^2=0.56$). Attachment avoidance did not demonstrate a main effect on depression ($R^2=0.003$, $p=0.61$). The main effect of lacking time for social relations was significant and explained 52.0% of the variance in our model ($\Delta R^2=0.52$, $p<0.001$). Attachment avoidance was found to significantly moderate the relationship between lack of time for social relations and depression, although this explained only 3.88% of the variance ($b=0.02$, $t(77)=2.61$, $p=0.01$, $\Delta R^2=0.04$). Figure 2 demonstrates that the relationship between depression and lacking time for social relations becomes stronger as attachment avoidance increases, and this is significant at low ($b=0.08$, $t(77)=4.48$, $p<0.001$), average ($b=0.11$, $t(77)=9.45$, $p<0.001$), and high ($b=0.14$, $t(77)=8.57$, $p<0.001$) levels of attachment avoidance. The relationships between depression and other CaTCoN subscales were not significantly moderated by attachment avoidance.

CaTCoN Subscales and Anxiety

The overall model of attachment avoidance as a moderator between the lack of time for social relations and anxiety, while controlling for age and recruitment type, was significant. This model explained 44.70% of the variance of anxiety ($F(5,74)=11.96$, $p<0.001$, $R^2=0.45$). Covariates explained 10.7% of the variance ($\Delta R^2=0.11$, $p=0.013$). Attachment avoidance did not yield a significant main effect on anxiety ($\Delta R^2=0.007$, $p=0.43$). The main effect of lack of time

for social relations significantly explained 29.8% of the variance (ΔR^2=0.30, p<0.001). Attachment avoidance was found to significantly moderate the relationship between lack of time for social relations and anxiety, however this only explained 3.37% of the variance (b=0.03, t(74)=2.12, p=0.037, ΔR^2=0.03). As depicted in Figure 3, as attachment avoidance increases, so does the strength of the relationship between lacking time for social relations and anxiety. The relationships were significant at low (b=0.05, t(74)=2.19, p=0.031), average (b=0.08, t(74)=6.02, p<0.001), and high levels of attachment avoidance (b=0.11, t(74)=5.90, p<0.001).

Attachment avoidance was not found to significantly moderate the relationships between needing help from HCP, caregiver workload, problems with the quality of information and communication from HCP, and lacking information from HCP.

Discussion

This investigation sought to better understand how caregiving experiences, general attachment anxiety, and general attachment avoidance contribute to symptoms of depression and anxiety among partner-caregivers of patients with ovarian cancer. This analysis built on findings published earlier that established a connection between the caregiver's role as part of the cancer care system, and their distress (Petricone-Westwood et al., 2020). Our hierarchical regression models were significant. The analyses on depression demonstrated that having a higher caregiving workload, lacking information from HCP, and lacking time for social relations due to caregiving responsibilities contributed an important portion of the variance in depression among partners of patients with ovarian cancer. In anxiety, only lacking time for social relations due to caregiving responsibilities significantly contributed to a portion of the variance among participants. Caregiving workload and lacking of information did not significantly explain variance in anxiety, and needing more help from the HCP and having problems with the quality

of information and communication with HCP did not significantly predict neither depression nor anxiety. Lacking information is often cited as an unmet need for cancer caregivers (Hand et al., 2018, 2019; Mazanec et al., 2018; Stenberg et al., 2010), and thus these findings suggest that the need for more information and help from the healthcare team may stem from a sense of being overburdened with responsibilities of care. Additionally, these findings may suggest that the demands of caregiving likely prevent caregivers from coping strategies such as turning towards their friends and family members.

General attachment insecurity, and particularly attachment anxiety, also contributed to symptoms of depression and anxiety among these caregivers. Both general and romantic attachment insecurity is widely considered an indicator and predictor of poorer mental health and coping (Carnelley et al., 2016; Mikulincer & Shaver, 2016a), including among patients with cancer and caregivers (Nissen, 2016). As such, our study suggests that individuals who might typically have lower distress due to low levels of insecure attachment, may still experience distress depending on the context of their caregiving. Caregivers are vulnerable to distress if they do not receive the information they need from the healthcare team, or if caregiving demands prevent them from accessing their typical support systems of friends and family members.

Only a few of the alternative hypotheses around moderation were accepted. In one moderation analysis with attachment anxiety, the opposite moderation interaction was found. Attachment anxiety moderated the relationship between needing help from HCP and anxiety, as the relationship was strongest at low levels of attachment anxiety. While this explained only a minor portion of the variance, this outcome suggests that low levels of attachment anxiety may serve as a protective factor for caregivers but only to a certain point. As the caregiver increasingly needs more help from the cancer care team, the protective effects of a secure

attachment may no longer prevent heightened anxiety. These caregivers develop anxiety levels comparable to their counterparts with higher insecure attachment.

Attachment avoidance moderated the relationship between lack of time for social relations and both distress outcomes. This also represented a minor portion the distress variance. Individuals with higher attachment avoidance, as with attachment anxiety, report poorer social support, which mediates the relationship between their attachment and distress (Mikulincer & Shaver, 2009; Rodin et al., 2007; Vogel & Wei, 2005). Our findings support existing literature that caregivers with higher levels of attachment avoidance may be more likely to perceive caregiving as having impacted their social support. It is also possible that these avoidant caregivers are more distressed at a time when their partners depend on them more, which coincides with a lack of time for other relationships.

These results provide support to the *wear and tear hypothesis* of caregiving (Bass & Bowman, 1990; Townsend et al., 1989), which posits that caregivers experience poorer health and mental health outcomes due to the long-term, unabated demands of caregiving. Our study has demonstrated that while indicators of resilience such as low levels of general attachment insecurity may act as a protective factor, the demands of caregiving likely are detrimental to the caregiver's mental health, particularly as their partner's ovarian cancer progresses. Our study provides a nuanced interpretation of the needs of partner-caregivers of patients with ovarian cancer as they pertain to their attachment insecurity. There are, however, important methodological limitations to consider.

Limitations and Future Directions

ECR Scale

Our study found some unusual findings in attachment, suggesting attachment outcomes should be interpreted with caution. For one, attachment anxiety and attachment avoidance were not significantly correlated with one another. These constructs are theoretically orthogonal, however typically there is at least a low level of correlation found (Cameron et al., 2012). Additionally, 90.2% of our sample reported clinical levels of attachment avoidance, which was not significantly correlated with either depression nor anxiety.

Attachment experts state that the ECR can be modified to ask about relationships in general, on romantic partners in general, or to focus on a particular person or partner (Mikulincer & Shaver, 2016d). Recent investigations however have found that the ECR's internal consistency is higher when respondents are asked to think of a specific person (e.g. mother, father, partner) as opposed to a general sample as we did (Scharfe, 2016). This may explain why our generalized ECR yielded poorer psychometric properties ($\alpha_{anxiety}$=0.72; $\alpha_{avoidance}$=0.78) as compared to the ECR's typical alpha-coefficients that are near or above 0.90 (Mikulincer & Shaver, 2016d). Another important consideration is that our participants were likely primed to think of HCP as they had completed the CaTCoN scale prior to the ECR-12. Taken together, our modification to the ECR-12 may have compromised the scale's reliability and construct validity.

Our initial exploratory factor analysis (EFA) separated attachment anxiety into two distinct factors, resembling fear of abandonment and anger about separation (Mikulincer & Shaver, 2016d). Lo and colleagues (2009) conducted a confirmatory factor analysis on the 36-item ECR with general prompts, using a sample of patients with advanced cancer. They found poor fit on a simple two-factor model of attachment anxiety and attachment avoidance. Instead, they found a four-factor model using an EFA that identified the same distinct groups for attachment anxiety as in our analysis, plus two distinct groups for attachment avoidance. A

higher-order factor analysis subsequently demonstrated the two sought factors, similarly to what we observed, which they employed to create their 16-item general ECR measure (ECR-M16; Lo et al., 2009). This higher-order structure of the ECR-M16 was also found in a German sample of patients with advanced cancer (Philipp et al., 2017), and in an Italian sample, however the latter study identified item overlap between the second-order dimensions (Ghirardello et al., 2018). A Greek sample with advanced cancer extracted three distinct factors in their EFA on the ECR-M16 (Tsilika et al., 2016). The general ECR thus may respond differently in the context of advanced cancer, and merits additional investigation.

A major source of worry, sadness and anticipatory grief for caregivers is the poor prognosis and mortality rates in ovarian cancer. The item "I worry a fair amount about losing others" was deleted due to poor factor loading. Participants may have reflected on the possibility of losing their partners to their ovarian cancer, as opposed to a belief that they would be abandoned or left due to beliefs of unworthiness of love and care. This may be a contributing factor the distinction between the two attachment anxiety subfactors. Future studies may seek to investigate how these items are interpreted in the context of life threatening illness.

Additional Limitations

Our sample was biased from a sociodemographic perspective, being mostly white, affluent and educated men. The lack of generalizability of our sample would benefit from further efforts to recruit minority and marginalized caregivers, who likely experience more barriers to managing their caregiving roles. Further, the direction of the relationship is to be considered, as it is possible that it is distress, combined with insecure attachment, that leads to poorer appraisals of their caregiving relationships. Depending on the gynecology oncology centre where their ill partners were treated, it is possible also that there were multiple oncologists or residents involved

in care, creating further variability in who caregivers considered when responding to CaTCoN items related to their relationships with HCP.

There were no specifications around the wife's current health status (i.e. having a recurrence, active treatment, palliation, remission), or specific timeframes on the CaTCoN, which may have varied caregiver responses. Future investigations may collect more detailed information on these phases of treatment and the patient's current health status and functioning, as this may influence both demands on the caregivers and their distress. The data additionally was subjective from the caregiver's perspective, and may have differed if data were collected through other means such as through the patients or HCP, or objective measures such as referrals, clinic attendance and use of hospital resources. Future investigations may evaluate external factors such as the environment of caregivers, rotating HCP versus specifically assigned HCP, or to look at objective data such as referrals and interactions in clinic.

A limitation of our study is that we were only looking at a certain "snap-shot" in time for each caregiver, and it is likely that their experiences evolved as they went through the cancer trajectory (Revenson et al., 2016). Future investigations may evaluate how the relationships with HCP evolves overtime, particularly in ovarian cancer where there are frequent recurrences and poorer prognoses. Lastly, despite conducting several regression analyses, we did not employ a Bonferroni correction to our alpha to reduce the risk of Type 1 error given the increased risk of Type 2 error. These results thus should be interpreted with caution, particularly when *p*-values were only slightly lower than 0.05.

Conclusion

This investigation has further elucidated the high levels of distress experienced by mostly male partners of patients with ovarian cancer as it pertains to both their general attachment

insecurity, and their experiences with HCP. As the healthcare system continues to depend on caregivers, it is important to consider how this dependence may lead to an increase in caregiver distress and compromises to their quality of life. Intrapersonal considerations, such as attachment insecurity, should be considered in determining vulnerability to distress, however it essential to consider how the healthcare team can support these caregivers, regardless of their personal vulnerability.

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Table 1

Pearson Correlations between Participant Sociodemographic and Patient Medical Variables with Distress, Attachment Insecurity, and Caregiving Experiences and Consequences Outcomes

	HADS		ECR		CaTCoN				
	Depr.	Anx.	Avoid.	Anx.	Social relat.	Need help	Work-load	Lack info.	Comm. problems
Sociodemographic variables									
Recruitment type	-.15	-.26*	-.10	-.17	-.04	-.12	-.04	-.14	-.26*
Age	-.15	-.26*	.10	-.02	-.08	.03	-.02	-.22*	-.28*
Education	.07	.01	-.09	-.04	.12	.01	-.14	.30**	.02
Income	.10	-.04	.05	-.25*	.04	-.02	-.01	.27*	.04
Race	.07	.01	-.17	-.04	-.05	.03	.03	.12	.13
Length of relationship	-.19	-.04	.02	-.14	-.05	.04	-.19	-.14	-.26*
Medical variables									
Treatments	-.10	-.24*	.03	-.38**	.01	.03	.08	-.13	-.33**
Time since diagnosis	-.05	.03	-.00	.00	.04	.11	-.07	-.01	-.06
Stage of ovarian cancer	.04	.02	.05	-.04	.13	.17	.17	-.15	-.27*

*$p < 0.05$. ** $p < 0.01$.

Table 2

Pearson Correlations between All Distress, Attachment Insecurity, and Caregiving Experiences and Consequences Outcomes

	HADS		ECR		CaTCoN				
	1. Depr.	2. Anxiety	3. Avoid.	4. Anx.	5. Social relations	6. Need help	7. Work-load	8. Lack info.	9. Comm. problems
1	—	.78**	.11	.31**	.72**	.53**	.56**	.52**	.26*
2	.78**	—	.09	.37**	.59**	.45**	.37**	.38**	.26*
3	-.09	-.11	—	.10	-.12	-.08	.11	-.09	-.17
4	.31**	.37**	-.07	—	.14	.20	.17	.06	.11
5	.72**	.59**	.10	.14	—	.48**	.56**	.49**	.24*
6	.53**	.45**	.10	.20	.48**	—	.37**	.56**	.29**
7	.57**	.37**	-.10	.17	.56**	.37**	—	.28*	.08
8	.52**	.38**	.02	.06	.49**	.56**	.28*	—	.62**
9	.26*	.26*	.13	.11	.24*	.29**	.08	.62**	—

*$p < 0.05$. ** $p < 0.01$.

Table 3

Hierarchical Regression Model for Attachment Insecurity, and Caregiving Experiences in Cancer Care as Predictors of Depression

				Correlations	
Steps and Predictors	β	R^2	ΔR^2	Partial	Part
Step 1		0.09*	.09*		
Attachment anxiety	0.29**			0.29	0.29
Attachment avoidance	0.09			0.09	0.09
Step 2		0.65***	.56***		
Problems with the quality of information and communication with HCP	-0.09			-0.12	-0.07
Lack of information from HCP	0.24*			0.24	0.15
Caregiving workload	0.20*			0.26	0.16
Lack of time for social relations	0.45***			0.48	0.32
Need more help from HCP	0.10			0.13	0.80

*$p < 0.05$. ** $p < 0.01$. *** $p < 0.001$

Table 4

Hierarchical Regression Model for Age and Recruitment Type, Attachment Insecurity, and Caregiving Experiences in Cancer Care as Predictors of Anxiety

				Correlations	
Steps and Predictors	β	R^2	ΔR^2	Partial	Part
Step 1		0.11*	0.11**		
Age	-0.21			-0.21	-0.20
Recruitment type	-0.22*			-0.23	-0.22
Step 2		0.22**	0.11**		
Attachment anxiety	0.33*			0.34	0.32
Attachment avoidance	0.15			0.16	0.14
Step 3		.50***	.28***		
Problems with the quality of information and communication with HCP	-0.04			-0.04	-0.03
Lack of information from HCP	-0.02			-0.02	-0.01
Caregiving workload	0.03			0.03	0.02
Lack of time for social relations	0.43***			0.40	0.31
Need more help from HCP	0.20			0.21	0.15

*$p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Figure 1

Moderating Effect of Attachment Anxiety on Relationship between Needing More Help from HCP and Anxiety

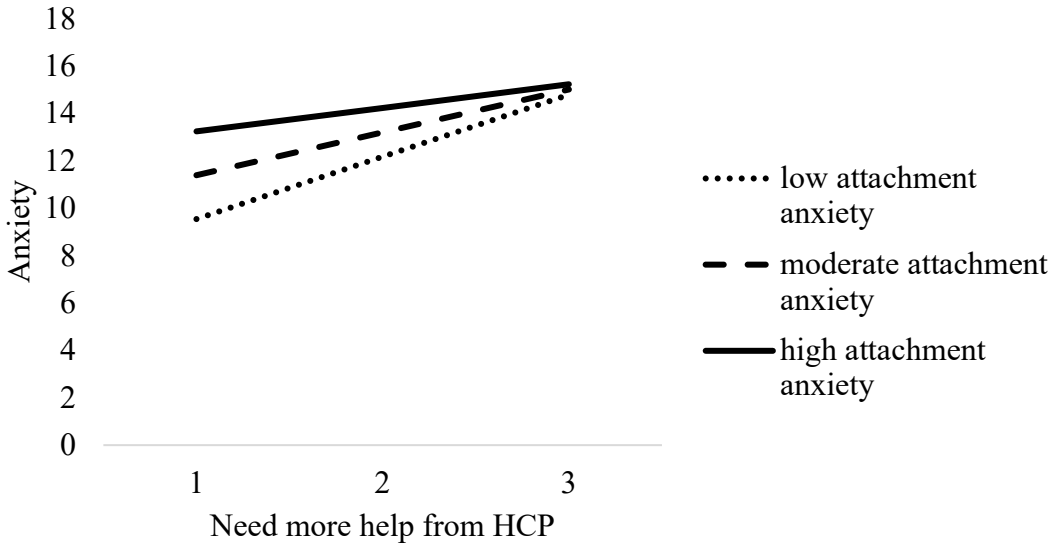


Figure 2

Moderating Effect of Attachment Avoidance on Lack of Time for Social Relations and Depression

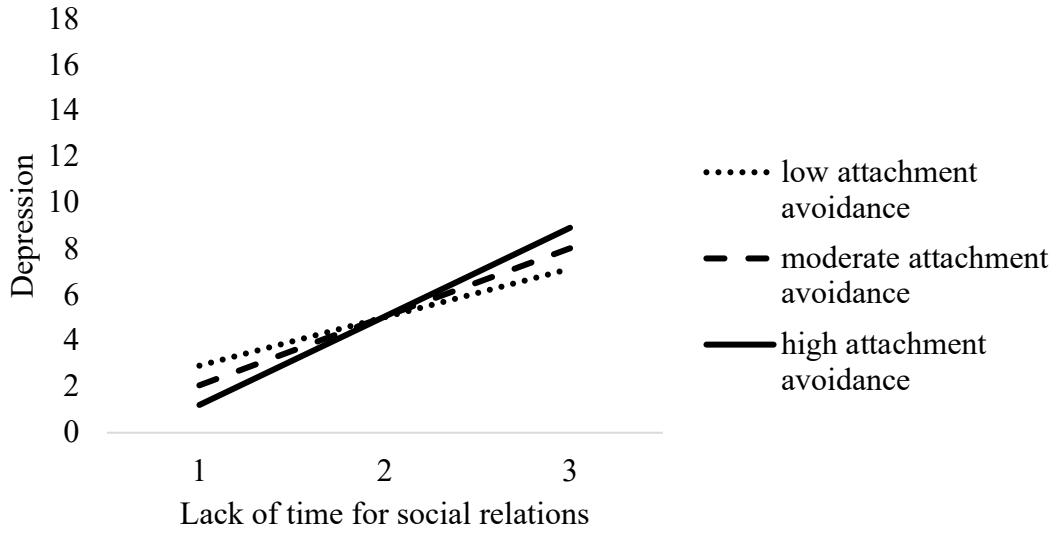
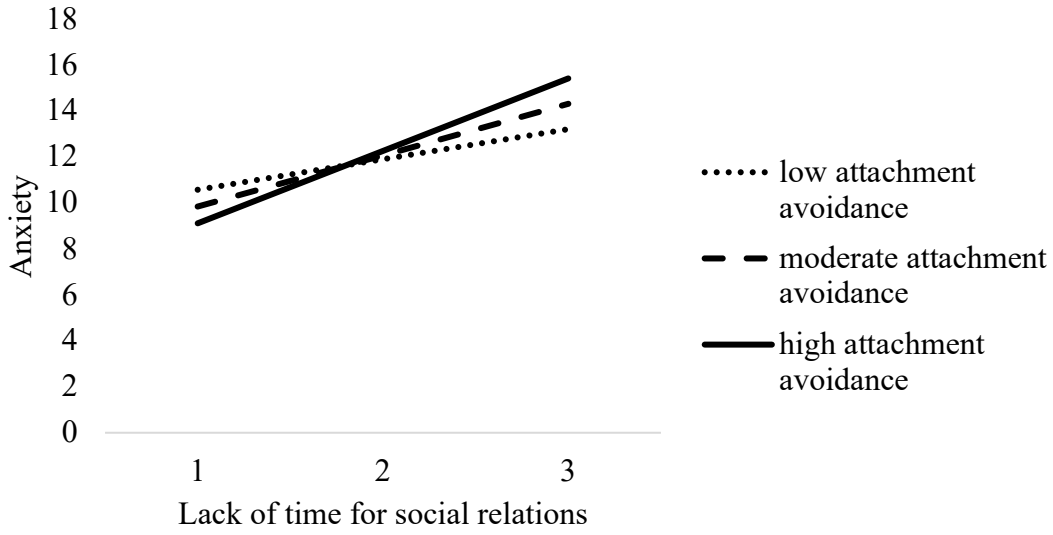


Figure 3

Moderating Effect of Attachment Avoidance on Relationship between Lack of Time for Social Relations and Anxiety



General Discussion

Summary of Research

This dissertation sought to investigate the understudied experiences of caregivers of individuals with ovarian cancer due to its unique nature and poor prognosis. Their partner-caregivers are often male- or men-identifying, who additionally are underrepresented in the general oncology caregiving literature, but may be both highly distressed and under-supported by the healthcare team. We employed attachment theory to help us to understand characteristics of the caregiver that may also contribute to their caregiving distress and experiences.

Study 1

We initiated this investigation by conducting a scoping review in order to describe the state of existing literature and knowledge on all informal caregivers of patients with ovarian cancer. This review confirmed that this specific and unique group of caregivers were largely underrepresented in the literature, with only 19 studies identified. A theme was identified with higher quality of life and lower symptoms of depression and anxiety found in the first year post-diagnosis, with a slow progression to poorer outcomes over the disease trajectory.

Through both qualitative and quantitative investigations, we identified another theme of studies citing unmet needs or concerns regarding the relationship with the healthcare team, including wanting to be recognized and offered more support. In contrast, positive caregiving experiences were noted from palliative care teams who offered support for the advanced disease and for caregiver bereavement. As such, we sought to further explore this theme to identify whether elements of the healthcare team might correlate with symptoms of depression and anxiety among these partners-caregivers. Given the intensity of care for ovarian cancer and changes in treatment related to progression, patients with ovarian cancer and their partners

depend heavily on the cancer care team. These findings led to the conceptualization of Studies 2 and 3.

Study 2

Using a cross-sectional correlational questionnaire study design, we recruited partner-caregivers across Canada through advertisements and in two Ontarian tertiary gynecology-oncology clinics to complete single-time questionnaires. Our second study identified that partner-caregivers had significant levels of depression and particularly anxiety, and the most highly endorsed concerns regarding caregiving were having a high caregiver workload, having problems with the quality of information and communication with healthcare providers (HCP), lacking information from HCP, lacking attention from HCP, and lacking time for social relations, i.e. other family members or friends, due to caregiving. Distress outcomes were correlated with certain, but not all characteristics of the relationship with the healthcare team or experiences caregiving as part of the oncology institutions. Having a higher caregiving workload, needing more help from HCP, having a lack of information from HCP, and lacking time for social relations, were all correlated with both depression and anxiety. Only depression was correlated with having problems with the quality of information and communication with HCP. Interestingly, having a lack of attention from HCP regarding how the caregiver was coping and handling the situation was not significantly correlated with distress, despite our hypothesis that it would. Lacking personal growth, needing more contact with other caregivers, and lacking privacy when communicating with the healthcare team were not significantly correlated with distress. These exploratory findings allowed us to narrow our focus on the caregiving experiences that related to caregiver distress, but had yet to understand how individual caregivers may be predisposed or at higher risk of distress as it pertains to support from the cancer care

team.

Study 3

Study 3 used attachment theory to investigate the established connection between caregivers' distress and involvements with the cancer care team in their caregiving tasks. We used the same sample to test whether general attachment anxiety and general attachment avoidance contributed to the variance in distress, and whether it moderated the relationship between caregiving experiences with the healthcare system and distress, given attachment insecurities influence on perceptions of social support. Despite our hypotheses, attachment insecurity only explained a small portion of the variance in distress. Attachment anxiety moderated only the relationship between needing more help from HCP and anxiety, and attachment avoidance moderated the relationships between lacking time for social relations and both distress outcomes. Our regression analyses demonstrated that the variables related to the caregiving experience explained most of the variance in depression and that lacking time for social relations explained most of the variance in anxiety amongst the caregivers.

Contributions of Thesis Research

Taken together, this thesis research has made an important contribution to the literature on caregivers of patients with ovarian cancer. This small population of caregivers is neglected in research, but in the present sample, were found to be both experiencing distress and lacking the support they need from the healthcare system. Low attachment insecurity served as a protective factor for distress, but overall did not yield the effect we anticipated in contributing to caregiver distress. Instead, our studies have demonstrated that the tasks of caregiving as part of the healthcare system explained a significant portion of their symptoms of depression and anxiety. Regardless of individual attachment, if the caregivers' workload, lack of information, and lack of

access to their support network is high enough, their roles as caregivers will have a deleterious effect on their mental health, in addition to the already distressing reality that their life partners may die from their disease.

Two predominant hypotheses are recognized as underlying the general caregiver literature in chronic illness; namely the wear and tear hypothesis and the adaptation hypothesis (Revenson et al., 2016). Experts in caregiving suggest that the adaptation hypothesis is most often supported by literature on caregivers with chronic illness, however this thesis supports both the wear and tear hypothesis and the adaptation hypothesis. Our first study found that caregiver wellbeing improved from diagnosis to 18 months. However, after approximately 18 months, there was an increase in unmet needs and distress as the patient's condition declined. Additionally, the limited protective nature of attachment suggests that with time, caregivers may become more and more depleted through the caregiving experience, particularly as the patient's health likely declines. We measured time since diagnosis, and this did not significantly correlate with our outcomes, however there may be interacting effects based on the severity and symptomology at time of diagnosis, and how the disease progresses. For example, surgeries typically are the first line of treatment, then chemotherapy, but at times chemotherapy is prescribed first. After recurrence, patients could be offered more surgery, more chemotherapy, or both (Lheureux et al., 2019). Treatments vary widely in effectiveness, complications or toxicities (Lheureux et al., 2019), suggesting there are fluctuations in patient wellbeing. As such, a linear correlation between wellbeing and time since diagnosis may miss the deleterious effects of ongoing treatment. Longitudinal investigations could compare caregiver outcomes with these treatments, patient responses, treatment side effects, and care demands involved with different disease milestones.

The reviewed literature suggested that the caregivers need to feel better attended to by the HCP (Lund et al., 2015; Nissim et al., 2017), however in our investigation, lacking attention from HCP was not predictive of symptoms of depression or anxiety. Instead, it seems that more practical help and missing assistance was more responsible for contributing to distress amongst caregivers. Consistent with other literature, lacking of information was both highly reported and a predominant contributor to distress (Hand et al., 2018; Mazanec et al., 2018; Wang et al., 2018).

The proposed *secure-base scripts* (Mikulincer et al., 2009) seems to reflect some relational needs of caregivers from HCP: caregivers want the healthcare team to respond to them in their roles as the person most responsible for their partner's health and survival. When unexpected symptoms or complications arise, caregivers may be less distressed if they can trust that the team will address the issue as the experts on the disease and those prescribing treatment. Without this assurance, however, caregivers may become increasingly preoccupied by a lack of availability of resources to address such ovarian cancer-related threats. An important distinction between traditional attachment needs and this context is that the caregiver wants the team to address issues related to the cancer specifically, as opposed to their general wellbeing overall, as would an attachment figure. Such nuances are important to consider as we study attachment theory in the context of advanced cancer caregiving.

Our findings on attachment were somewhat distinct from the existing literature. For example, using proposed normative cut-offs (Brassard et al., 2012), a very large portion of our sample reported elevated levels of attachment avoidance, which was not significantly correlated with distress. Attachment anxiety is well established to predict distress (Dagan et al., 2018; Mikulincer & Shaver, 2016c; Nissen, 2016; Simpson & Rholes, 2012), consistent with our

findings. Attachment avoidance has also been established to predict distress (Mikulincer & Shaver, 2016c; Nissen, 2016), however there are more often mixed findings with avoidance (Dagan et al., 2018; Mikulincer & Shaver, 2016c). Attachment avoidance is characterized by a deactivation of emotional needs and down regulation of emotions in an effort to distance themselves from others, resulting in lower reports of distress while simultaneously demonstrating physiological activation (Mikulincer & Shaver, 2016c). In sustained stressful situations, however, Mikulincer and Shaver (2016) propose that the attachment avoidance activation eventually collapses, leading to distress equivalent to individuals with high attachment anxiety.

The implicit nature of emotional suppression, particularly in a study that may have heightened distressing thoughts related to their sick partner's cancer, may have contributed to both higher reports of attachment avoidance but possibly underreporting of distress. As discussed in Study 3, there are also many measurement precautions around interpreting these results. One meta-analysis examining the relationship between depression and attachment as measured by the Adult Attachment Interview found that insecure-dismissive attachment (similar to attachment avoidance) only yielded significantly higher depression scores than securely attached participants in studies that used dimensional scores of the AAI as opposed to categorical scores (Dagan et al., 2018). Taken together, the measurement and study of attachment in advanced cancer needs further refinement and exploration to distinguish the interacting components of attachment activation, grief, and intensive caregiving experiences.

Younger age among caregivers was correlated with more anxiety in our sample, which is consistent with most literature. Among patients with ovarian cancer, individuals with recurrent or advanced disease and younger patients have been found to be most distressed (Norton et al., 2004; Roland et al., 2013), and more affected by concerns related to infertility and sexual health

(Trivers et al., 2013). This is consistent with literature that younger caregivers, too, are more distressed (Geng et al., 2018; Northouse & McCorkle, 2015). Interestingly, though, in our regression analyses, age was no longer a contributing factor to the model that included recruitment type, attachment dimensions, and variables related to the caregiving experience.

Strengths

Our studies had strengths that allowed to further understand the experiences of caregivers of individuals with ovarian cancer. Many studies had to be excluded from the scoping review because they combined ovarian cancer with other diseases, including gynecological diseases like uterine or cervical which have notably better prognoses (Canadian Cancer Statistics Advisory Committee on Cancer Statistics, 2019), or because the caregiver data was not separated from the patient data. This demonstrates how often the caregiver experience may be missed when they are combined with other samples, and our studies allowed to elucidate their experiences. While our sample was modest in size, it is strengthened by its exclusive focus on partner-caregivers of patients with ovarian cancer, unlike many studies reported in the scoping review. Our sample size was comparable to the quantitative studies reported in our scoping review, among which five studies recruited 50 or fewer participants, one study had a sample of 90, another of 101, and three investigations from the same study reported samples of 99, 101, and 373, respectively. This cohort was a quality of life subsection of a 3.5-year long population-based cohort trial conducted across Australia (n=627 patients with ovarian cancer; Jordan et al., 2007). Further, a review on survivors of ovarian cancer had participants who were on average seven years post-diagnosis (Trivers et al., 2013), meaning much of the literature was not representative given the 5- and 10-year survival rates of 45% and 36%, respectively (Canadian Cancer Statistics Advisory Committee on Cancer Statistics, 2019). Our caregiver participants reported that their partners on

average were 1.7 years (*SD*=2.3) post-diagnosis. Our study thus was strengthened by limiting recruitment to include those who were closer to diagnosis and thus likely more representative of the general ovarian cancer experience.

Employing the Cancer Caregiving Tasks, Consequences and Needs Questionnaire (CaTCoN) provided a nuanced description of caregiving needs as they pertain to their essential roles as part of the cancer care system, and their interactions with the healthcare team (Lund et al., 2012). This measure allowed us to compare different elements of the caregiving experience, as opposed to the existing quantitative literature that alludes to or mentions the healthcare team, but does not distinguish, for example, between needing more help from HCP and needing more attention regarding their wellbeing. The subscale pertaining to lacking time for social relations explicitly asks caregivers if this was as a result of their caregiving responsibility. This specification is a minor but important distinction from lacking social support in general, which is known to relate to both increased distress and attachment insecurity (Nissen, 2016). We additionally chose two widely used measures for our outcomes, the Hospital Anxiety and Depression Scale (HADS), and the Experiences in Close Relationships Scale (ECR), which allowed our study findings to easily be compared against other studies in the literature.

Limitations

Measurement and Study Design

Given the intensive period of caregiving, we made significant efforts to limit the burden on caregivers completing the study and the patients who were asked to identify a partner-caregiver. We thus only asked participants to complete a one-time questionnaire study, however a longitudinal evaluation would have furthered our understanding of changes overtime. To limit burden on patients and increase accessibility to caregiver-participants, caregivers were asked to

report their understanding of patient medical data, which may have yielded some error. We additionally did not include many variables related to the patient's functioning, treatment history, or recurrences. We used open-ended responses for race and gender, so participants could indicate how they identified, but this meant at times yielding unclear or blank responses.

The measures we employed have some limitations that should be considered. It important to consider that the ECR does not encompass the entire scope of possible anxiety and avoidance dimensions, and does not align with Bartholomew's four-category model of attachment (Scharfe, 2016). This limits its generalizability to attachment studies employing other measures. Attachment typically is conceptualized in four attachment styles (Bartholomew, 1990), including fearful-avoidant attachment styles with high attachment avoidance and high attachment anxiety. Fearful-avoidant styles are often related to more distress (Mikulincer & Shaver, 2016c), but we did not examine low and high combinations of both attachment dimensions predicted distress.

The HADS is a widely used measure in psychosocial oncology and health psychology, including with caregivers. There are however some criticisms of the factor loading on the HADS to be able to truly distinguish symptoms of depression and anxiety (Cosco et al., 2012; Coyne & van Sonderen, 2012; Zakrzewska, 2012) because of mixed results evaluating the latent structures of the measures (Cosco et al., 2012). However, articles have supported its use as a screening tool (Bjelland et al., 2002; Mitchell et al., 2010), and it has been validated for use in a sample of caregivers (Lambert et al., 2011). The authors of the HADS recognize that this tool should not be used as a diagnostic tool (Zigmond & Snaith, 1983). Alternative measures that could be used include the Centre for Epidemiological Studies Depression scale (Radloff, 1977), which is often used in psychosocial oncology research, and has been used to measure depressive symptoms in caregivers in cancer (Geng et al., 2018). The Generalized Anxiety Disorder- 7 item scale (Spitzer

et al., 2006) is an alternative measure that has been used in studying anxiety in patients with cancer (e.g. Rodin et al., 2018) and caregivers (e.g. Ullrich et al., 2017).

Finally, the CaTCoN was an ideal measure for our purposes as it described many components of the caregiving experiences, including with the healthcare team in general. This measure however did not account for specific differences between providers. As we recruited from tertiary care clinics in teaching hospitals, it is possible that some of our participants had encountered multiple physicians and residents throughout their partner's ovarian cancer experience. Additionally, we did not consider whether the caregiving role was shared with other family members, and so the caregiving responsibilities on the spouse may have varied.

Analyses and Models Tested

Our study was exploratory and our regression models were theoretically conceptualized to understand how these caregiving experiences and attachment insecurity influenced distress. It would be important however to consider how distress may have predicted the reports of unmet needs related to the caregiving experience, perceiving a higher caregiving workload, and feeling more pressure. Further, we tested multiple models without employing a Bonferroni correction. The minor variance found for moderation effects thus should be interpreted with caution, particularly as the predictor and outcome variables were not always correlated.

Recruitment and Inclusion Criteria

Ovarian cancers medically encompass various heterogenous diseases that differ in pathology, specific tumor location, risk factors, prognosis, and treatment (Torre et al., 2018). Participants with any form of ovarian cancer were included, including those with granulosa cell tumors and endometrioid adenocarcinoma of the ovary. In comparison to serous ovarian cancer, endometrioid adenocarcinoma of the ovary tends to have better prognoses, is diagnosed in earlier

stages, and is typically diagnosed at a younger age (Bouchard-Fortier et al., 2017). In a cohort study of 533 patients with both histological presentations, 83.7% of endometrioid adenocarcinoma of the ovary were diagnosed in stage I or II, while 86.2% of the serous ovarian cancers were diagnosed in stage III or IV. For these reasons, we determined it would be adequate to control for disease staging to allow us to capture the outcome differences between low and high stages of ovarian cancer. Seventy-five percent of our sample, however, was diagnosed with stage III or IV disease, and there were no significant differences between stages. Further research may collect this information in order to determine how different histological presentations may distinguish experiences of caregiving.

Although we aimed to make the study questionnaires brief and accessible, caregivers who were experiencing burnout or exhaustion from caregiving duties may have been less inclined to participate. It is possible that caregivers who have positive relationships with HCP and the cancer care institution were more willing to participate. Recruitment through Ovarian Cancer Canada may have mitigated this bias, as seen by the discrepancies in distress scores, but those participants were a smaller portion of our participants. Research on clinical trial participation has found that patients with cancer are more likely to participate in trials if they were asked to participate by a trusted healthcare provider (Bell & Balneaves, 2015), which further suggests a limitation of our study and in cancer caregiving research in general.

Future Directions

An important consideration of our findings is that data in the scoping review and both cross-sectional studies collected only the perspective of the caregiver. Future studies may evaluate characteristics of HCP and how this may contribute to variance in caregiver distress. For example, healthcare provider attachment insecurity, attention given to caregivers, values of

including the family caregivers in care, communication ability, and time spent with patients and family per visit may contribute important considerations to this research.

Future research may investigate the relationship with HCP across all caregivers in cancer. It should be investigated to see if other variables influence the strength of this relationship, such as the dependence on the healthcare team, or duration of care. It would also be important to consider if different healthcare practitioners have different influences on the caregivers (for example, nurses, oncologists, social workers) due to their differing role in information provision, care, and social support, or if multidisciplinary teams influence outcomes.

As was highlighted by our scoping review, several areas still remain to be investigated to gain more insight on experiences of caregivers in ovarian cancer. Future research on caregiver wellbeing could be conducted longitudinally, to follow the distress levels of caregivers overtime, and to further test the *wear and tear* hypothesis. Such research can also monitor disease-specific events, such as the first or subsequent recurrences, when the disease becomes platinum-resistant, when patients enter a survivorship phase, or as they begin to receive end-of-life care. This would also allow for studies to account for drop out and attrition related to these variables. Structural equation modeling may be beneficial in these investigations to understand the relationship between the investigated variables in the model, particularly to integrate general or romantic attachment insecurity and how different caregiving responsibilities and unmet needs may influence one another. Such a model could examine interacting effects related to time since diagnosis, severity of illness and related events, and objective caregiving responsibilities and tasks, in order to situate the caregiver in the disease trajectory. This would require a larger sample size, however, and may be better suited for a general sample of cancer caregivers.

Additionally, we measured attachment insecurity using the prompt of general

relationships, as opposed to their sick partners. As discussed in Study 3, this may have affected the reliability of the measure. This also means that we did not account for romantic attachment insecurity as it pertains to their attachment figure, the partner with ovarian cancer. Future attachment investigations may study how ovarian cancer affects the patient's capacity to reciprocally support the caregiver, as well as the threat that the ovarian cancer will likely take their partner's lives. Attachment to the patient should be accounted for in other future studies to clarify how the attachment system may be activated in this trying time for a couple facing ovarian cancer.

Indeed, developing and testing models involving the patient and caregiver couple, or systemic models additionally involving healthcare providers would allow for a more comprehensive understanding of attachment in cancer care. For example, models of dyadic coping and attachment may be designed as they pertain to the caregiving experiences with the healthcare system in having both the patients and partner-caregivers respond to perceptions of the types of support they receive from the cancer care team and perceived unmet needs. By using structural equation modeling, we can evaluate the interacting effects of one partner's romantic attachment insecurity, distress, and unmet needs related to the healthcare team may provide. Additionally, systemic studies of the effectiveness of a healthcare team and a caregiver or patient's perception of their dependability, in addition to their general attachment insecurity levels, may further elucidate how attachment-related constructs such a depending on others may be heightened be cancer care team's capacity to communicate effectively and work as a team.

It is encouraging that so much research is being conducted on patients with ovarian cancer through medical trials and quality of life research. Medical and psychosocial researchers are encouraged to collaborate, and to consider adding study arms investigating partners, in order

to continue to grow this research and understand the caregiving role in their research questions.

Clinical Implications

Collectively, our studies bolster the argument for more accessible caregiver support from the cancer care system. Some meta-analyses have examined how caregivers, patients, and caregiver-patient dyads benefit from psychotherapeutic intervention, however they report only small to medium effect sizes and several methodological limitations (Kent et al., 2016). Among caregivers, the effect sizes were typically stronger for benefit finding, coping and knowledge, and moderate effects were found for self-efficacy, relationships with the patients, and their physical wellbeing (Kent et al., 2016). A recent multi-state American study on caregivers of older adults with cancer found that a large portion of these caregivers were highly interested in receiving support. The study found however that among those who wanted services, only approximately half had received any (Dionne-Odom et al., 2018). Predictors of the use of support services included being a family member other than a spouse to the patient, feeling that the caregiving role did not disrupt a significant portion of their lives, and feeling prepared for the caregiving role (Dionne-Odom et al., 2018). Additionally, a combination of neglecting self-care and lacking time have been named as barriers to caregivers attending support services (Nissim et al., 2017). Caregivers with less severe distress and less caregiving demands thus may be most appropriate for psychosocial services and as such, there is a window of opportunity to support these caregivers. For those who are more burdened however, alternative measures are needed.

Caregivers of gynecological cancer patients have reported wanting convenient resources accessible online or through guidebooks and 24/7 support lines so that a provider can be available in the difficult caregiving moments (Hand et al., 2018). They requested integrative services for caregiver in the healthcare system, training on how to provide care, and an assigned

caregiver-navigator to help the caregiver with the system (Hand et al., 2019). Caregivers have asked that HCP more routinely screen them for distress and offer them support resources (Nissim et al., 2017). Certain challenges, however, have been identified when considering how to integrate caregivers into the healthcare system, including a lack of financial capacity for medical billing or insurance, limitations on licensure, constraints in the organization, and staff turnover (Kent et al., 2016). Institutions have begun to implement important psychosocial caregiver supports, including a clinic dedicated to caregivers (Nissim, 2020), however more efforts are required at an institutional and systemic level to properly mandate caregiver support.

Psychosocial oncology clinicians play a role in providing psychotherapeutic support to caregivers and their family members. In addition to their clinical roles, however, clinicians can also act as advocates for the caregiver within the cancer centre. As members of the healthcare team, they can communicate with the cancer care team around the caregiver's concerns and unmet needs. They can additionally advocate for systemic changes to cancer care practices to palliate how much is asked of caregivers in terms of their caregiving workload and lack of practical support from the healthcare team.

Systemic Implications

The sample size accrued over two years of recruitment efforts is reflective of institutional barriers to caregiver research in the field. Some institutions could not house our research, as caregivers of patients were not considered to be within their mandate of care. In institutions where caregiver research was permitted, consent from patients was needed to contact caregivers. These patients, however, were already asked to participate in many studies (for example, one clinic indicated that patients with ovarian cancer were approached for eight medical trials in their initial consult). Our study design thus required several complex considerations around how to

recruit the caregiver through patients with ovarian cancer while trying to limit additional burden on them. Indeed, most caregiver research is contingent on patients granting access to their caregivers, meaning our sample was impacted by a common bias present in many caregiver studies. Patients may be overwhelmed or burdened by research project requests, or may be too unwell and focused on their recovery. Consequently, this may deter them from participating or deter the research staff from approaching them for participation. This poses a barrier to accessing caregivers who may be struggling the most as their partners are so unwell.

Our study was thus limited by the cancer care system design: we were trying to conduct research from *within* the medical system on individuals *beyond* the medical system's scope of practice. Caregivers are a fundamental part of cancer care, but they are not formally considered to be users of the medical system. Caregivers are thus left with the responsibility of ensuring their loved ones get all the care they need to fight their disease, but need to do so as an "outsider." This systemic chasm brings forward an important question: of the caregivers we do study, how many of them have partners who are more open, doing well, or are particularly considerate of their partners in the cancer trajectory? If our findings are based on caregivers who are coping more favorably, or who feel considered by the healthcare team, we likely do not have caregiver research that truly represents the population. Resultingly, this may undermine the necessity to implement and dedicate institutional supports to caregivers.

Cancer care institutions could begin to better support caregivers by systematically providing them with their own independent medical records, as they do with patients. This would not only allow more direct access to caregivers, but also would signal that the institution recognizes them as important individuals in the cancer care process who are worthy of attention, resources, and care. This may also circumvent other commonly reported problems such as giving

caregivers space to ask their questions, and providing HCP a confidential space to document communications with these caregivers. Researchers have encouraged rethinking how we access minority, high risk, and vulnerable caregivers (Ugalde et al., 2020), and recommended the development of policy and clinical practices that better serve these individuals (Ugalde et al., 2020). This standardized integration of caregivers into cancer care may therefore be a first step to allow both research and clinical efforts to reach marginalized and underserved caregivers.

Conclusion

In conclusion, this thesis sought to study the experiences of caregivers of individuals affected by ovarian cancer, a unique and challenging form of cancer. This group of caregivers merit specific focus and further investigation as identified by their high levels of distress and unmet needs as they pertain to their cancer caregiving experiences. Attachment theory suggested some explanation as to why caregivers need better support from the healthcare team, however the burden of care put on caregivers by cancer care institutions seem to play a more significant role. Individual psychosocial support for caregivers is important, however systemic and institutional supports for caregiver are recommended to improve the wellbeing of caregivers supporting their loved one with ovarian cancer.

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Appendix A

Recruitment Posters

uOttawa

SEEKING PARTNERS OF INDIVIDUALS DIAGNOSED WITH OVARIAN CANCER

Researchers at the University of Ottawa are conducting a study on how the caregiver's relationship with the cancer care team affects their psychological health through a **BRIEF, ONE-TIME QUESTIONNAIRE STUDY** (online or by post).

We are looking for all partners (married or common law) who are:

- Over 18 years of age
- English or French speaking
- The primary caregiver to their wives.
- Have met their wife's/partner's cancer care team
- Wives must be within 5 years of the ovarian cancer diagnosis or recurrence
- In Canada

Participants will be **COMPENSATED** through their choice of a **$10 gift card to Tim Horton's**, or a **$10 donation will be made on your behalf to Ovarian Cancer Canada.**

For more information, or to participate, please contact:
Danielle Petricone-Westwood, doctoral candidate and investigator, at XXX-XXX-XXXX, ext. XXXX, or by email at xxxxxx@uottawa.ca*

This study has been approved by the University of Ottawa's Research Ethics Board.

**Please be advised that communication via e-mail is not absolutely secure, thus please do not communicate personal sensitive information via e-mail.*

uOttawa

À LA RECHERCHE DE CONJOINT(E)S DE PERSONNES ATTEINTES DU CANCER DES OVAIRES

Des chercheurs de l'Université d'Ottawa étudient comment la relation entre les conjoint(e)s et l'équipe oncologique influence leur santé psychologique. Les participants sont invités à compléter **UN QUESTIONNAIRE BREF** par la poste ou en ligne.

Nous cherchons des conjoint(e)s qui :

- Ont plus de 18 ans
- Parlent anglais ou français
- Sont les soignants primaires de leur épouse
- Ont rencontré l'équipe de soin de leur conjointe
- La conjointe doit avoir reçu le diagnostic de cancer des ovaires, ou avoir eu une récidive il y a de cela moins de 5 ans
- Habitent au Canada

Les participants seront **RÉCOMPENSÉS** au choix soit par **une carte-cadeau Tim Horton's d'une valeur de $10** ou bien **un don de $10 qui sera remis à l'organisme Cancer de l'ovaire Canada**

Pour plus d'information ou pour participer à cette étude, contactez:
Danielle Petricone-Westwood, étudiante au doctorat et chercheure, au XXX-XXX-XXXX, poste XXXX, ou par courriel à xxxx@uottawa.ca*

Cette étude a été approuvée par le Bureau d'éthique et d'intégrité de la recherche de l'Université d'Ottawa.

**Notez que la communication par courriel n'est pas absolument sécure, veuillez donc s'il vous plait ne pas inclure aucune information confidentielle via courriel.*

Appendix B

Study Screening Documents

uOttawa REB # H05-17-02 Research assistant initials _____

Participant Pre-Screening, Recruitment & Data collection Form

PSID_____ Date & Time _____

1) Participant interested? *Yes* *No*
   a. No: Reason for decline if available _____

Pre-screening questions

2) Over 18 years of age? *Yes* *No (ineligible)*
3) Speaks and Reads English or French: *English* *French* *None (ineligible)*
4) Spouse/common law partner of patient with ovarian cancer? *Yes* *No (ineligible)*
5) Patient currently in remission? *Yes* *No*
   a. If YES, since when (if over 5 years ago, ineligible): _____

If participant still eligible, proceed to explain the study and review consent form with them

6) Informed verbal consent? *Yes* *No*

☐ Purpose of study	☐ Confidentiality and anonymity
☐ Choice of compensation explained	☐ Conservation of data
☐ Possible risks of emotional upset	☐ Voluntary participation
☐ Benefits to participating	☐ Options of online or paper package
☐ Participation requiring one questionnaire package completion	☐ Explained nature of proxy rating for EORTC QLQ-C30

7) Participant understands that returning questionnaire package implies consent?

Yes *No* *N/A (requested online version)*

8) Questionnaire package sent with instruction sheet, two consent forms (labelled theirs and ours to sign and return), questionnaire package: *Yes* *No*

   a. Questionnaire given by: Mail (Date:_____)

      Email (Date:_____)

   b. Mailing address: _____

      _____

   c. Phone number: _____ Permission to leave VM? *Yes* *No*

   d. Email address: _____

9) Questionnaire package returned on (Date) _____

10) Choice of compensation:

Donation to Ovarian Cancer Canada *Tim Horton's gift card (collect mailing information)*

Narrative and comments (*questions asked during consent, calls with no answer or VM, follow up calls*):_____

_____

_____

_____

_____

_____

_____

_____

_____

Appendix C

Recruitment Invitation Letter to Identified Patients from Gynecology Oncology

[DATE]

Re: *Caregiving for patients diagnosed with ovarian cancer: An examination of relationships with healthcare providers using attachment theory.*

To patients of the gynecology oncology clinic,

We are writing to kindly ask that you consider inviting your partner to participate in a psychosocial study being conducted by Dr. Sarah Hales, psychiatrist in Psychosocial Oncology at the Princess Margaret Cancer Centre. We will ask them questions related to their well-being, their relationships with your cancer care team, and experiences related to your cancer and treatments. Participants are asked to complete a one-time questionnaire online or by post-mail, and will be provided with their choice of a $10 gift-card to Tim Horton's, or a $10 donation will be made to Ovarian Cancer Canada.

If you are comfortable, we invite you to pass this package onto your partner to complete. Your partner is eligible to participate if they are over 18 years of age; they are English or French speaking; they are your primary caregiver; you have been diagnosed or treated for ovarian cancer within the last 5 years; they have met your healthcare team; and they live in Canada.

If your partner is not interested in participating, or if you would prefer not to invite them, please contact Danielle Petricone-Westwood, who is the doctoral student involved with this project. She can be reached by email at xxxxxxx@uhnresearch.ca or you can leave a message at XXX-XXX-XXXX ext. XXXX. If we do not hear from you, we will contact you to determine if you have any questions, and to ask whether your partner would like to participate.

They can also participate right away at the following link: http://uottawapsy.az1.qualtrics.com/jfe/form/SV_4HewLr3kC5ptWh7. If so, please indicate your Participant Study Identification (PSID) as ____ so that we can identify that you have participated.

Thank you for your consideration of inviting your partner to participate in this study.

Dr. Sarah Hales
Principal Investigator
Staff Psychiatrist, Department of Supportive Care
Princess Margaret Cancer Centre

[Name of treating physician]
Surgical Oncology, Gynecology Site Group
Princess Margaret Cancer Center

Danielle Petricone-Westwood, Ph.D. Candidate
Department of Supportive Care
Princess Margaret Cancer Centre

Appendix D

Letters to Consenting Participants

Université d'Ottawa | University of Ottawa
École de psychologie | School of Psychology

136 Jean-Jacques Lussier, Ottawa, ON K1N 6N5

[DATE]

Re: *Caregiving for patients diagnosed with ovarian cancer: An examination of relationships with healthcare providers using attachment theory.*

Dear participant,

You are receiving this package as you agreed to participate in our research study on spouses of patients living with ovarian cancer. In order to maintain your confidentiality, we have assigned you a participant study identification number (PSID), which is _____. The ethical aspects of this study have been approved by the Research Ethics Board of the University of Ottawa.

Within this package you will find:

1) A copy of our study consent form
2) A questionnaire package
3) A self-addressed, stamped envelop
4) A list of resources offering psychosocial supports for caregivers of patients with cancer

Please take a moment to review the consent form. In returning the questionnaire package, we assume that you consent to participating in the study.

We are very grateful for your participation. Through this research, we hope to better understand the experiences of partners of patients with ovarian cancer. If you have any further question, please contact us anytime at XXX-XXX-XXX x XXXX.

Sincerely,

Danielle Petricone-Westwood, BA
Doctoral student at the University of Ottawa

Sophie Lebel, Ph.D., C. Psych.
Associate Professor at the University of Ottawa

[DATE]

Re: *Caregiving for patients diagnosed with ovarian cancer: An examination of relationships with healthcare providers using attachment theory.*

Dear participant,

You are receiving this package as you agreed to participate in our research study spouses of patients living with ovarian cancer. In order to maintain your confidentiality, we have assigned you a participant study identification number (PSID), which is _____. The ethical aspects of this study have been approved by the Research Ethics Board of the University of Ottawa.

Within this package you will find:

5) A copy of our study consent form
6) A questionnaire package
7) A self-addressed, stamped envelope

Please take a moment to review the consent form. In completing and returning the questionnaire package, your consent is implied in participating in the study.

We are very grateful for your participation. Through this research, we hope to better understand the experiences of partners of patients with ovarian cancer. If you have any further question, please contact us anytime at XXX-XXX-XXXX ext. XXXX.

Sincerely,

Dr. Sarah Hales
Principal Investigator
Staff Psychiatrist, Department of Supportive Care
Princess Margaret Cancer Centre

Danielle Petricone-Westwood, Ph.D. Candidate
Department of Supportive Care
Princess Margaret Cancer Centre

[DATE]

Re: *Caregiving for patients diagnosed with ovarian cancer: An examination of relationships with healthcare providers using attachment theory.*

Dear participant,

You are receiving this package as you agreed to participate in our research study on spouses of patients living with ovarian cancer. In order to maintain your confidentiality, we have assigned you a participant study identification number (PSID), which is _____. This study has been reviewed for ethical compliance by the Research Ethics Boards of Queen's University and the University of Ottawa.

Within this package you will find:

8) A copy of our study consent form
9) A questionnaire package
10) A self-addressed, stamped envelop
11) A list of resources offering psychosocial supports for caregivers of patients with cancer

Please take a moment to review the consent form. In returning the questionnaire package, we assume that you consent to participating in the study.

We are very grateful for your participation. Through this research, we hope to better understand the experiences of partners of patients with ovarian cancer. If you have any further questions, please contact us anytime at XXX-XXX-XXXX x XXXX.

Sincerely,

Jacqueline Galica, R.N., M.Sc., Ph.D., CON(C).
Adjunct Professor, Queens University

Sophie Lebel, Ph.D., C. Psych.
Associate Professor, University of Ottawa

Danielle Petricone-Westwood, BA
Doctoral student, University of Ottawa

Appendix E

Consent Forms

uOttawa
Université d'Ottawa | University of Ottawa
École de psychologie | School of Psychology
136 Jean-Jacques Lussier, Ottawa, ON K1N 6N5
613-562-5801

Caregiving for patients diagnosed with ovarian cancer: An examination of relationships with healthcare providers using Attachment Theory.

Consent Form—Mailed questionnaire

Danielle Petricone-Westwood, B.A.
Doctoral candidate in the School of Psychology, Faculty of Social Sciences
University of Ottawa
XXX-XXX-XXXX ext XXX, xxxxxx@uottawa.ca

Sophie Lebel, Ph.D., C. Psych
Associate Professor in the School of Psychology, Faculty of Social Sciences,
University of Ottawa
XXX-XXX-XXXX ext XXX; xxxxxx@uottawa.ca

Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Danielle Petricone-Westwood, in the context of a Ph.D. thesis, under the supervision of Dr. Sophie Lebel.

Purpose of the Study: The purpose of the study is to investigate psychological constructs of partners of patients with ovarian cancer, and how their relationship with the patient's healthcare team influences their psychological wellbeing.

Participation: My participation will consist essentially of the completion of one questionnaire package which should take approximately 20 to 30 minutes through a mailed package.

Risks: My participation in this study will entail that I volunteer personal information and answer sensitive questions regarding my experience with a partner with ovarian cancer and my mental health, and this may cause me to feel emotionally upset. Researchers will provide resources that may help me with any psychological distress, including contact information of Dr. Sophie Lebel. Dr. Lebel is a clinical psychologist with experience in psychosocial oncology, who can provide me with appropriate resources (and not psychological services).

Benefits: My participation in this study will not benefit me specifically, but will allow for the advancement of knowledge on the experience of having a partner diagnosed with ovarian cancer. This will additionally contribute to the advancement of knowledge in the relationship between family members and the cancer care team.

Confidentiality and anonymity: I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used only for research purposes. Questionnaire data will be kept in a document separate from any

identifying information, and will be kept in a password-protected document on an encrypted computer.

Anonymity will be protected as participants will be assigned an identification number, separate from any identifying information.

Conservation of data: The data collected through hard copy questionnaires will be kept in a secure manner as it will be locked in a cabinet within Dr. Lebel's locked laboratory at the University of Ottawa. Questionnaire data will be entered into a password-protected, encrypted computer also found in Dr. Lebel's locked laboratory. Only the investigators will have access to this data, and the data will be conserved for 10 years as of the end of data collection.

Compensation: I will be compensated for my participation with my choice of either a $10 Tim Horton's gift card, or a $10 donation to Ovarian Cancer Canada. If I choose to withdraw from the study, I will still receive this compensation.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be kept unless I specify that I would like it no longer to be used by the research team.

Acceptance: I agree to participate in the above research study conducted by Danielle Petricone-Westwood of the School of Psychology in Faculty of Social Sciences at the University of Ottawa, whose doctoral research is under the supervision of Dr. Sophie Lebel. **By filling out and returning this questionnaire, my consent is implied.** This is to ensure no identifying information is contained in the returned package.

If I have any questions about the study, I may contact the researcher or her supervisor.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca
This consent form is mine to keep for my records.

Researcher's signature: _____ Date: _____
(Signature)

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Caregiving for patients diagnosed with ovarian cancer: An examination of relationships with healthcare providers using Attachment Theory.

Investigators: Dr. Sarah Hales, M.D., Ph.D., XXX-XXX-XXXX x XXXX, Danielle Petricone-Westwood, Ph.D. Candidate, and Dr. Sophie Lebel, Ph.D., C. Psych.

Contact Information: xxxxxxxx@uhnresearch.ca, XXX-XXX-XXXX ext. XXXX

Sponsor: Faculty of Social Sciences, University of Ottawa

Introduction:
You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on study's risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision and ask the study staff to explain anything that you do not understand. Participation in this study is voluntary.

Background/Purpose:

In the general cancer population, research has shown that family members of patients diagnosed with cancer show similar levels of psychological concerns, for example feeling worried or down, as compared to the person diagnosed with cancer. Ovarian cancer is a unique disease, and it is well documented in the literature that the quality of life of individuals diagnosed with this disease is often compromised throughout the treatment. This is particularly true for their mental health. To date, however, there is little research that has investigated the experiences of partners of patients with ovarian cancer, which may be different from the general population. The purpose of the study is to investigate how partners of patients with ovarian cancer are doing throughout the cancer treatment, and how their relationship with the patient's healthcare team influences psychological concerns such as feelings of worry, being overwhelmed, feeling down, or losing interest in activities.

Risks:
Taking part in this study has some psychological risks such as anxiety, distress, or feelings of sadness and anger that may arise from the questionnaires regarding sensitive issues around you and your partners health and mental health. If you have any questions or concerns, or would like resources for psychosocial supports, you can contact the following study investigators:

- Danielle Petricone-Westwood, study coordinator, for a list of psychosocial resources
- Dr. Sarah Hales, Principle Investigator and psychiatrist in Supportive Care
- Dr. Sophie Lebel, study co-investigator, clinical psychologist from the University of Ottawa

Benefits:
You will not directly direct benefit from being in this study. Information learned from this study may help us to better understand the experience of being a spouse-caregiver to patients with ovarian cancer throughout the cancer trajectory.

Confidentiality:
Personal Information
If you agree to join this study, the Principle Investigator and her study team will look at your personal information and collect only the information they need for the study. Personal information is any information that could identify you and includes your:

- name,
- address,
- age in years

The following people may come to the hospital to look at the study records and at your personal information to check that the information collected for the study is correct and to make sure the study is following proper laws and guidelines:

- Representatives of the University Health Network (UHN) including the UHN Research Ethics Board

The study investigators will keep any personal information about you in a secure and confidential location for 10 years. A list linking your study number with your name will be kept by the study investigator in a secure place, separate from your study file.

As this study is being conducted in collaboration with the University of Ottawa, please note that your de-identified information will be accessible to the Principle Investigator from that site, Dr. Sophie Lebel. Dr. Sophie Lebel is an Associate Professor in the School of Psychology. All information shared with the University of Ottawa will be transmitted through secure means.

Study Information that Does Not Identify You
All information collected during this study, including your personal information, will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study.

Your study information from this research project will be shared with the University of Ottawa, but your identifiers will be removed. They will not be able to identify you.

Voluntary Participation:
Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind later. You may leave the study at any time without it affecting your partner's care. We will give you new information that is learned during the study that might affect your decision to stay in the study.

Withdrawal from the Study:
If you decide to leave the study, you have the right to request withdrawal of information collected about you. Let a study investigator know. If you leave the study without specifying the withdrawal of your information, the information that was collected before you left the study will still be used in order to help answer the research question. No new information will be collected without your permission.

Costs and Reimbursement:
You will not have to pay to be involved with this study. You will be compensated for your participation through your choice of a donation of $10 to Ovarian Cancer Canada, or a $10 Tim Horton's gift card will be sent to you.

Rights as a Participant:
By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

Questions about the Study:
If you have any questions, concerns or would like to speak to the study team for any reason, please call: Study Coordinator at XXX-XXX-XXXX ext. XXXX or Dr. Sarah Hales at XXX-XXX-XXXX ext. XXXX

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

You can keep this signed copy of the consent form.

Consent:
I understand this study and know to contact the investigators with any remaining questions. I know that I may leave the study at any time. I agree to the use of my information as described in this form. I agree to take part in this study. I understand that in returning the questionnaire package, **my consent is implied.**

_____ _____
Danielle Petricone-Westwood, Ph.D.(C) Signature

_____ _____
Sarah Hales, M.D., Ph.D. Signature

Caregiving for patients diagnosed with ovarian cancer: An examination of relationships with healthcare providers using Attachment Theory.

Consent Form—Mailed questionnaire

Jacqueline Galica, RN, MSc, PhD, CON(C)
Assistant Professor, School of Nursing, Faculty of Health Sciences
Queen's University
XXX-XXX-XXXX ext XXXXX, xxxxx@queensu.ca

Danielle Petricone-Westwood, BA
Doctoral candidate in the School of Psychology, Faculty of Social Sciences
University of Ottawa
XXX-XXX-XXXX ext XXXX, xxxxxxx@uottawa.ca

Sophie Lebel, PhD, C.Psych.
Associate Professor in the School of Psychology, Faculty of Social Sciences,
University of Ottawa
XXX-XXX-XXXX ext XXXX; xxxx@uottawa.ca

Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Danielle Petricone-Westwood, in the context of a Ph.D. thesis, under the supervision of Dr. Sophie Lebel and in collaboration with Dr. Jacqueline Gallica.

Purpose of the Study: The purpose of the study is to investigate psychological constructs of partners of patients with ovarian cancer, and how their relationship with the patient's healthcare team influences their psychological wellbeing.

Participation: My participation will consist essentially of the completion of one questionnaire package which should take approximately 20 to 30 minutes through a mailed package.

Risks: My participation in this study will entail that I volunteer personal information and answer sensitive questions regarding my experience with a partner with ovarian cancer and my mental health, and this may cause me to feel emotionally upset. Researchers will provide resources that may help me with any psychological distress, including contact information of Dr. Sophie Lebel. Dr. Lebel is a clinical psychologist with experience in psychosocial oncology, who can provide me with appropriate resources (and not psychological services).

Benefits: My participation in this study will not benefit me specifically, but will allow for the advancement of knowledge on the experience of having a partner diagnosed with ovarian cancer. This will additionally contribute to the advancement of knowledge in the relationship between family members and the cancer care team.

Confidentiality and anonymity: I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used only for research purposes. Questionnaire data will be kept in a document separate from any identifying information, and will be kept in a password-protected document on an encrypted computer.

Anonymity will be protected as participants will be assigned an identification number, separate from any identifying information.

Conservation of data: The data collected through hard copy questionnaires will be kept in a secure manner as it will be locked in a cabinet within Dr. Lebel's locked laboratory at the University of Ottawa. Questionnaire data will be entered into a password-protected, encrypted computer also found in Dr. Lebel's locked laboratory. Only the investigators will have access to this data, and the data will be conserved for 10 years as of the end of data collection. The Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board may review the research data files for auditing and quality assurance purposes.

Compensation: I will be compensated for my participation with my choice of either a $10 Tim Horton's gift card, or a $10 donation to Ovarian Cancer Canada. If I choose to withdraw from the study, I will still receive this compensation.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be kept unless I specify that I would like it no longer to be used by the research team. I understand that I should notify the research team by July 1st, 2019, if I would no longer like for my data to be used in this study. I understand that not consenting or withdrawing my consent will have no impact on my partner, nor my own current or future healthcare services at the Cancer Centre of Southeast Ontario.

Acceptance: I agree to participate in the above research study conducted by Dr. Jacqueline Galica of Queen's University, and Danielle Petricone-Westwood of the School of Psychology in Faculty of Social Sciences at the University of Ottawa, whose doctoral research is under the supervision of Dr. Sophie Lebel. **By filling out and returning this questionnaire, my consent is implied.** This is to ensure no identifying information is contained in the returned package.

If I have any questions about the study, I may contact the researcher or her supervisor.
If I have any questions regarding the ethical conduct of this study, I may contact the Research Ethics Board at Queen's University.
Tel.: 613-533-2988
Email: urs@queensu.ca
This consent form is mine to keep for my records.

Researcher's signature: _____ Date: _____

Appendix F

Thank You Letters Sent with Gift Cards

uOttawa

Université d'Ottawa | University of Ottawa
École de psychologie | School of Psychology
136 Jean-Jacques Lussier, Ottawa, ON K1N 6N5
613-562-5801

DATE

Re: *Caregiving for patients diagnosed with ovarian cancer: An examination of relationships with healthcare providers using attachment theory.*

Dear participant,

Thank you for your participation my doctoral thesis project. Please find in this letter a $10.00 gift card to Tim Horton's.

We are very grateful for your participation. Through this research, we hope to better understand the experiences of partners of patients with ovarian cancer. If you have any further question, please contact us anytime at XXX-XXX-XXXX x XXXX.

Sincerely,

Danielle Petricone-Westwood, BA
Doctoral student at the University of Ottawa

Sophie Lebel, Ph.D., C. Psych.
Associate Professor at the University of Ottawa

[DATE]

Re: *Caregiving for patients diagnosed with ovarian cancer: An examination of relationships with healthcare providers using attachment theory.*

Dear participant,

Thank you for your participation in our study. Included with this letter, you will find a $10 Tim Horton's gift-card. We are very grateful for your participation. Through this research, we hope to better understand the experiences of partners of patients with ovarian cancer. If you have any further questions, please contact us anytime at XXX-XXX-XXXX ext. XXXX or by email at xxxxxx@uhnresearch.ca.

Sincerely,

Dr. Sarah Hales
Principal Investigator
Staff Psychiatrist, Department of Supportive Care
Princess Margaret Cancer Centre

Danielle Petricone-Westwood, Ph.D. Candidate
Department of Supportive Care
Princess Margaret Cancer Centre

DATE

Re: *Caregiving for patients diagnosed with ovarian cancer: An examination of relationships with healthcare providers using attachment theory.*

Dear participant,

Thank you for your participation in my doctoral thesis project. Please find in this letter a $10.00 gift card to Tim Horton's.

We are very grateful for your participation. Through this research, we hope to better understand the experiences of partners of patients with ovarian cancer. If you have any further question, please contact us anytime at XXX-XXX-XXXX x XXXX.

Sincerely,

Jacqueline Galica, R.N., M.Sc., Ph.D., CON(C).
Adjunct Professor, Queens University

Sophie Lebel, Ph.D., C. Psych.
Associate Professor, University of Ottawa

Danielle Petricone-Westwood, BA
Doctoral student, University of Ottawa

Appendix G

Questionnaire Package

Demographics & Patient medical information

PSID_____ Date & Time _____

Please complete the following information about yourself

1) Date of birth (YYYY-MMM-DD)_____

2) Gender : _____

3) Primary language:_____

4) Education level:

a. Some high school ☐ b. High school diploma ☐
c. Some post-secondary ☐ d. Post-secondary degree ☐
e. Some post-graduate ☐ f. Post-graduate diploma ☐

5) Total household annual income:

a. Less than $20,000 ☐ b. $20,000-$40,000 ☐ c. $40,000-$60,000 ☐
d. $60,000-$80,000 ☐ e. $80,000-$100,000 ☐ f. Over $100,000 ☐

6) Ethnicity: _____

7) Length of relationship with ovarian cancer patient: _____

Please complete the following information about your partner receiving treatment for ovarian cancer:

1) Stage of ovarian cancer: _____

2) Date of diagnosis (YYYY-MMM):_____

3) Treatments (select all that apply):

a. Surgery ☐ b. Radiation ☐ c. Chemotherapy ☐

CaTCoN

Questions 1–5 concern the help and support you have given the patient

1. To what extent have you had to provide:
   (Please tick one answer in each line)

	None	A little	Some	A lot	Don't know/ not relevant
a. Practical help to the patient?	☐	☐	☐	☐	☐
b. Personal care to the patient?	☐	☐	☐	☐	☐
c. Psychological support to the patient?	☐	☐	☐	☐	☐

2. It is the responsibility of the hospitals to make referrals and appointments for examination and treatment. Have you felt that you have been partially responsible for keeping track of whether the patient has been referred and called for examinations and treatments quickly and correctly?

   ☐ Not at all ☐ To a low degree ☐ To some degree ☐ To a high degree
   ☐ Don't know/not relevant

3. Have you felt that you have had too much responsibility in relation to home care (personal care, medications, etc.)?

   ☐ Not at all ☐ To a low degree ☐ To some degree ☐ To a high degree
   ☐ Don't know/not relevant

4. Have you spent time transporting the patient?

   ☐ No, not at all ☐ Yes, a little ☐ Yes, some ☐ Yes, a lot
   ☐ Don't know/not relevant

5. As a caregiver one cannot necessarily set aside a long time for each appointment at the hospital (in connection with for example consultations, examinations and treatment). Have you felt that this has been taken into consideration at the hospitals?

   ☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
   ☐ Don't know/not relevant

Questions 6–9 concern the consequences you may have experienced in connection with being a caregiver

6. Has the patient's cancer disease:
(Please tick one answer in each line)

	No, not at all	Yes, a little	Yes, some	Yes, a lot	Don't know/ not relevant
a. Caused you stress?	☐	☐	☐	☐	☐
b. Had a negative effect on your own physical health?	☐	☐	☐	☐	☐
c. Meant that you have <u>not</u> had enough time for (the rest of) your family?	☐	☐	☐	☐	☐
d. Meant that you have <u>not</u> had enough time for (the rest of) your friends/acquaintances?	☐	☐	☐	☐	☐
e. Increased your awareness of the important things in life?	☐	☐	☐	☐	☐
f. Caused you to make positive changes?	☐	☐	☐	☐	☐
g. Made you value your relationships with other people more?	☐	☐	☐	☐	☐

7. Have you been able to take time off, get a leave of absence from work, or make similar arrangements to the extent it has been necessary?
(If you have <u>not</u> been working during the course of the illness, you may tick 'not relevant')

☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
☐ Don't know/not relevant

8. Has the patient's illness meant that you have had to be absent from work so much so that it has posed problems at your workplace?
(If you have <u>not</u> been working during the course of the illness, you may tick 'not relevant')

☐ Not at all ☐ To a low degree ☐ To some degree ☐ To a high degree
☐ Don't know/not relevant

9. Have you experienced negative financial consequences of being a caregiver?

☐ Not at all ☐ To a low degree ☐ To some degree ☐ To a high degree
☐ Don't know/not relevant

Questions 10–13 concern your contact with the health care professionals in the hospitals

10. Have the health care professionals paid attention to you?

☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
☐ Don't know/not relevant

11. Have the health care professionals shown interest in how you have been feeling?

☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
☐ Don't know/not relevant

12. Have the health care professionals involved you in the patient's illness/treatment/care in the way in which you have wished to be involved?

☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
☐ Don't know/not relevant

13. Have you any thoughts about how to improve the involvement of caregivers? If so, please write them here:

_____
_____
_____
_____
_____
_____

Questions 14–24 concern knowledge and information from the health care professionals in the hospitals

14. We would like to know whether you have <u>lacked</u> (more) information about different areas. Have you as a caregiver:
(Please tick one answer in each line)

	Not at all	To a low degree	To some degree	To a high degree	Don't know/ not relevant
a. Lacked information about how the health care system works in relation to treating cancer?	☐	☐	☐	☐	☐
b. Lacked information about how long one has to wait at different times in the process?	☐	☐	☐	☐	☐
c. Lacked information about when to press for an answer?	☐	☐	☐	☐	☐
d. Lacked information about the paper flow in the health care system?	☐	☐	☐	☐	☐
e. Lacked information about 'normal' waiting times in the out-patient clinic?	☐	☐	☐	☐	☐
f. Lacked information about the illness and its course?	☐	☐	☐	☐	☐
g. Lacked information about what symptoms and side-effects to keep an eye on as a caregiver?	☐	☐	☐	☐	☐
h. Lacked information about the best ways to help and support a person with cancer?	☐	☐	☐	☐	☐
i. Lacked information about likely psychological reactions in a person with cancer?	☐	☐	☐	☐	☐

(Continued from previous page)
Have you as a caregiver:

	Not at all	To a low degree	To some degree	To a high degree	Don't know/ not relevant
j. Lacked information about nutrition?	☐	☐	☐	☐	☐
k. Lacked information about how to search for information on the internet?	☐	☐	☐	☐	☐
l. Lacked information about who to turn to as a caregiver after discharge, should any questions or problems arise?	☐	☐	☐	☐	☐
m. Lacked information about rights and possibilities of assistance on discharge and generally (for example home care, psychologist, leave of absence, insurances, etc.)?	☐	☐	☐	☐	☐

15. Have you telephoned health care professionals to ask questions?

☐ No
☐ Yes. Have you received adequate assistance when you telephoned?
- ☐ Always/almost always
- ☐ Mostly
- ☐ Only sometimes
- ☐ Rarely/never
- ☐ Don't know/not relevant

16. Have you needed help from health care professionals to find out the best way for you and the patient to handle the illness <u>in practical terms</u>?

☐ No
☐ Yes. Has your need for help been met?
- ☐ To a high degree
- ☐ To some degree
- ☐ To a low degree
- ☐ Not at all
- ☐ Don't know/not relevant

17. Have you needed help from health care professionals to find out the best way for you and the patient to handle the illness <u>emotionally</u>?

☐ No
☐ Yes. Has your need for help been met?
- ☐ To a high degree
- ☐ To some degree
- ☐ To a low degree
- ☐ Not at all
- ☐ Don't know/not relevant

18. Have you felt that the health care professionals have given you an unrealistically positive idea of the patient's situation?

☐ Not at all ☐ To a low degree ☐ To some degree ☐ To a high degree
☐ Don't know/not relevant

19. Have you felt that the health care professionals have deprived you of hope?

☐ Not at all ☐ To a low degree ☐ To some degree ☐ To a high degree
☐ Don't know/not relevant

20. Have you needed financial counselling?

☐ No
☐ Yes. Have you had the offer of financial counselling? ☐ Yes ☐ No

21. Do you think enough time has been spent informing caregivers?

☐ To a high degree ☐ To some degree ☐ To a low degree ☐ Not at all
☐ Don't know/not relevant

22. Have you had to ask the health care professionals questions in order to get the information you have needed?

☐ Rarely/never ☐ Only sometimes ☐ Mostly ☐ Always/almost always
☐ Don't know/not relevant

23. Have you lacked being given information from the health care professionals, without having to ask for it yourself?

☐ Rarely/never ☐ Only sometimes ☐ Mostly ☐ Always/almost always
☐ Don't know/not relevant

24. All in all how well do you think the hospitals have informed you as a caregiver?

☐ Very well ☐ Pretty well ☐ Pretty poorly ☐ Very poorly
☐ Don't know/not relevant

Questions 25–28 concern communication with the health care professionals in the hospitals

25. How well do you think the health care professionals have communicated with you?

☐ Very good ☐ Pretty good ☐ Pretty bad ☐ Very bad
☐ Don't know/not relevant

26. If you have experienced communication problems, please describe them here:

_____
_____
_____
_____
_____

27. Do you think that information has been given to you in a good and sensitive way?

☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
☐ Don't know/not relevant

28. Have the health care professionals generally signalled that it is OK for you as a caregiver to ask questions?

☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
☐ Don't know/not relevant

Questions 29–31 concern support from the health care system (i.e. from hospitals and general practitioner)

29. Have the health care professionals in the hospitals shown interest in whether you as a caregiver have been able to handle the situation?

☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
☐ Don't know/not relevant

30. Have the health care professionals in the hospitals noticed and reacted to signals from you, if you have not been doing well?

☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
☐ Don't know/not relevant

31. Have you as a caregiver received adequate support from your own and/or the patient's general practitioner?
(If you have not needed support from the general practitioner, you may tick 'not relevant')

☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
☐ Don't know/not relevant

Question 32 concerns contact with other caregivers

32. Have you wanted contact with other caregivers in the hospital?

☐ No
☐ Yes. Has your need for contact with other caregivers been met?
☐ To a high degree
☐ To some degree
☐ To a low degree
☐ Not at all
☐ Don't know/not relevant

Questions 33–34 concern help for yourself

33. Have you *lacked* information about where to get help as a caregiver?

☐ Not at all ☐ To a low degree ☐ To some degree ☐ To a high degree
☐ Don't know/not relevant

34. Have you needed to see a psychologist as a consequence of the patient's illness?

☐ No
☐ Yes. Have the health care professionals offered you the opportunity to see a psychologist? ☐ Yes ☐ No

Questions 35–37 concern the physical framework for caregivers in the hospitals

35. Have the health care professionals' conversations with you (with or without the patient) taken place without being disturbed?

☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
☐ Don't know/not relevant

36. Have the health care professionals' conversations with you (with or without the patient) taken place out of the earshot of other patients and caregivers?

☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never
☐ Don't know/not relevant

37. Have you needed a physical framework at the hospitals that has made it possible for you to:

a. Withdraw? ☐ No
☐ Yes. Has your need been met?
☐ To a high degree
☐ To some degree
☐ To a low degree
☐ Not at all
☐ Don't know/not relevant

b. Stay overnight? ☐ No
☐ Yes. Has your need been met?
☐ To a high degree
☐ To some degree
☐ To a low degree
☐ Not at all
☐ Don't know/not relevant

c. Talk to other caregivers? ☐ No
☐ Yes. Has your need been met?
☐ To a high degree
☐ To some degree
☐ To a low degree
☐ Not at all
☐ Don't know/not relevant

Questions 38–41 concern the role as a caregiver

38. Have you had the <u>need</u> to be able to take a break from the practical tasks (in the role of caregiver) in connection to the illness?

☐ To a high degree ☐ To some degree ☐ To a low degree ☐ Not at all
☐ Don't know/not relevant

39. Have you felt that you have had <u>the possibility</u> to take a break from the practical tasks?

☐ To a high degree ☐ To some degree ☐ To a low degree ☐ Not at all
☐ Don't know/not relevant

40. Have you had the <u>need</u> to lead a 'normal' life at the same time as you have been a caregiver?

☐ To a high degree ☐ To some degree ☐ To a low degree ☐ Not at all
☐ Don't know/not relevant

41. Have you felt that you have had <u>the possibility</u> to lead a 'normal' life at the same time as being a caregiver?

☐ To a high degree ☐ To some degree ☐ To a low degree ☐ Not at all
☐ Don't know/not relevant

Hospital Anxiety and Depression Scale (HADS)

Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire. Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, though-out response.

A	D			A	D
		I feel tense or 'wound up'	**I feel as if I am slowed down**		
3		Most of the time	Nearly all the time		3
2		A lot of the time	Very often		2
1		From time to time, occasionally	Sometimes		1
0		Not at all	Not at all		0
		I still enjoy the things I used to enjoy	**I get a sort of frightened feeling like 'butterflies' in the stomach**		
	0	Definitely as much	Not at all	0	
	1	Not quite so much	Occasionally	1	
	2	Only a little	Quite often	2	
	3	Hardly at all	Very often	3	
		I get a sort of frightened feeling as if something awful is about to happen	**I have lost interest in my appearance**		
3		Very definitely and quite badly	Definitely		3
2		Yes, but not too badly	I don't take as much care as I should		2
1		A little, but it doesn't worry me	I may not take quite as much care		1
0		Not at all	I take just as much care as ever		0
		I can laugh and see the funny side of things	**I feel restless as if I have to be on the move**		
	0	As much as I always could	Very much indeed	3	
	1	Not quite so much now	Quite a lot	2	
	2	Definitely not so much now	Not very much	1	
	3	Not at all	Not at all	0	
		Worrying thoughts go through my mind	**I look forward with enjoyment to things**		
3		A great deal of the time	As much as I ever did		0
2		A lot of the time	Rather less than I used to		1
1		Not too often	Definitely less than I used to		2
0		Very little	Hardly at all		3
		I feel cheerful	**I get sudden feelings of panic**		
	3	Never	Very often indeed	3	
	2	Not often	Quite often	2	
	1	Sometimes	Not very often	1	
	0	Most of the time	Not at all	0	
		I can sit at ease and feel relaxed	**I can enjoy a good book or radio or television programme**		
0		Definitely			
1		Usually	Often		0
2		Not often	Sometimes		1
3		Not at all	Not often		2
			Very seldom		3

Now check that you have answered all the questions

	A	D
TOTAL		

ECR-12

The following statements concern ***how you generally feel in close relationships.*** Respond to each statement by indicating how much you agree or disagree with it. Write the number in the space provided, using the following rating scale:

1	2	3	4	5	6	7
Disagree Strongly	***Disagree***	***Disagree Slightly***	***Neutral/ Mixed***	***Agree Slightly***	***Agree***	***Agree Strongly***

___ 1. I feel comfortable depending on others.
___ 2. I worry that others won't care about me as much as I care about them.
___ 3. I usually discuss my problems and concerns with others.
___ 4. I worry a fair amount about losing others.
___ 5. I tell my close relationship partners just about everything.
___ 6. I worry about being abandoned.
___ 7. I don't mind asking others for comfort, advice, or help.
___ 8. I worry about being alone.
___ 9. I don't feel comfortable opening up to others.
___ 10. I need a lot of reassurance that I am loved by others.
___ 11. I feel comfortable sharing my private thoughts and feelings with others.
___ 12. If I can't get others to show interest in me, I get upset or angry.

Appendix H

Resources for Caregivers

RESOURCES FOR PSYCHOSOCIAL SUPPORT FOR CAREGIVERS OF PATIENTS WITH OVARIAN CANCER

Organizations and resources for support

Cancer Chat Canada at the De Souza Institute

- Professionally led online support groups for patients, survivors, and family members
- https://cancerchat.desouzainstitute.com/

Canadian Cancer Society

- Phone peer-support services
- Organization may direct caregivers to regional resources

Ovarian Cancer Canada

- Organization may direct caregivers to regional resources

Canadian Association of Psychosocial Oncology

- Information Booklet: Emotional Facts of Life with Cancer http://capo.ca/docs/bookletREVISED.pdf

Coping with Cancer website

- Tool for navigating the circle of care and accessing different resources based on needs http://www.copingwithcancer.ca/

Clinical psychologist specializing in psychosocial oncology

Dr. Sophie Lebel, C. Psych.

- Can be contacted by telephone in her office: XXX-XXX-XXXX x XXXX