



## Review article

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



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## HIGHLIGHTS

- Important gaps in literature regarding experience of ovarian cancer caregivers
- 1.5 years post-diagnosis pivotal time when wellbeing begins decline to end-of-life
- Spiritual and social support in ovarian cancer caregivers are protective factors

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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 ovarian cancer caregivers. This population experiences physical and psychosocial challenges that merit exploration, to subsequently aid in designing interventions.

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## 1. Background

In 2009, ovarian cancer was the fifth leading cause of female cancer deaths among Canadians [1], despite representing only 2.9% of the 93,600 new Canadian female cancer diagnoses in 2014 [1]. 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 [2]. Due to the lack of screening methods and nonspecific early symptoms, approximately 75% of patients are diagnosed with advanced disease [3]. 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 [3].

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 [4]. 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 [4]. 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 [4].

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 [4]. To date, the psychological needs and concerns of individuals diagnosed with ovarian cancer are well documented [5]. As do most patients diagnosed with any cancer, this population of patients experiences high levels of distress [5,6], particularly in levels of depression and anxiety [5–7]. 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 [5], 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 [6]. Among ovarian cancer patients, younger patients and patients with advanced or recurrent disease tend to be the most psychologically distressed [5,6].

In recent years, psychosocial oncology researchers have begun to focus on the experiences of the family and friends of cancer patients and their quality of life throughout the cancer trajectory [8,9]. 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 [8,9], 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 [10]. Caregivers report higher psychological morbidity as illness becomes more advanced or as the focus of patients' care becomes palliative instead of curative [8].

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 ovarian cancer caregiving 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 ovarian cancer caregivers. 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 [11]. 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

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