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Patient quality of life and caregiver experiences in ovarian cancer: How are they related?

Elisa Stragapede[1] · **Danielle Petricone-Westwood**[2] · **Sarah Hales**[3] · **Jacqueline Galica**[4] · **Sophie Lebel**[1]

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Abstract

Purpose Patients with ovarian cancer and their spousal caregivers report similarities in health-related quality of life (HRQoL) and experiences throughout the cancer process. Previous research has reflected these shared experiences, demonstrating caregivers' capacity to accurately rate their patient-partner's HRQoL as a proxy. In response, this study examines associations between caregivers' perceptions of their patient-partner's HRQoL and their own caregiving responsibilities, consequences to well-being, and desired assistance from the healthcare system. This study will be beneficial when developing supports to assist caregivers throughout the cancer journey.

Methods Using a cross-sectional survey design, spousal caregivers ($N = 82$) of patients with ovarian cancer completed measures on perceived patient HRQoL and caregiver experiences. Correlation analyses determined medical and sociodemographic covariates. A multivariate multiple regression was conducted using four proxy HRQoL functioning subscales and three factors of reported experiences as caregivers in cancer. Post-hoc univariate regression analyses were run on significant factors to assess the associations that exist.

Results Caregiver-perceived patient physical functioning was significantly associated with more caregiving tasks after controlling for education, age, and stage of ovarian cancer, but no other HRQoL functioning scale (i.e., role, emotional, social) was associated with caregiver experiences.

Conclusion The study provides a unique perspective into the caregiver experience by attending to interpersonal factors in relation to caregiver experiences. Results may be able to guide interventions aimed at supporting caregivers through the cancer process by offering more assistance with tasks as their partner's physical condition worsens.

Keywords Caregivers · Ovarian cancer · Quality of life · Experiences · Tasks

Plain English summary

Caregivers are important for patients through the cancer journey. Caregivers, specifically those who are the spousal caregivers of a patient, take on a lot both physically and psychologically but are less often included in research. Since both caregivers and patients are experiencing the cancer journey together, it is possible that a patient's quality of life may have an impact on the care a caregiver is able to provide. In this study, we explored the link between patient quality of life and caregiver outcomes. In particular we looked at whether the tasks a caregiver takes on, their needs, and the consequences of caregiving are greater when a patient's quality of life is lower. We found that when patient's physical quality of life was reported as worse, caregivers took on more tasks (e.g., helping a patient with personal care, more responsibility to care for the home). With our results, it may be helpful to develop supports for caregivers that improve their own experience, and ultimately, the experience for a patient.

✉ Elisa Stragapede
estra036@uottawa.ca

[1] School of Psychology, Vanier Hall, University of Ottawa, 136 Jean Jacques Lussier Private, Ottawa, ON K1N 6N5, Canada

[2] Juravinski Cancer Centre, Hamilton Health Sciences, Hamilton, Canada

[3] Department of Supportive Care, Princess Margaret Cancer Centre, University Health Network, Toronto, Canada

[4] School of Nursing, Faculty of Health Sciences, Queen's University, Kingston, Canada

Introduction

Patients with ovarian cancer and their caregivers report similarities in quality of life and experiences throughout the cancer process [1, 2]. Health related quality of life (HRQoL) refers to one's daily level of ability and functioning, specifically in relation to disease and treatment [3, 4]. For patients, HRQoL can be severely impacted over time as their physical capabilities lessen and/or if they lack proper support from healthcare teams [5]. Their caregivers (e.g., partner, family member, friend) have also reported lower physical and psychological HRQoL over time especially when they have unmet needs [6]. This may be because caregivers share many experiences with patients such as hospital visits in addition to caretaking responsibilities. Within patient-caregiver dyads, both parties report a need for information, transparency, and strong communication from the healthcare team [1]. Family members, such as spouses, can, and often do, take on the role of the caregiver for their partner with cancer [7, 8]. As a *caregiver* of someone with cancer, a person takes on the health-related tasks and responsibilities (e.g., medication adherence, appointment management) that their partner is not able to complete independently [9]. As a *partner* of someone with cancer, the developed emotional and romantic connection could be useful to aid in empathic understanding of a patient's experience. When an individual is both a caregiver *and* a partner, they may rely on both health-related knowledge and intimate connection in order to properly perform tasks and responsibilities associated with caring for their partner with cancer. These shared and intraindividual experiences may give caregivers an accurate perception of the state of their partner and may be helpful when they are reporting on behalf of their patient-partner's HRQoL. While there may be improved advocacy if caregivers can accurately perceive their partner's HRQoL, this may also contribute to more caregiver tasks and caregiver distress. This emphasizes the importance of understanding the relationship between caregiver distress and their reports of patients HRQoL.

It is possible that the combination of involvement with the cancer process and personal knowledge of the patient's emotional and physical well-being gives caregivers the ability to better understand their partner's state better. In fact, recent work with head and neck cancer populations has demonstrated there may be discrepancies among caregiver perceptions of patient HRQoL [10]. In contrast, breast and prostate cancer caregivers were better than healthcare providers at accurately reporting domains of patient HRQoL [11]. Similarly, a study including ovarian cancer caregivers demonstrated they were able to accurately report many domains of patient HRQoL such as physical functioning, role functioning, and symptom experience [12]. This suggests that caregivers may be able to provide accurate descriptions of their partner's HRQoL (e.g., their mental, physical, and emotional state), which is especially useful in cases when the patient is unable to provide this information themselves.

At the same time, there is a mental and physical toll applied to caregivers during the cancer process, which can add to their tasks (e.g., workload and responsibilities) and needs (e.g., informational, attentional, communicational) and can contribute to negative consequences associated with caring for a loved one [6, 13]. A caregiver whose partner has more physical demands (e.g., difficulty with daily living) likely takes on more caregiving responsibilities [14] and/or requires more assistance from the healthcare system [15]. This is particularly the case with ovarian cancer, which often occurs later in life, and requires multiple intensive interventions that necessitate greater assistance with physical and daily living tasks [6]. Similarly, a caregiver who has less time to spend on hobbies or social activities could experience more negative consequences to their own well-being [6]. Qualitative research with ovarian cancer patients and carers has illustrated their similar emotional experiences (fear, helplessness, and uncertainty) and needs (gaining information from HCPs, social and personal life changes, and needing support during the cancer process) [2]. This work provides evidence for the physical and emotional demands that can exist during the cancer process and focuses the attention on the responsibilities and needs during care that may have consequences on both the patient's and caregiver's life. The similarity in physical and emotional experiences suggests that a caregiver's perception of patient HRQoL may have a direct impact on their experiences and responsibilities (e.g., tasks, needs, and consequences), and while these two variables have been studied individually, to our knowledge no work has examined them together.

The present study was designed to examine the interpersonal factors that play a role in the experiences for partner-caregivers of patients with ovarian cancer. Most research has focused on the intrapersonal characteristics of caregivers (e.g., attachment [16]; anxiety and depressive symptoms [17]; personality [18]), but it is possible that caregivers' appraisal of the patient's state could play a role in their responsibilities during the cancer process, and needs from the healthcare team. Therefore, the present study analyzed caregiver reported patient HRQoL (i.e., physical, role, emotional, cognitive, and social functioning) and caregiver experiences (i.e., tasks, needs, and consequences) in ovarian cancer caregivers. Though exploratory in nature, we hypothesized that caregiver perceived patient HRQoL would be associated with caregiver experiences, such that lower scores on physical, role, emotional and/or social functioning would be associated with higher scores on caregiving tasks, needs, and consequences.

Methods

This study is part of a larger cross-sectional study examining the experiences of partner-caregivers of patients with ovarian cancer [19].

Participants

Participants were recruited if they identified as the partner of a patient with ovarian cancer and met the eligibility criteria. Data were collected through surveys sent to eligible participants recruited from advertisements (i.e., newsletters and conferences) and cancer centres: the Princess Margaret Cancer Centre of the University Health Network (UHN), and the Cancer Centre of Southeastern Ontario (CCSEO).

Inclusion criteria

To be recruited for the study, participants had to (1) be over the age of 18 years old, (2) be the spouse and primary caregiver for the patient with ovarian cancer, (3) be English or French speaking, and 4) have met the patient's healthcare provider (i.e., their oncologist). Participants were excluded if their partner had been diagnosed and completed cancer treatment more than five years prior.

Data collection

EORTC-QLQ-C30 version 3.0

The European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ-C30 [20]) version 3.0 is a well-validated measure of HRQoL and includes a proxy rating scale which was designed to allow caregivers to complete the questionnaire from their perspective on the patient's HRQoL [21]. The scale consists of 30 items divided into symptom and functioning subscales. For this study, only the functioning subscales (i.e., physical, role, emotional, cognitive, social) were used. By using this method, instead of a global health score, each of the subscales can identify caregivers' perceived patient level of functioning for each domain, with higher scores indicating better functioning. This is beneficial for the present study because examining these domains more specifically with caregiver experiences provides a unique perspective that has yet to be addressed in caregiver literature. For each item, participants used a 4-point scale ranging from 1 "Not at all" to 4 "Very much"; higher scores indicated more healthy functioning within that scale [22]. Cronbach's alpha coefficient for physical functioning, role functioning, emotional functioning, and social functioning ranged from 0.72 to 0.88 indicating good internal consistency. Cognitive functioning did not meet adequate internal consistency (a = 0.61) and was removed from further analyses. It should be noted that an addition to the EORTC-QLQ-C30 was developed specifically for ovarian cancer (QLQ-OV28 [23]) but questionnaire length and time constraints deterred the possibility of its inclusion.

CaTCoN

The Caregiver Tasks, Consequences and Needs Questionnaire (CaTCoN [24]) was designed to assess caregiver experiences throughout the cancer process. During the initial creation of the questionnaire, Lund and colleagues [24] outlined 72 items, two of them open-ended questions (not used for this analysis), fitting into three factors: (1) tasks, (2) consequences, and (3) needs.[1] The authors then divided 48 of these items into nine subscales pertaining to caregiver experiences: workload, lack of attention from HCP, lack of information from HCP, lack of personal growth, lack of privacy during conversations with HCP, lack of time for social relations, need for contact with other caregivers, need for help from HCPs, and problems with quality of information and communication from HCPs. Caregivers are given a total score for each of the nine subscales which summarize the extent to which they experience difficulties in each category. This can be useful when disseminating which aspects of the caregiver experience are difficult for a given population of caregivers. Though the subscales are most often used in analyses, they do not incorporate all original items and thus leave out a lot of useful data (i.e., 24 items) about the caregiver experience. In this way, it becomes useful to examine the items more broadly, for instance, through their overarching factors (i.e., tasks, consequences, and needs) as each factor's total score is more inclusive of the items asked within the questionnaire while still attending to the varying difficulties that may be experienced as a caregiver.

A total of 55 items were included in the analyses and the division of questions is outlined in Online Resourse 1. The *Tasks* factor consists of 6 items asking about the physical and psychological assistance caregivers provide to patients, their home, and themselves and their collaboration with the healthcare team. The *Needs* factor consists of 40 items asking about involvement and communication with healthcare professionals, informational needs related to the cancer

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[1] The present study uses the original three factors (i.e., tasks, needs, and consequences) to provide stronger, more comprehensive interpretations to explain caregiver experiences. The main researcher, E. S., contacted Dr. Line Lund (CaTCoN [24]) who indicated this method would be suitable.

process, and caregiver tasks and relationships. The *Consequences* factor consists of 9 items asking about the positive and negative consequences associated with functioning as a caregiver.

The CaTCoN has been validated in previous work [25], and for the present study, the three factors generated adequate to strong Cronbach's alpha coefficient: Tasks (a = 0.72), Needs (a = 0.91), and Consequences (a = 0.75).

Data analysis

All data were analysed using IBM SPSS (Statistical Package for the Social Sciences) Version 27.0. Descriptive statistics, including mean, standard deviation, percentages, and minimum and maximum values were computed for continuous variables. There were only 1.43% missing data, which were handled using a simple imputation method. Our target sample size of 77 participants was generated using a medium effect size for multiple regression ($f^2 = 0.15$) and four predictor variables to achieve adequate power and significance ($b = 0.80$, $a = 0.05$).

Correlations and covariates

Correlational analyses for potential covariates in the regression model examined caregiver and patient variables using Pearson (i.e., age of caregiver) and Spearman (i.e., dichotomized stage of patient's ovarian cancer and education of caregiver) correlations.

Multivariate multiple regression

We used a multivariate multiple regression (MMR) as a first step in examining the data. We conducted preliminary analyses to address assumptions associated with multiple regression, to which the data showed no violations of the assumptions of normality, linearity, and multicollinearity.

MMR was used to examine the effect of the four independent variables of caregiver perceived patient HRQoL on each of the three dependent variables of caregiver experiences. Because this study is exploratory and novel, a Bonferroni correction was not deemed necessary during these initial analyses. MMR was performed to assess whether caregiver perceived patient HRQoL (physical, role, emotional, and social functioning) predicted caregiver experiences (tasks, needs, consequences). Before proceeding to examine any effects on dependent variables, a preliminary multivariate test was conducted. A preliminary test, using Wilks' Lambda for example, can be conducted in multivariate statistics to provide researchers with information on how well the outcome variables fit the model using a combination of dependent variables, with only the significant associations being analyzed further [26, 27]. In the present analyses, Wilks' Lambda was computed using the four caregiver perceived HRQoL variables with caregiver experiences as a total of the dependent variables (i.e., tasks, needs, consequences). Thus, MMR allows for further examination of significant results, whereby post-hoc univariate analyses of the individual items of caregiver experiences could be conducted to determine more specifically where the significance exists.

Univariate regression analyses

To further understand associations, post-hoc analyses were computed using physical functioning and the six items of the caregiver tasks grouping. A Bonferroni correction was applied to these univariate analyses such that only those regressions with an alpha below 0.008 would be considered significant.

Results

Demographic characteristics

We had a response rate of 35.7% from UHN, but were unable to ascertain response rates from other recruitment methods (i.e., advertisements, CCSEO). Reasons for non-participation are unknown. The sample consisted of 82 mostly white (89.9%), mostly male (97.5%) partner-caregivers with an average age of 57.2 (SD = 12.1; min: 45.1, max: 69.3). Participants were highly educated (62.2% with post-secondary education or higher) with high household incomes (52.5% with total income over $100,000). On average, the length of the caregiver-patient relationship was 28.5 years (SD = 14.8; min: 13.7, max: 43.3). Patients were diagnosed with ovarian cancer, on average, 20.8 (SD = 28.6) months prior to enrolling in the study. Most participants were diagnosed with stage III disease (53.9%) and had surgery and chemotherapy (80.2%). These socio-demographic characteristics and medical statistics are repeated from previously published work [19].

Correlations and covariates

Caregiver education level was positively correlated ($\rho = 0.31$, $p = .004$) and caregiver age was negatively correlated ($r = -.23$, $p = .041$) with the physical functioning scale of the EORTC, as perceived and reported by caregivers. This suggests that caregivers who were more educated and younger reported better perceived patient physical functioning than caregivers who were less educated and older. Stage of ovarian cancer was negatively correlated with the physical functioning scale ($\rho = -0.346$, $p = .002$) and the

Table 1 Pearson and Spearman correlations with CI 95% [LB, UB] between sociodemographic variables and caregiver perceived patient quality of life functioning scales

	Correlation method	Physical functioning	Role functioning	Emotional functioning	Social functioning
Highest level of caregiver education	Spearman	.311** [.094, .499]	.114 [− .112, .329]	.000 [− .223, .223]	.160 [− .066, .371]
Caregiver age	Pearson	− .230* [− .427, − .012]	− .065 [− .280, .155]	.132 [− .089, .341]	.102 [− .399, .036]
Stage of patients' ovarian cancer	Spearman	− .346** [− .535, − .124]	− .247* [− .453, − .016]	− .067 [− .294, .168]	− .213 [− .424, .020]

CI 95% [LB, UB] = confidence intervals 95% [lower bound, upper bound]

$^{*}p < .05$

$^{**}p < .01$

Table 2 Correlations and CI 95% [LB, UB] between caregiver perceived patient quality of life functioning scales and caregiver experience factors

	1	2	3	4	5	6	7
1. Physical functioning	–						
2. Role functioning	.600** [.440, .723]	–					
3. Emotional functioning	.413** [.215, .578]	.504** [.322, .650]	–				
4. Social functioning	.592** [.431, .717]	.696** [.564, .793]	.452** [.261, .609]	–			
5. Caregiver tasks	− .463** [− .618, − .274]	− .398** [− .566, − .199]	− .413** [− .578, − .215]	− .416** [− .581, − .219]	–		
6. Caregiver needs	.007 [− .210, .244]	− .147 [− .353, .072]	− .193 [− .394, .025]	− .214 [− .412, .003]	.263* [.049, .454]	–	
7. Caregiver consequences	− .196 [− .396, .022]	− .156 [− .361, .063]	− .265* [− .456, − .051]	− .314** [− .497, − .104]	.497** [.314, .644]	.497** [.314, .645]	–

CI 95% [LB, UB] = confidence intervals 95% [lower bound, upper bound]

$^{*}p < .05$

$^{**}p < .01$

role functioning scale ($\rho = -0.247$, $p = .031$) indicating that a higher stage of cancer was associated with caregivers perceiving lower patient physical and role functioning. Recent work has suggested that only variables with correlations greater than or equal to 0.30 be included as covariates [28]. Age did not meet this cut-off, however, there is justification to include age as a covariate given reported differences among younger and older caregivers [29, 30]. Thus, in subsequent analyses, education, age, and stage of ovarian cancer were controlled for as covariates. See Table 1 for significant correlations of sociodemographic variables and HRQoL variables.

Caregiver tasks was negatively correlated with physical functioning ($r = -.46$, $p < .001$), role functioning ($r = -.40$, $p < .001$), emotional functioning ($r = -.41$, $p < .001$), and social functioning ($r = -.42$, $p < .001$) meaning more caregiver tasks were associated with poorer perceived patient physical, emotional, and social functioning. Caregiver consequences was negatively correlated with emotional functioning ($r = -.27$, $p = .016$) and social functioning ($r = -.31$, $p = .004$) but not with physical functioning or role functioning, meaning that more consequences were associated with less perceived patient emotional and social functioning, Caregiver needs was not correlated with any of the functioning scales. See Table 2 for all correlations between functioning subscales and caregiver experiences.

Patient HRQoL and caregiver experiences

Multivariate multiple regression

After controlling for caregiver education level and age, and patient stage of ovarian cancer, physical functioning was significantly related to caregiver experiences (F = 2.93,

Table 3 Multivariate multiple regression analysis of four caregiver-perceived quality of life functioning scales and three caregiver experience factor, while controlling for caregiver education and age, and patient stage of ovarian cancer

Predictors	*B*	CI 95% [LB, UB]	SE	*t*	*p*	Partial eta-squared
Physical functioning						
Caregiver tasks	− 1.818	[− 3.346, − .291]	.765	− 2.376	**.020**	.078
Caregiver needs	5.193	[− 4.471, 14.856]	4.841	1.073	.287	.017
Caregiver consequences	− .908	[− 3.168, 1.351]	1.132	− .802	.425	.010
Role functioning						
Caregiver tasks	− .169	[− 1.398, 1.060]	.616	− .275	.784	.001
Caregiver needs	− 1.112	[− 8.844, 6.660]	3.894	− .286	.776	.001
Caregiver consequences	1.326	[− .491, 3.143]	.910	1.456	.150	.031
Emotional functioning						
Caregiver tasks	− .962	[− 2.273, .348]	.657	− 1.466	.147	.031
Caregiver needs	− 1.347	[− 9.636, 6.942]	4.153	− .324	.747	.002
Caregiver consequences	− 1.057	[− 2.995, .881]	.971	− 1.088	.280	.017
Social functioning						
Caregiver tasks	− .287	[− 1.653, 1.079]	.684	− .420	.676	.003
Caregiver needs	− 6.696	[− 15.334, 1.941]	4.328	− 1.547	.126	.035
Caregiver consequences	− 1.906	[− 3.926, .113]	1.012	− 1.884	.064	.050

SE = standard error; CI 95% [LB, UB] = confidence intervals 95% [lower bound, upper bound]

Bold values indicate statistical significance

p = .040), whereas role functioning (F = 1.40, *p* = .252), emotional functioning (F = 0.79, *p* = .502), and social functioning (F = 1.43, *p* = .241) were not. As physical functioning was the only significant independent variable, it is the only caregiver perceived patient HRQoL variable that was examined further. Follow-up MMR analyses using physical functioning and the dependent variables (i.e., tasks, needs, consequences) demonstrated that physical functioning was significantly associated with caregiver tasks (F = 5.64, *p* = .020, partial eta squared = 0.078), but not with needs (F = 1.15, *p* = .287) or consequences (F = 0.64, *p* = .425) when controlling for education, age, and disease stage. The full MMR is included in Table 3.

Univariate regression analyses

Two caregiver tasks items were significantly related to physical functioning: providing personal care to the patient (F = 6.17, *p* = < .001) and having too much responsibility for home care (F = 4.24, *p* = .004).

Discussion

The present study examined the association between caregiver perceived patient HRQoL factors (i.e., physical, role, emotional, and social functioning), and caregiver experiences (i.e., tasks, needs, and consequences). We found that physical functioning was significantly related to caregiver tasks, with providing personal care to the patient and excessive household responsibilities as having the most significant effect on their experiences. The results of this study provide insight into caregiver perspectives and experiences and elaborate on our understanding of caregiver's interpersonal factors during their partner's cancer journey.

In the conducted analyses, caregivers' perception of their partner's physical functioning was linked with caregiver tasks and was the only HRQoL scale that was significantly associated with caregiver experiences. Caregivers' tasks can include assisting patients with their medication and treatment, collaborating with the healthcare team on the patients' behalf, caring for the home, among others [8]. Previous work has demonstrated that caregivers have more emotional and physical responsibilities as patients' report more physical needs and less independence [2]. It makes sense, then, that spousal caregivers who perceived their partner as having limited physical functionality would also indicate taking on more tasks as a caregiver.

To expand, univariate analyses demonstrated that providing personal care to the patient and having too much responsibility for home care had the most significant effect for caregivers. The responsibility to provide care to one's partner, self, and home can be an overwhelming and daunting task for one individual. In fact, some caregivers have described scenarios where they stopped looking after themselves during their partner's cancer journey as it was too much work to keep up their own personal care and social life [2, 6, 31]. Caregivers tend to focus their attention on tasks associated with their partner's health and well-being and with household maintenance, but this can become all-consuming and distressing [9, 13]. Previous qualitative work illustrated the emotional hardship caregivers go through during their partners cancer, with some participants emphasizing added tension or frustration due to suppressed emotions [2]. The association between physical functioning and responsibilities for care becomes clear as caregivers who perceive their partner as being less capable to assist with tasks given their reported physical state, are required to take on more of the responsibility despite what this may mean for their own well-being.

Though we did not see any significant relationships between social and emotional factors, it is possible they play a role in coping throughout the cancer process [9, 31]. A patient's inability to engage intimately with their partner or socially with a group of peers could lead a caregiver to perceive lower HRQoL in those areas of functioning. Additionally, patients have identified social support as a main factor that aids in their cancer journey [2]. A caregiver who perceives their partner having poor emotional or social functioning may require more support from healthcare providers, family, or community. Our insignificant results in relation to emotional functioning may be because items were difficult for a caregiver to perceive and thus did not adequately represent the patient's true experience. For instance, one item asks about worry, which can be difficult to interpret if there are few cues from a patient. In this sense, it is possible that self-reported HRQoL would be more impactful when relating to caregiver experiences. As for social functioning, it is possible that our sample consisted of caregivers who perceived their partners as having strong support systems in place, and thus did not feel that emotional or social components, nor their caregiver experience, were impacted.

Interestingly, role functioning did not have a significant impact on caregiver experiences. This was surprising considering the average relationship length in our sample was nearly 30 years. In this length of time, many roles in the relationship have been established such that interruptions like a cancer diagnosis, would shift the other partner's responsibilities and create possible consequences of taking on these new duties [32]. It is possible that the caregivers in our sample had already adjusted their experience to the cancer diagnosis and created a new normal way of living whereby they did not perceive their partners' role functioning to be so limited that it impacted their own experiences. Similarly, it is possible that the older age of this sample may contribute to having fewer roles related to work outside the home or child rearing, leaving minor role transitions to be made after a cancer diagnosis. In this way, well-adjusted caregivers may have attributed their own positive changes to their perceptions of their partners' role functioning, thus perceiving higher functioning and fewer associated difficulties. Like emotional functioning, it may be preferable to use patient-reports for subscales like role functioning that reflect on personal perceptions in relation to the caregiver experience. Future research should consider examining patient role functioning through different age populations and family compositions, as factors such as younger age of cancer diagnosis or having children could impact the way a caregiver perceives their partner's functioning and ultimately how they experience their own role as a caregiver.

Oncology clinicians may consider re-evaluating caregivers' status as they recognize a decline in patients' performance status or physical functioning, in an effort to determine whether caregivers require more homecare supports (e.g., for highly symptomatic patients from disease or side effects of treatment). Future work should address psychosocial factors, such as anxiety and depression symptoms, among caregivers to identify how these aspects of well-being may be impacted by a greater workload.

Limitations

There are limitations that should be acknowledged to improve future work in this area. First, this study used a novel method of assessing items on the CaTCoN scale. To our knowledge, published work with the CaTCoN has used subscales in analyses rather than a factor method. Thus, it is possible that grouping items into three categories rather than its original nine subscales could have reduced the reliability of the results. Though we received approval for this strategy and believe it was analyzed in a way that encouraged transparency and reduced error, it may not have provided as meaningful results as the nine subscales. For the HRQoL measure, it is possible that caregivers had difficulty answering subscales, such as emotional functioning, as they pertained to the patient. While some literature suggests caregivers are adequately able to report on a patient's condition, differences in expressions of empathy and openness with experiences may limit the abilities of caregivers to accurately perceive a patient's HRQoL in various areas (i.e., role, emotional, social). This may have contributed to the null findings.

Second, as mentioned briefly earlier, our response rate was low, and sample was small. Though we applied a Bonferroni correction to account for multiple analyses, the reduced *p*-value and small sample size may contribute to Type II error in our results. It is also possible that our study became underpowered after applying the Bonferroni correction. Additionally, our sample consists of predominantly white men who were, on average, well-educated and had high household incomes. The lack of diversity in our sample may have been due to sampling bias, such that participants with higher socioeconomic status had more opportunity to participate. It is also possible that results may differ for other caregiver populations (e.g., children) who differ in social support, informational, and personal needs [33], or in predominantly female populations who have identified poorer quality of life and lower satisfaction compared to male caregivers [34]. Finally, we did not collect information on whether patients were receiving treatment or had experienced recurrence, which may have impacted caregiver reports of perceived functioning and their own experiences. These combined limitations with our sample reduce the generalizability of our findings to other cancer populations and are an area of opportunity in future work.

Finally, this study used a cross-sectional design to collect data. Cross-sectional studies limit our ability to deduce long-term impacts of a patient's health on the caregiver, and how a caregiver adapts to these changes. It would be interesting to follow caregivers overtime throughout the cancer journey to see how their perception of patient HRQoL, as well as their caregiver experiences, may change.

Conclusions

Caregivers' role in their partners cancer journey can be rewarding [35], but also emotionally and physically exhausting [13]. The results of this study can aid in the development of supports geared towards improving the lives of caregivers as it illustrates how their perceptions of their partner with cancer (i.e., having poorer physical functioning) can have an impact on their experiences (i.e., the tasks for which they are responsible for). Future studies planning to analyze these variables should examine different populations and age groups as experiences and perceptions can differ with cancer site and throughout life.

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Author contributions All authors contributed to this study's conceptualization. Data were initially collected for a larger study by Drs. Danielle Petricone-Westwood and Sophie Lebel. Data analysis for this study was performed by Elisa Stragapede. The first draft of the manuscript was written by Elisa Stragapede and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability The data presented in this study are available from the corresponding author upon reasonable request. The data are not publicly available due to privacy.

Declarations

Conflict of interest The authors have no relevant financial or non-financial interests to disclose.

Ethics approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of Institutional Review Boards of the University of Ottawa (Approved 19 July 2017, REB#: H05-17-02), Queen's University (Approved 19 November 2018, REB#: NURS-455-18), and the University Health Network (Approved 25 February 2019, REB#: 18-5213).

Consent to participate Informed consent was obtained from all individual participants included in this study.

Consent to publication The authors affirm that all individual participants provided informed consent for the publication of results. No identifying information is included in this manuscript.

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