



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 characterized by late-stage diagnoses, frequent recurrences, and treatment changes. Ovarian cancer caregivers (OCC) are thus heavily involved with cancer care and often are highly distressed.

Methods We explored the relationship with OCC distress and caregiving experiences within the healthcare system and with the healthcare providers (HCP), using a cross-sectional questionnaire study. OCC provided sociodemographic and patient medical information, and completed measures of consequences of caregiving and needs from HCP, and of depression and anxiety. We recruited participants through advertisements and two cancer centers.

Results $N = 82$ OCC 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 OCC 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 OCC 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

Background

Ovarian cancer

In 2019, ovarian cancer accounted for 5% of cancer deaths among women [1], and its 5-year survival rate is 41% for stage III and 20% for stage IV [2]. Seventy-five percent of ovarian cancers are diagnosed at an advanced stage due to a lack of effective early detection strategies [3]. Treatments typically involve surgery, chemotherapy, and targeted drugs, often with a high risk of side effects [1]. As the disease progresses, treatments become limited and care increasingly becomes family members' responsibility [4]. Research suggests that ovarian cancer patients experience more distress than other cancer patients [5], and their caregivers also are highly distressed [6, 7].

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Caregiving for survivors across disease sites

Caregivers are heavily involved in the patient's disease management, assisting in treatment adherence, and providing emotional support [8–10], typically providing 70–80% of patient care [11]. Caregivers report prioritizing the patient's health and well-being over their own and struggling with self-care [12, 13]. They are equally and sometimes more distressed than patients [6, 14], and this distress may in part stem from unmet needs [15]. Cancer caregivers frequently report concerns with their relationship with healthcare providers (HCP), including insufficient support in dealing with difficult feelings [13]. They report needing more help making cancer-related decisions [13], which is correlated with higher levels of depression and anxiety [15].

A large sample of cancer caregivers ($N = 590$) was recently investigated to describe the caregiving experience in relation to the healthcare system [16]. 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 [16].

The significance of the caregiving role has been increasingly recognized; however, most research focuses on general cancer samples, or more prevalent tumor sites (e.g., breast and prostate) [9]. As ovarian cancer is characterized by late diagnosis, multiple recurrences, and changes in treatment, their caregivers merit specific focus [7]. Additionally, many ovarian cancer caregivers (OCC) are male-spouse caregivers, who are underrepresented in the literature [8].

Ovarian cancer caregivers

A scoping review on OCC found that relationships with HCP influenced the caregiving experience [7]. OCC reported needing more information from HCP throughout the disease trajectory [17], and wanting more recognition and support from HCP [17]. OCC have reported feeling abandoned by the cancer care team when they were not helped, and that they were passive in relation to OCC needs [17]. OCC often lack time to attend to all of their responsibilities and disrupted schedules due to their role [18, 19]. This merits consideration as OCC have reported higher levels of depression and anxiety as compared with non-clinical community norms, and their distress increases over the disease trajectory [20].

Distress related to caregiving in the healthcare system

North American cancer care is highly reliant on informal caregivers [21–23], but it is unclear how the relationship between

caregivers and cancer care may influence OCC distress. Frequently rated unmet needs among caregivers are not always predictive of their distress [15], and thus these correlations should be tested. Our objectives were thus to describe the OCC experience of cancer care and to determine which experiences are 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 [24]. It yields nine subscales: caregiving workload, lack of attention from HCPs around caregivers' well-being, 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 [25].

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 [10, 13, 17, 18], lacking attention from HCP on caregiver well-being [17] and caregiver workload [10, 13], and lacking time for social relations [10, 18]. The other CaTCoN subscale was tested, but due to insufficient literature, these correlational analyses were exploratory.

Methods

This analysis was part of a larger multicenter study investigating partner caregivers of ovarian cancer patients. 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 centers 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 patients 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 2 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.

Sociodemographic 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 [25]. 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 so long as half the subscale items were weight-bearing [16]. 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 [25, 26]. 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 [27]. 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 [28]. This scale has been used in several studies evaluating both patient and caregiver depression and anxiety outcomes [29]. This self-report scale has 14 items that are equally divided into two subscales: anxiety (HADS-A) and depression (HADS-D) [28, 30]. The internal validity is statistically acceptable, as a good level of internal consistency was determined (HADS-A: Cronbach’s $\alpha = 0.85$; HADS-D: Cronbach’s $\alpha = 0.84$). Factor analyses support the two-factor structure of the HADS, and recent literature discourages the use of a total score [31]. 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 [28].

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 sociodemographic 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 [32].

Results

A total of *N* = 82 participants returned questionnaires between October 2017 and 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

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	<i>N</i> (%)
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)
Ethnicity	
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)

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 well-being (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

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	Cron. alpha
<i>Workload (4 items total)</i>	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		
<i>Problems with the quality of information and communication with healthcare providers (7 items total)</i>	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 healthcare 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		
<i>Lack of information from healthcare providers (8 items total)</i>	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		
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		
<i>Lacking attention from healthcare providers around the caregiver's well-being (4 items total)</i>	72 (87.8) ^b		51.8 (30.4)	.86
Have the healthcare professionals in the hospitals shown interest in whether you as a caregiver have been able to handle the situation?				

Table 2 (continued)

Subscale Subscale items ^a	N (%)	%	Mean (SD) ^c	Cron. alpha
Always/almost always		18.3		
Mostly		23.2		
Only sometimes		18.3		
Rarely/never		34.1		
Have the healthcare 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		
<i>Lack of time for social relations (2 items total)</i>	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		
<i>Lacking privacy during conversations with healthcare providers (2 items total)</i>	44 (53.6) ^b		24.4 (29.8)	.66
Have the healthcare professionals' converse 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		
Have the healthcare professionals' converse 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		
<i>Need help from healthcare providers (2 items total)</i>	30 (36.6) ^b		12.8 (21.0)	.79
Have you needed help from healthcare professionals to find out the best way for you and the patient to handle the illness in practical terms?				
<i>Responded yes, and then asked "was need met?"</i>		46.3		
To a high degree		17.1		
To some degree		23.2		
To a low degree		3.7		

Table 2 (continued)

Subscale Subscale items ^a	N (%)	%	Mean (SD) ^c	Cron. alpha
Not at all		2.4		
Have you needed help from healthcare professionals to find out the best way for you and the patient to handle the illness emotionally? <i>Responded yes, and then asked “was need met?”</i>		31.7		
To a high degree		4.9		
To some degree		15.9		
To a low degree		6.1		
Not at all		3.7		
<i>Lack of personal growth (3 items total)</i>	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

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 was 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 with 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 was 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 ($r = 0.56$; $p > 0.00$), and 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

Table 3 Correlations between caregiving experiences with the healthcare system and depression and anxiety scores

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

^a These scores were controlled for age and site

^b *N* values are reported as participants could respond “do not know/not relevant,” in which case their scores were not considered, and bolded values indicate statistically significant correlations

information and communication with HCP ($r = 0.26$; $p = 0.02$). Lacking attention from HCP around the caregiver’s well-being and personal growth and lacking privacy during conversations with HCP were not 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 well-being, and having problems with the quality of information and communication with HCP and personal growth were not 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 sub-clinical 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 cancer caregivers ($M = 3.80$; $SD = 3.63$ for depression; $M = 6.40$; $SD = 4.5$ for anxiety) [31]. The prevalence was also higher as compared with 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 [33].

Caregiving consequence 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 well-being, 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, OCC studies on personal growth have found no relationship with distress [34].

Our study findings highlight important variables of the caregiving experience that may be contributing to caregiver distress. Specifically, OCC 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 [35] that posits that coping with stressful circumstances depends on the availability of necessary resources 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 [24]. OCC's higher distress compared with the general caregiving population may suggest a bigger discrepancy between the demands of care required from OCC 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 [8], 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 [36], and clinicians tend to underestimate men's distress [37]. Our study results also highlight sociodemographic 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 with major cities with large cancer centers. 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 [38]. 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 [39]. 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 [40]. Systemic barriers to caregiver support in cancer care may disproportionately disadvantage less-privileged caregivers [39], 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 [41]. Such investigations may also help to identify caregiver support needs from HCP.

Our study highlights an understudied disease population, but neglects socioeconomic, 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, OCC 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. OCC may feel better supported by cancer care teams if they are given time to discuss their needs and ask questions. Distressed OCC 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, OCC are not formally recognized as part of cancer care, and our study suggests that this major chasm has a direct impact on OCC 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.

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Data availability Not applicable.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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.

Code availability Not applicable.

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