



Conflicting views during gynecologic cancer care: a comparison of patients' and caregivers' perceptions of burden

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Abstract

This study describes the experiences of cancer caregivers and compares these experiences with patients' assessment of cancer's toll on their caregiver. Participants (16 patient-caregiver dyads) were recruited from a NCI cancer center of excellence in the northeastern United States. Patients were in treatment for ovarian ($n=7$), uterine ($n=2$), or endometrial ($n=7$) cancers. Caregivers included 7 women and 9 men who described themselves as spouse/partner ($n=7$), adult child ($n=4$), sister ($n=2$), parent ($n=1$), nephew ($n=1$), and friend ($n=1$). Participants completed semi-structured individual interviews that focused on perceptions of caregiver burden or the impact of the patient's diagnosis on the caregiver specifically. Data were coded inductively to identify themes present within participants' responses. This process included open and axial coding. Two overarching themes emerged: (1) patient-caregiver agreement and (2) patient-caregiver disagreement. Patient-caregiver agreement included two subthemes: (1) weight gain and (2) weight loss. Patient-caregiver disagreement consisted of two subthemes: (1) differing perspectives of quantity and quality of caregiving provided and (2) withholding of caregiver concerns. Overall, there was 56% agreement between patient and caregiver responses. The results may inform intervention development to address patient-caregiver communication, cancer caregiver needs, and ultimately improve caregiver quality of life.

Keywords Caregiver burden · Cancer communication · Protective buffering · Topic avoidance · Gynecologic cancer

Cancers of the uterus and ovaries are the most common gynecologic cancers in American women. In 2022, there will be approximately 80,050 new uterine and 19,880 new ovarian cancer cases diagnosed, and 16,830 uterine and 12,810 ovarian cancer deaths [1]. Cancers of the uterus and ovaries are understudied compared to how common they are and how many deaths they cause [2]. Most gynecologic cancer patients present with advanced disease and are treated with a combination of surgery and chemotherapy that has a modest cure rate, with a high probability of recurrence [3]. Moreover, the 5-year survival rates for women diagnosed

with metastatic uterine cancer are only 17% and 30% for metastatic ovarian cancer [1]. The treatment regimen is intense and patients often experience significant medical complications [4, 5]. There is also a high prevalence of psychological distress among women undergoing treatment for ovarian cancer [6]. These treatment and emotional effects burden not only patients but also family members or friends who care for them [7, 8].

Approximately 2.8 million Americans report providing care or assistance to an adult family member or friend because of a primary diagnosis of cancer [9]. The typical unpaid, non-professional cancer caregiver is female (58%), middle-aged (average 53 years old), white non-Hispanic (66%), has less than a college degree (60%), and reports less than \$75,000 in household income [9]. Gynecologic cancer provides a unique context to study both the male and female caregiving experience. Patients may be cared for by their romantic partner (often male) but may also be cared for by female friends or family members. Cancer caregiving is characterized as being physically, emotionally, and financially demanding [10–12]. Tasks include but are not

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limited to feeding and dressing, watching for side effects of treatment, managing symptoms (pain, nausea, and fatigue), administering medications, performing medical/nursing tasks, care coordination and advocacy, transportation support, and providing social support [13–15]. Findings from the *Caregiving in the United States* survey conducted by the National Alliance for Caregiving and AARP Public Policy Institute (2015) provide additional insight into the demands experienced by cancer caregivers. Half of cancer caregivers described their caregiving tasks as difficult or physically taxing [9]. Moreover, 20% of cancer caregivers reported that caring for their loved one with cancer had made their own health worse [9]. Cancer caregivers also expressed feeling high levels of emotional stress, with 40% requesting more help to manage their own stress [9]. Female caregivers consistently reported higher levels of stress and burden compared to male caregivers [16, 17]. Lastly, 25% of cancer caregivers reported high levels of financial strain as a result of their caregiving responsibilities [9]. Working cancer caregivers indicated needing accommodations such as coming in late or leaving early, switching from full-time to part-time work, and taking a leave of absence [9].

While the effects of cancer caregiving are well documented [18], less is known about comparative perceptions of burden between patients and caregivers [19, 20]. Research has measured patient self-perceived burden on caregivers also known as perceived burdensomeness [19] and recorded its association with anxiety, depression, loss of dignity, hopelessness, guilt, and poor quality of life among cancer patients [21]. Fewer studies have investigated the role of consistent and contradictory views of burden on cancer caregiver outcomes. The limited research in this area found caregivers experience greater levels of emotional distress when there are discrepant assessments of burden and patients minimize caregiver contributions [22]. This finding emphasizes the need to examine patient-caregiver communication about individual experiences of burden in order to inform intervention development to ultimately improve caregiver outcomes [22]. The current study aims to address the identified need by comparing responses of patient and caregiver dyads to questions about the physical, emotional, and financial demands of cancer caregiving described above.

Method

Setting

The current study on perceptions of caregiver burden is part of a larger research project that focuses on how sharing/withholding of thoughts and feelings is associated with gynecologic cancer symptom management and quality of life, particularly when caregivers accompany patients to oncology

visits. Participants were recruited from a NCI cancer center of excellence in a semi-urban area of the northeastern USA. Procedures were approved by both the University Institutional Review Board and the Cancer Institute's Scientific Review Board.

Participant recruitment and eligibility criteria

Research staff provided information to patients about the study during an outpatient visit. Patient eligibility criteria included being 18 or older, having sufficient English language skills to understand a consent form and participate in the telephone interview without assistance, consenting to record the interview, being in treatment for first appearance of ovarian ($n=7$), uterine ($n=2$), or endometrial ($n=7$) cancers, between treatment cycles 2 and 5 (i.e., having experienced initial treatment and met the oncology team previously), and reporting a caregiver who regularly attended treatment appointments. If willing to participate, patients scheduled a phone interview and provided contact information for their caregiver. Participant recruitment continued until data saturation was reached. Staff identified 38 patients who met the target criteria and treatment cycle dates. Eight (22%) people approached did not meet inclusion criteria, and five (16%) did not agree to participate. Of those who agreed in person ($n=25$), 18 (72%) responded to follow up contact and completed the interview.

For caregivers, eligibility criteria included being 18 or older, having sufficient English language skills to understand a consent form and participate in the telephone interview without assistance, consenting to record the interview, serving as caregiver for the patient meeting above criteria, and attending some or most cancer-related appointments with the patient. Of the 18 caregivers identified, 2 (11%) declined to participate. As a result, only data from the matching 16 patient-caregiver dyads are included in this study.

Data collection

Three trained researchers conducted semi-structured interviews by phone. After obtaining consent, participants were asked permission to audio record interviews (all agreed). Patients were asked to focus on one person who attends visits with them, and caregivers focused on the patient for most of the questions. Beside demographics and disease history, the interview guide of the larger research project consisted of five main sections. This study focused on one of the five sections, perceptions of caregiver burden or the impact of the patient diagnosis on the caregiver specifically. A series of potential follow-up questions/prompts for each area followed based on the participant's response. The interview

Table 1 Interview questions for patients and caregivers

Patient
1. Overall, how do you think your cancer has affected your [family member/friend]?
2. While you have been ill, what has your [family member's/friend's] health been like?
a. How about their eating?
b. How about their exercise?
c. How about their usual routine such as hobbies?
3. Is there anything related to their health that you are not discussing with each other?
a. Not followed up on?
b. Changes for them?
c. Are they going to their own appointments regularly?
Caregiver
4. Overall, how do you think [your family member's/friend's] cancer has affected you?
5. While [your family member/friend] has been ill, what has your health been like?
a. How about your eating?
b. How about your exercise?
c. How about your usual routine such as hobbies?
6. Is there anything related to your health that you are not discussing with each other?
a. Not followed up on?
b. Changes for you?
c. Are you going to your own appointments regularly?

probes and follow-ups are listed in Table 1. Each participant individually received a \$50 gift card.

Interviews averaged 40.88 min ($SD = 13.69$), ranging in length for patients from 22:57 to 67:59 min ($M = 40.15$, $SD = 13.17$) and caregivers 21:14 to 71:02 min ($M = 41.61$, $SD = 14.59$). Interviews were transcribed verbatim, verified by two others, and deidentified, producing 9 to 26 ($M = 14.38$, $SD = 4.53$) pages of transcribed single-spaced text for patients, and 10 to 21 ($M = 14.50$, $SD = 3.41$) pages of transcribed single-spaced text for caregivers.

Data analyses

Two authors independently read the transcripts, identified emergent themes relating to caregiver burden, and compared themes to discuss any differences in interpretation. Inductive or flexible coding was used to identify specific examples that emerged during analysis of the patient and caregiver interview transcripts. This process included open coding and creating categories. Open coding refers to the analytical process of examining, comparing, and categorizing qualitative data to develop thematic concepts [23, 24]. Next, axial coding was conducted, which involved coding similar data sequences to link thematic concepts to one another in a meaningful way. This process grouped naturally-collapsing categories into higher order headings. Two overarching themes emerged: (1) patient-caregiver agreement and (2) patient-caregiver disagreement.

Responses were coded as agreement when patient and caregiver pairs mentioned the same caregiving-related challenge and/or consequence. Patient-caregiver agreement included two subthemes: (1) weight gain and (2) weight loss. Whereas, if a caregiving-related challenge and/or consequence was mentioned by only the patient or only the

caregiver that was coded as disagreement. In addition, if the same caregiving-related challenge and/or consequence was described as significant by the caregiver but not by the patient (or vice versa) that was coded as disagreement. Patient-caregiver disagreement consisted of two subthemes: (1) differing perspectives of quantity and quality of caregiving provided and (2) withholding of caregiver concerns. Overall, 9 out of 16 dyads expressed similar perceptions and 7 out of 16 dyads expressed contrasting views of caregiver burden yielding 56% agreement and 44% disagreement between patient and caregiver responses, respectively.

Results

Participants

Participants included 32 people, 16 linked patient-caregiver dyads. The patients were all female. Chart review included description of patients ranging from stage I to stage IV at diagnosis. Of patients' cancer stages that were known ($n = 15$), most were advanced-stage cancers ($n = 10$, 63%). Patient ages ranged from 45 to 88 years old. Time since diagnosis ranged from 1 to 16 months. Caregivers included 7 women and 9 men whose ages ranged from 30 to 72 years old. Table 2 provides additional sample description.

Findings

Patient-caregiver dyads were asked the same interview questions listed in Table 1. Two themes emerged: "patient-caregiver agreement" and "patient-caregiver disagreement."

Table 2 Demographic characteristics for patients and caregivers

Characteristic	Patients <i>n</i> (%)	Caregivers <i>n</i> (%)
Gender		
Female	16 (100%)	7 (44%)
Male		9 (56%)
Race/ethnicity		
Caucasian	10 (62%)	11 (68%)
Hispanic	3 (19%)	2 (13%)
African American	2 (13%)	2 (13%)
Multiple race/ethnicities	1 (6%)	1 (6%)
Education		
High school	7 (44%)	3 (19%)
Some college or trade school	3 (19%)	4 (25%)
Undergraduate degree	3 (19%)	6 (37%)
Postgraduate or professional degree	3 (19%)	3 (19%)
Cancer type		
Endometrial	7 (44%)	
Ovarian	7 (44%)	
Uterine	2 (12%)	
Relationship to patient		
Spouse or partner		7 (44%)
Adult child		4 (25%)
Sister		2 (13%)
Friend		1 (6%)
Nephew		1 (6%)
Parent		1 (6%)

Participant quotes are identified by their role as patient or caregiver and assigned dyad number.

Agreement

The first theme, “patient-caregiver agreement,” revealed that patients and caregivers acknowledged increased stress levels experienced by caregivers. Both parties attributed high levels of caregiver stress to concern about the patient’s cancer diagnosis, adjustment to the caregiving role (having to perform new tasks), and multiple caregiver responsibilities (competing time demands). Patients and caregivers reported that increased stress levels resulted in visible changes in caregiver physical appearance. Subthemes included caregiver weight gain and caregiver weight loss.

Agreement: weight gain

Patient 2 explained her husband’s tendency to turn to food in times of stress and need to manage multiple chronic conditions, “He’s a stress eater. ... And he’s not thin. He’s a heavy guy. So, I’ve been getting nervous with that. You know, like I said, he’s also a diabetic. He takes insulin. He takes a shot

every morning. ... He now takes a high blood pressure pill because I guess of all of this. So, yeah, he hasn’t really been taking care of himself. ... Sometimes he’ll cancel them [blood pressure appointments] because he has to pick his daughter up from school or, you know, the appointment is made so late he doesn’t want to go.”

Caregiver 2 mirrored his wife’s response about his unhealthy coping mechanisms and need to engage in better self-care, “I guess I’m a stress eater so it’s been difficult to manage my diabetes. And, I guess my blood pressure since this has happened. It’s a lot. ... At first I did cancel a couple, early on [blood pressure appointments]. But, I don’t miss them anymore. I’ve rescheduled them and I’ve caught up. I quickly realized that I had to need to take care of myself.”

Agreement: weight loss

Other patients described loss of appetite due to stress and subsequent weight loss among caregivers. For example, patient 6 highlighted a drastic change in her husband’s weight, “He lost a lot of weight. He hasn’t really been eating a whole lot.” Caregiver 6 reinforced his wife’s observation and current efforts to encourage himself to eat, “Honestly, I lost a lot of weight but I feel healthy.... I try to make sure that I eat at least something. A lot of people told me I have to make sure that I stay well because I cannot create a bigger problem and you know we already have [Patient’s name]. So, I was conscientious of that. But obviously, it’s not easy. Like I said, I lost weight, but I’m very healthy.”

In summary, cancer caregiving-related stress led to increased appetite in some caregivers and loss of appetite in others. The easy to observe changes in eating habits and subsequent weight transformations were mentioned by both patients and caregivers.

Disagreement

The second theme, “patient-caregiver disagreement,” demonstrated that patients were unaware of some physical, emotional, and financial challenges faced by caregivers as a result of providing care for their family member or friend with cancer. Subthemes included differing perspectives of quantity and quality of caregiving provided and withholding of caregiver concerns.

Disagreement: differing perspectives

Several discrepancies were identified in patients’ and caregivers’ perceptions of cancer caregiving. Patients and caregivers disagreed about the amount effort exerted and sacrifice experienced by the caregiver. Patient 1 viewed her husband as doing the bare minimum and putting his needs over hers, “He just comes to take me for my chemo and

that's it. I mean, I'm lucky I get that out of him. ... Let's put it this way, [husband] will take care of [husband]." In contrast, caregiver 1 said nothing was more important than caring for his wife including quitting a job in order to be her full-time caregiver, "I left [my job] because of the scenario here with my wife. OK. Now it was time for me to do the caregiving at home. When I did this [caregiving for wife], I thought I would just be doing this once in a while, a little bit, but I didn't realize the extent to what you got to do. But you know what? Look who I'm doing it for [wife], so it couldn't be a better thing."

Another husband-wife dyad had divergent viewpoints. Patient 9 described her husband as "selfless" and "totally amazing." She detailed the multiple caregiving tasks he regularly performed, "From day one of me being ill, he took over my care 100%. He shops, he cooks, he cleans the house, he does the laundry, gives me major support when I have questions about stuff. He figured out what I should eat, what I should not eat, how much to eat, what time to eat. He made sure the refrigerator was loaded with everything that I should eat. He cleaned out all the kitchen cabinets and got rid of everything that I should not touch." Whereas, caregiver 9 expressed anger and resentment about having to serve as the caregiver for his wife, "My life has gone down the toilet. I like to travel and had to cancel a trip to Japan and Korea. I was gonna be gone for a month. I'm a birder, so I like to go out and watch birds. And basically, all my energy is now focused here on the house and working with [Patient's Name] to, you know, improve her health. I'm feeling kind of bad about that because, I'm older and I'm sure that my mortality is creeping up on me. I do not know how many more good years I have to travel, to go birding, and, participate in some volunteer opportunities and things."

Another patient did not think her cancer diagnosis affected her sister. In fact, patient 8 critiqued her sister's lack of presence, "I never see my sister. She doesn't drive in the morning or do Sundays." Whereas, caregiver 8 identified multiple disturbances in her own life due to her sister's cancer diagnosis, "I dropped everything to help her [sister] out. I turned down a job offer, all kinds of things, to be her primary caregiver. ... It's [sister's diagnosis] affected my stress level and my blood pressure's gone up."

In summary, patient-caregiver dyads differed in their perceptions of burden experienced by caregivers. Some patients viewed caregivers as exerting little effort while those same caregivers felt as if they had given up a great deal to assist patients in need. Other patients described caregivers as willing to sacrifice even though those same caregivers expressed resentment towards putting their life on hold in order to provide care.

Disagreement: caregiver withholding of concerns

Comparison of patient and caregiver responses revealed physical and emotional concerns mentioned only by caregivers. Patients were unaware of several instances of burden due to caregivers withholding from them. As a result, this study section contains only caregiver quotations.

Caregivers did not bring up sleep disturbances in order to avoid increasing patient stress levels. Caregiver 4 described trying to hide her difficulty sleeping from her sister, "I don't sleep very well. That's part of the deal, I've decided. You know. When you're stressed, that's what happens. You don't sleep well. It's a constant thing [sister's cancer diagnosis] on my shoulders, on my head. It's a terrible thing happening that's out of my control. I'm a fixer, but I can't fix it. I don't sleep the night before [chemo appointment], but I try hard not to let my sister know that."

Other caregivers mentioned avoiding discussion of personal health issues so as not to further upset or worry patients. As caregiver 12 reported withholding diabetes-related information from his mother, "I don't want to burden her with me. Being the only child, I don't want to start unloading on her. I don't tell her my blood sugar number went up last night. I don't want her to worry about stuff like that. I'll tell my wife but not her."

Caregivers also reported withholding fears and concerns about patient prognosis and future in order to continue being a source of strength for the patient. For example, caregiver 15 described how he holds back negative cancer-related thoughts from his wife, "I have a little bit of depression thinking about it [wife's cancer diagnosis]. The negative thoughts creep into my head at work. I keep them to myself because I want to keep my wife on the positive side." Similarly, caregiver 16 discussed the brave face she puts on not to let her daughter know she is constantly worried about her, "I'm trying to carry on with my life to try to make it as normal as possible. But it's [daughter's cancer diagnosis], you know, always there, and it's very, very difficult. You know, I can't allow myself to relax, you know what I mean? I'm a very 'up' person and I'm always laughing and I'm always joking. And when I'm with people, I try to be that way, but I'm crying on the inside, if you know what I mean."

In summary, caregivers frequently mentioned withholding stressful thoughts such as cancer-related concerns from patients. Even though caregivers feared that the patient could die, they refrained from expressing those fears in order to avoid further burdening the patient.

Discussion

Because little prior research has explored how cancer patients and caregivers perceive caregiver burden [19, 20], there is a gap in how we are assisting patients and caregivers in navigating cancer diagnosis and treatment [22]. Thus, the purpose of this study was to examine alignment in patients' and caregivers' reports of cancer caregiving demands. Results suggest several implications for patient-caregiver dyads.

Although there was 56% agreement among patients and caregivers responses, differing viewpoints were also mentioned. Dyads that echoed each other's responses mentioned easy to identify issues like visible changes in caregiver appearance (i.e., weight gain and weight loss). Whereas, dyads that contradicted each other's responses expressed different interpretations of caregiver effort and sacrifice. Caregivers reported physical and financial demands consistent with findings from *Caregiving in the United States* (2015) survey [9]. Additionally, caregivers admitted they hold back from sharing specific information about physical and emotional concerns with patients. This finding is consistent with prior research on cancer-related topic avoidance [25, 26] and protective buffering [27].

Selection of gynecologic cancer patients yielded a larger representation of male caregivers (56%) compared to broader statistics showing that 58% of unpaid, non-professional cancer caregivers are female [9]. This study choice provided a unique context to compare the male and female caregiving experience. Patients and male caregivers consistently attributed burden to the spousal caregiver's lack of preparedness for the caregiving role. Role problems were not mentioned by patient and female caregiver dyads. This finding is consistent with prior research on gender differences and perceptions of caregiver burden [16]. Conflicting views between patients and caregivers about quality of care received/provided were expressed by both male and female caregivers. This suggests something besides gender such caregiver type and/or patient-caregiver relational quality may influence conflicting views of caregiver burden. For example, patients may expect more from their husbands who they live with compared to close friends who only attend medical appointments. Likewise, husbands who provide care 24/7 may experience greater levels of burden compared to friends who help for a limited amount of time. Familial relationships that already have low levels of relational satisfaction may be more prone to divergent viewpoints of caregiver burden. Patients may already be frustrated by their family member's lack of assistance prior to their cancer diagnosis and view the caregiver as selfish despite the quality of care they provide. Caregivers may more be resentful of providing care to

an individual they do not feel close to. These observations warrant future research.

Based on sources of patient-caregiver disagreement, there is a need for conversation starters between patients and caregivers about cancer caregiving demands. Some patients and caregivers who are not aligned are cognizant of the differences in perceptions while others seem oblivious to how their perceptions of caregiver burden dramatically diverge. In these latter cases, it would be challenging for the patient or the caregiver to raise the challenges in a constructive manner due to their lack of awareness. In some instances, underlying relationship dynamics are carried into the healthcare interaction, affecting the patient, caregiver, and healthcare providers [28].

Because caregivers' motivation for withholding personal information was to protect patients, development of self-care materials for caregivers may be beneficial. Caregiver interventions have been developed but are not widespread [29]. Additional focus on support for the caregiver, including but not limited to respite care, would be beneficial for both the patient and the caregiver. Healthcare providers may also notice changes in caregivers and initiate conversations if possible. Healthcare providers could facilitate discussions with patients and caregivers during treatment visits if there is some mis-alignment in perceptions of how best to support both the patient and the caregiver.

Limitations

Several study limitations need to be acknowledged. First, the sample size was small and predominantly non-Hispanic white, limiting generalizability to other races/ethnicities. Second, the specific gynecologic cancer diagnosis limits generalizability to other types of cancer. Third, there was variation in caregiver type and gender. It is unclear whether expectations of caregiver assistance (from the patient perspective) and caregiver obligation (from the caregiver perspective) are based on caregiver type and/or gender. Lastly, these data were part of a larger research project and only three broad caregiver burden questions were asked in the semi-structured interview. Future research should devote more time to exploring perceptions of caregiver burden.

Conclusion

This study examines perceptions of burden between gynecologic cancer patients and their caregivers. Both parties attributed high levels of caregiver stress to concern about the patient's prognosis, the learning curve associated with becoming a caregiver, and diverse cancer caregiver responsibilities. Although there was 56% agreement among patients and caregivers, a large percentage of participants

expressed contradictory views about care received versus care provided. Future research is needed to facilitate patient-caregiver conversations about caregiver burden in order to reach dyadic consensus.

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Data availability The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Code availability Not applicable.

Declarations

Competing interests The authors declare no competing interests.

Ethics approval The study was approved by the Rutgers University Institutional Review Board and the Rutgers CINJ Scientific Review Board.

Consent to participate Informed consent was obtained from all individual participants included in the study. Please refer to the “Data collection” section under the “Method” heading for additional information.

Consent for publication The authors affirm that human research participants provided informed consent for publication of their quotations.

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