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Caregiver Burden in End-Stage Ovarian Cancer

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Abstract

Background—Caregiver burden associated with caring for women with ovarian cancer has received limited focus. However, these patients often have complex needs, requiring a high level of care at home and imposing substantial burdens on caregivers.

Objectives—This pilot study assessed the level of caregiver burden experienced by the primary caregivers of patients with end-stage ovarian cancer and identified variables associated with caregiver burden.

Methods—Caregiver burden was assessed using the Caregiver Reaction Assessment. Fifty caregivers completed an anonymous and voluntary survey. Pearson correlations and independent samples t tests were used to analyze data.

Findings—Most participants were Caucasian, married or living with a partner, and college graduates, with an annual household income of less than \$90,000. Caregiver ages ranged from 29–81 years. Participants agreed most with the self-esteem scale, indicating they had pride in caring for their loved ones. Disrupted schedules and financial problems were the most burdensome factors in providing care. Because financial issues affected caregiver burden, nurses should facilitate interdisciplinary support. Future research is needed to determine the impact of nurse-led interventions to reduce caregiver burden.

Graphical abstract

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Keywords

end-stage ovarian cancer; caregiver burden; quality of life

About 22,280 U.S. women will receive a new diagnosis of ovarian cancer in 2016, and about 14,240 women will die from this disease in the same year (American Cancer Society [ACS], 2016). Advances in the treatment of ovarian cancer have led to increased survival and the consideration of ovarian cancer as a chronic disease. This shift has required more care outside of the hospital setting by caregivers who are often left to provide complicated care and support in the home. This pilot study explores the concept of caregiver burden among caregivers of women with end-stage ovarian cancer.

Epithelial Ovarian Cancer and Treatment

Staging of ovarian cancer includes abdominal washing cytology, peritoneal biopsies, bilateral salpingo-oophorectomy, hysterectomy, infracolic omentectomy, pelvic lymph node dissection, and para-aortic lymph node dissection. Only about 20% of women with ovarian cancer are diagnosed with early-stage disease (stage IA and IB) in which the cancer is confined to the ovary, and treatment is of curative intent; 90%–100% of these patients are cured of their disease (National Comprehensive Cancer Network [NCCN], 2015). For early-stage disease, the NCCN treatment guidelines recommend debulking surgery, in which only the affected ovary is removed, and then observation, which includes computed tomography scans and follow-up with an oncologist every three to six months for three years, and then annually for five years (Cass & Karlan, 2003; NCCN, 2015).

However, 60% of patients are diagnosed with advanced stages of disease (stage III or IV), and outcomes are much graver than for those with earlier-stage diagnoses. About 36% of women with stage III ovarian cancer survive five years after their diagnosis, and 18% of patients with stage IV disease survive for this period (Stewart, Rim, & Richards, 2011). If the disease has spread beyond the ovary, a total abdominal hysterectomy and bilateral salpingo-oophorectomy is performed, and adjuvant chemotherapy, such as carboplatin (Paraplatin[®]) and paclitaxel (Taxol[®]), will be administered (Hennessy, Coleman, & Markman, 2009).

Women with advanced disease are surviving longer. Registry data from one cancer center show an improvement in five-year survival in patients with late-stage disease, from 14% in the 1980s to 35% in 2004 (Markman, 2013). In addition, evidence suggests that overall survival has improved because of the availability of multiple antineoplastic agents, such as gemcitabine (Gemzar®), liposomal doxorubicin (Doxil®), and topotecan (Hycamtin®) (Markman, 2013). The use of monoclonal antibodies is being explored with treatment options specific to the *BRCA* gene mutation (Aravantinos & Pectasides, 2014; Gallagher et al., 2011). When surgery is performed by a gynecologic oncologist rather than a general gynecologist, patients have an additional six to nine months survival benefit; general surgeons often perform a less aggressive surgery (Fader & Rose, 2007). In patients who had no residual microscopic cancer postsurgery and received intraperitoneal (IP) therapy, one study showed a median survival of nine years (Markman, 2013). When the tumor is optimally debulked—less than 1 cm of disease remains—patients have a 66-month survival benefit over patients whose tumor is suboptimally debulked (Fader & Rose, 2007). New forms of treatment, such as combined IP and IV chemotherapy instead of IV chemotherapy alone, have also improved patient outcomes. Combination IP and IV treatments showed a median survival time of 16 additional months compared to patients who receive IV treatment alone (65.6 months versus 49.7 months) (Fader & Rose, 2007).

Most women with ovarian cancer present with advanced disease that requires complicated oncologic care for a longer period of time (Price et al., 2010). In addition to common treatment side effects (e.g., infection, pain, fatigue, anemia, nausea and vomiting, constipation, swelling of lower extremities), women with end-stage ovarian cancer have the potential for serious complications, including ascites, bowel and bladder obstructions, and pleural effusions (Herrinton et al., 2007). Removal of fluids in the pleural and abdominal spaces can relieve dyspnea and discomfort (Rubatt, 2015). The ability to drain the fluid on an outpatient basis provides comfort and relief of the symptoms and also permits patients to stay at home.

Background

The concept of caregiver burden has been explored in numerous studies around the world. This burden can arise when a family member or close friend takes on the role of providing care for his or her sick loved one. Given, Kozachik, Collins, DeVoss, and Given (2001) define caregiver burden as the “multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers’ personal time, social roles, physical and emotional states, financial resources, and formal care resources given to multiple roles they fulfill” (pp. 679–680). Patients with chronic illness, such as end-stage ovarian cancer, spend less time in the hospital and, when discharged, require more high-level care at home (Cryer, Shannon, Van Amsterdam, & Leff, 2012; Nijboer et al., 2000), and this burden falls on the primary caregiver.

Administering care can be challenging, complicated, and demanding because caregivers have very little down time (Northouse, Williams, Given, & McCorkle, 2012). Caregivers often assume their role with little to no preparation for what is expected of them, and they may not be prepared for potential changes in their lives (e.g., relationship with their loved

one, demands on time, financial issues, other responsibilities). In addition, physical demands can result in fatigue and even injury or illness, which can have a negative effect on the caregiver's physical health (Given et al., 2001). The financial status of the caregiver may be affected because of missed days at work, change in work schedule from full-time to part-time, and the cost of medication or supplies (Le et al., 2003). Caregiver burden may cause cognitive and emotional issues, resulting in depression and anxiety in caregivers (Bakas, Austin, Jessup, Williams, & Oberst, 2004; Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Grov, Fosså, Sørebo, & Dahl, 2006; Grunfeld et al., 2004; Kim, Chang, Rose, & Kim, 2012; Nijboer et al., 2000). Many of these studies focused on caregivers of patients with breast and rectal cancers, as well as those of patients with mental disorders, dementia, stroke, and other terminal illnesses.

In a study of caregivers of patients with colorectal cancers requiring surgery, Nijboer et al. (2000) found that low income, residence alone with the patient, and a distressed relationship between caregiver and patient contributed to high levels of caregiver burden. Kim et al. (2012) studied caregivers of patients with dementia and determined that functional decline of the patient was the most significant predictor of caregiver burden; in this study, caregiver sociodemographic factors (e.g., age, gender, relationships, co-residence) and caregiving-related factors (e.g., total hours of caregiving, number of helpers, coping strategies) resulted in caregiver burden. In a study by Emanuel et al. (2000) involving caregivers of patients with terminal illnesses, caregiver burden increased when care needs imposed greater economic hardship on their families; in this study, about 10% of household income was spent on healthcare costs, with families reporting selling assets and taking out loans to make payments. Emanuel et al. (2000) also documented an increased level of depression in caregivers when caring for dying patients. However, caregivers who felt that physicians listened to them about the patient's needs, illness, and treatments reported experiencing less depression. Bakas et al. (2004) found that depression was common among caregivers of stroke survivors with behavioral problems, such as moodiness, irritability, confusion, and memory loss. In addition, caregivers also had difficulty carrying out household tasks and managing finances, but educating caregivers and informing them that changes in patient behavior are a result of the stroke were found to be helpful (Bakas et al., 2004).

In an exploration of caregiving in the palliative phase, Grov et al. (2006) reported that depression and anxiety were associated with caregiver burden, and that caregivers with poorer health had increased levels of depression and anxiety. These results were consistent with those in a study by Grunfeld et al. (2004), who reported that depression and anxiety were experienced by caregivers. Depression experienced by the patient and the caregiver was similar at 12% and 11%, respectively, at the start of the palliative period. However, more caregivers than patients became depressed as the patient's condition deteriorated (30% versus 9%, respectively). Similarly, caregivers were more anxious than patients (35% versus 19%, respectively). These psychological morbidities in caregivers occurred at the patient's initial diagnosis of breast cancer and progressed as the caregiver's burden increased and the patient's condition reached its terminal stage. Grunfeld et al. (2004) also indicated that caregiving resulted in economic and occupational burdens near the end of the patient's life, with 77% of caregivers reporting missing work. As the patient's condition deteriorated, 5% of caregivers stopped working, whereas others reduced their work hours or took leave.

Prescription medications were reported to be the most significant financial burden. Families without extended healthcare coverage experience more burden (Grunfeld et al., 2004).

Caregiver Burden and Ovarian Cancer

Research is emerging to evaluate the burden specifically experienced by caregivers of patients with ovarian cancer. Price et al. (2010) found that the rate of anxiety in patients was 15%, similar to the community norm, but depression among patients was 6%, double the community norm. In contrast, 42% of caregivers reported elevated anxiety, 19% rated at a clinical level, and 5% had clinical depression. Lower social support and optimism were predictors of depression and anxiety in this sample of patients and caregivers. Another study of caregivers' quality of life (QOL) when caring for patients with ovarian cancer in their last year of life indicated that caregivers' mental and physical well-being deteriorated over time, with an increase in distress (Butow et al., 2014). This distress was also related to the lack of social support from family and friends but also from the cancer care team. The caregivers' unmet needs changed over time, from receiving support and discussing the disease with family to experiencing issues such as disappointment and fear of the unknown. Studies evaluating the QOL of caregivers of patients with ovarian cancer during chemotherapy treatment showed similar findings. Le et al. (2004) found a 77% improvement in QOL in caregivers at the completion of chemotherapy, and a correlation was observed between the caregiver's QOL and the patient's emotional, functional, and concern domains of QOL, indicating increased patient-related stress connected to worsening QOL of the caregiver. Qualitative research has also explored this concept of interrelated patient and caregiver experiences. In one study of the lived experience of ovarian cancer, patients discussed the difficulties of having ovarian cancer and the perceived caregiver burden (Strumpf & Buhler-Wilkerson, 2010). Themes that emerged included the economic, physical, and mental costs of unpaid caregiving; changes in the relationship between the caregiver and the patient; and issues related to the decision-making process (i.e., who should make decisions and how to make decisions).

The primary objective of this pilot study was to determine the level of caregiver burden experienced by the primary caregiver of a patient with end-stage ovarian cancer. A secondary aim was to identify the variables associated with caregiver burden to gain insight into the impact on caregivers of caring for patients with end-stage ovarian cancer.

The conceptual framework used to guide this study was Lazarus and Folkman's (1984) theory of stress, appraisal, and coping. It is a transactional model in which stress can be thought of as resulting from an imbalance between demands and resources or as occurring when pressure exceeds one's perceived ability to cope.

Methods

This pilot study used a descriptive, cross-sectional design. The primary investigator (PI) is a nurse practitioner at an urban comprehensive cancer center. The PI identified a convenience sample of 50 patients with end-stage ovarian cancer with Karnofsky Performance Scale scores of 30 or less. Karnofsky scores range from 0–100, with 0 indicating death and 100

indicating a patient with normal physical functioning; a score of 30 equates to a severely disabled or debilitated patient for whom hospital admission is indicated but death is not imminent. The eligible patients indicated their primary caregiver who was approached for participation. In this study, caregivers included the patients' spouses, significant others, children, and close friends. The sample was limited to participants who could read and write in English. This study was determined to be exempt from review by the center's institutional review board.

A survey packet and cover letter stating the goals, purpose, and anonymous, voluntary nature of the survey were given to each patient and primary caregiver. The survey contained the Caregiver Reaction Assessment (CRA) instrument and basic demographic questions that were completed by the caregiver only in reference to himself or herself. The CRA is a 24-item scale that is divided into five subscales: disrupted schedules, financial problems, lack of family support, health problems, and caregiver self-esteem (Given et al., 1992). Items on this scale are rated on a five-point Likert-type scale ranging from 1 (strong agreement) to 5 (strong disagreement). Psychometric testing in various populations has supported the CRA's construct validity, and internal consistency has been reported to range from 0.57–0.85 (Given et al., 1992; Grov et al., 2006; Nijboer et al., 2000).

To ensure anonymity and confidentiality, caregivers placed the survey, completed or not, in a sealed envelope and returned it to the PI. Because this study was a pilot study, responses were collected until 50 participants completed the survey. Fifty-six patients were approached, with six caregivers choosing not to participate as indicated by the return of blank forms. Because the survey was anonymous, determining reasons for nonparticipation was not possible. Data collection took four months.

Data were analyzed using Pearson correlations and independent samples t tests to assess the relationship between CRA subscales and demographic variables. Analyses were conducted using SPSS®, version 19.0.

Results

Caregiver ages ranged from 29–81 years, ($\bar{X}=52.6$ years, $SD = 13.7$). Most participants were Caucasian ($n = 36$) and married or living with a partner ($n = 38$). The majority of the primary caregivers had a college degree ($n = 32$) and earned less than \$90,000 annually ($n = 28$).

Participants, in general, agreed most with the self-esteem scale, indicating that they enjoyed and felt privileged to be caring for their loved one. Nonetheless, subscale scores showed that disrupted schedules and financial problems were burdensome to the caregivers. Pearson correlation testing (see Table 1) showed significant moderate positive correlations between most of the negatively themed subscales (all but the self-esteem subscale were negatively themed), with the exception of disrupted schedules and financial problems. The self-esteem subscale did not significantly correlate with any of the negative subscales, indicating that the caregiver's personal feelings about providing care were independent of the difficulties associated with the provision of care.

Analysis of demographic variables and CRA subscales did not, in general, suggest a relationship between the two, with the exception of financial problems and disrupted schedules. Predictably, caregivers who reported an income of less than \$90,000 per year noted greater financial burden than caregivers whose income exceeded \$90,000. However, caregivers in the higher income group reported higher levels of schedule disruption than those in the lower income group. Similarly, participants without a college degree had greater levels of financial burden than those with a college degree. Unemployed or retired participants reported higher levels of schedule disruption than those who were employed (see Table 2).

Discussion

This study demonstrates that caregiving of women with end-stage cancer is burdensome. In the CRA subscales, participants agreed with the self-esteem scale, indicating that the caregivers enjoyed and felt privileged to be caring for their loved ones. However, subscale scores showed that disrupted schedules and financial problems were burdensome to the caregivers. Caregivers were not prepared for the potential changes in their life, such as demands on time, adjustments to work schedules, financial issues, and additional responsibilities. As previously noted, financial issues occurred as caregivers reduced work from full-time to part-time and also increased expenses for medications and supplies (Le et al., 2004).

Except for the disrupted schedules and financial problems, Pearson correlation testing showed significant moderate positive correlation between the negatively themed subscales. For example, the self-esteem subscale did not significantly correlate with any of the negative subscales, indicating that the caregiver's personal feelings about providing care were independent of the difficulties associated with the provision of care. This emphasized that the caregivers felt privileged and enjoyed providing care to their loved ones despite the difficulties. No relationship was shown between the analysis of the demographic variables and CRA subscales, except for the disrupted schedules and financial problems.

Emanuel et al. (2000) reported that patients with increased care needs imposed great economic hardship on the family. About 10% of the household income was spent caring for the patient, resulting in the family taking out loans, getting second jobs, and finding other means to pay for healthcare costs. Caregivers with lower incomes had increased burdens and stress when financially supporting their sick loved ones. In addition, caregivers who earned less had fewer resources to devote to healthcare supplies and patient needs, resulting in increased stress, worries, and burdens (Emanuel et al., 2000; Nijboer et al., 2000).

In the current sample, caregivers earning more than \$90,000 annually had greater difficulties with adjusting their schedule. One solution is a multidisciplinary team to ensure that the caregiver is informed of the patient's condition, health changes, and needs. Nurses and social workers can provide support and referrals to resources for financial and medication assistance, as well as help from community organizations and support groups. Providing respite from caregiver duties is important because disruption of schedules has been demonstrated to be problematic. Burdens can also be reduced by implementing interventions

that can provide assistance with patient care without extra cost or effort on the part of the caregiver (e.g., hospice, homecare services, unskilled caregivers). Caregivers not only need to know how to care for the patient but also how to care for themselves (Bakas et al., 2004).

Opportunities for additional research include studies to examine how the health status of caregivers is affected by caring for terminally ill patients with ovarian cancer. Identifying cost-effective interventions for patient–caregiver dyads and determining how they affect the overall cost of patient care and use of services may also be important.

Implications for Nursing

Nurses are counselors and educators who can help caregivers with coordination of care. Caregivers need preparation to meet the demands of their responsibilities, including physical, psychological, social, and spiritual support. Education and support are necessary to address caring for a loved one and maintaining their own health status, including medical and dental care. Nurses can provide symptom management education prior to discharge and also make the patient and his or her family aware of a 24-hour telephone support line offered by CancerCare (1-800-813-HOPE) that is available to answer questions confronting caregivers. Referrals can include assistance from the dietitian for patients with eating problems and support from rehabilitation for issues including fatigue, decreased stamina, and dyspnea. Referrals to a social worker may include psychological support, as well as information on how to address legal, financial, and health insurance problems. Nurses can also make caregivers aware of networks that can be of assistance, such as the ACS, Caregiver Action Network, and National Alliance for Caregiving.

Conclusion

As a result of improved treatments and changes in healthcare systems, women with advanced ovarian cancer are living longer and often require complicated care in their home by a family member or friend. This study found that caregiving for these patients is burdensome, but caregivers enjoyed it and felt privileged to care for their loved ones. The largest burdens related to disrupted schedules and financial problems. Preparing the caregiver to meet various caregiving demands, as well as providing education regarding symptom management and assistance with referrals to resources for financial and medication assistance, are among the primary nursing responsibilities. The caregiver should be encouraged to take respite from caregiving duties, whenever possible.

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Implications for Practice

- ▶ Help coordinate and prepare caregivers to meet the increased demands and responsibility of caring for someone with advanced ovarian cancer.
- ▶ Provide information on symptom management and contacts for support.
- ▶ Encourage caregivers to take care of themselves and use caregiver support groups.

TABLE 1

Pearson Correlations Among Caregiver Reaction Assessment Subscales

Variable	Caregiver Esteem	Lack of Family Support	Financial Issues	Scheduling Issues	Health Issues
Caregiver esteem	–	–0.24 *	–0.24 *	–0.19	–0.21
Lack of family support	–	–	0.41 **	0.52 **	0.45 **
Financial issues	–	–	–	0.17	0.44 **
Scheduling issues	–	–	–	–	0.33 *
Health issues	–	–	–	–	–

*
p < 0.05,
**
p < 0.001

TABLE 2

T Scores for Caregiver Reaction Assessment Subscales (One-Sided)

Variable	Education		Income		Employment	
	T Score	p	T Score	p	T Score	p
Caregiver esteem	0.26	0.4	1.16	0.13	0.42	0.34
Lack of family support	1.39	0.09	0.12	0.45	1.57	0.06
Financial issues	2.23	0.02	1.8	0.04	1.57	0.06
Scheduling issues	0.62	0.27	1.93	0.03	2.39	0.01
Health issues	1.35	0.09	0.31	0.38	0.33	0.37