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Symptom management in women with recurrent ovarian cancer: Do patients and clinicians agree on what symptoms are most important?

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Abstract

Objective—We sought to [1] compare symptoms identified as a priority by patients with recurrent ovarian cancer to symptoms most frequently documented by their clinicians, and [2] examine the association between clinician documentation of symptoms and subsequent clinical intervention.

Methods—Single-institution, retrospective chart review of patients enrolled in WRITE Symptoms Study (GOG 259), a randomized controlled trial of internet-based recurrent ovarian cancer symptom management. As part of the trial, women completed the Symptom Representation Questionnaire for 28 symptoms and selected 3 priority symptoms (PS). We compared patient-reported PS to clinician documentation of symptoms and interventions over the time period corresponding to study enrollment.

Results—At least one PS was documented in 92% of patients. Of 150 PS reported by patients, 53% were never documented by clinicians; these symptoms tended to be less directly related to disease or treatment status. Symptoms not identified by patients as PS were frequently documented by clinicians; these symptoms tended to relate to physiologic effects of disease and

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Conflict of Interest Statement

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treatment toxicity. 58% of patients had at least one PS intervention. PS intervened for were documented at 2.58 visits vs 0.50 visits for PS not receiving intervention ($p = <0.0001$).

Conclusions—Discordance was identified between symptoms reported by patients as important and symptoms documented by clinicians. Symptoms more frequently documented were also more frequently intervened for. Our study illustrates the need to improve identification of symptoms important to patients, and suggests that improving communication between patients and clinicians could increase intervention rates to enhance quality of life in women with recurrent ovarian cancer.

Introduction

Ovarian cancer is diagnosed in approximately 20,000 women in the United States each year(1), with more than 70% diagnosed at an advanced stage(2). While women diagnosed at advanced stages often respond to treatment initially, overall prognosis is poor, with less than 50% surviving 5 years after diagnosis(3). Ovarian cancer recurrence is generally not curable, and thus treatment goals shift to include quality as well as quantity of life(4). Recurrent ovarian cancer is associated with a high symptom burden, both in the number and severity of symptoms(5, 6). Successful management of cancer and treatment-related symptoms is essential to promoting quality of life and requires [1] good patient-clinician communication, [2] accurate symptom assessment, and [3] effective intervention and follow-up assessment.

Lack of communication can impact effective symptom management. One study of 279 patients with active ovarian cancer (96% recurrent) found that only 61% had discussed the symptom they reported noticing most with their clinician in the past month; 5% had never discussed their most noticed symptom with their clinician(6). When communication does occur, discrepancies between patient experience and clinician assessment can still exist. Clinicians frequently underestimate or downgrade symptom intensity(7, 8). When comparing patient-report to clinician documentation of symptoms, concordance is seen more frequently with objective symptoms such as vomiting and diarrhea, and less frequently with subjective symptoms such as fatigue(7–10). Symptom severity also appears to impact clinician assessment, with higher symptom intensity associated with increased rates of clinician documentation and clinical intervention(11). However, in a review of symptoms reported by patients with ovarian cancer after completion of therapy, patients reported significantly more moderate to severe symptoms than physicians documented, and particular discordance was seen in psychological and sexual symptoms(12). While communication and accurate assessment are essential, clinical intervention is also necessary to provide effective strategies to reduce symptom burden. Unfortunately, clinicians frequently do not provide symptom management recommendations(6, 11). Ovarian cancer patients who do not receive management recommendations have lower perceived symptom control regardless of whether they discuss the symptoms with their clinician (6).

Using patient-reported symptom data from a randomized controlled trial we sought to (1) compare symptoms identified as a priority by patients with recurrent ovarian cancer to symptoms most frequently documented by their clinicians, and (2) examine the association between clinician documentation of symptoms and subsequent clinical intervention. This dataset provides a unique opportunity to focus on symptoms that patients have identified as

“wanting to get better control over” and thus represents symptoms that require patient-clinician communication and intervention. Examining current areas of discordance between patient-report and clinician documentation, and understanding the impact of this on clinical intervention, provides the groundwork to inform development of new interventions to strengthen symptom communication and management.

Methods

We conducted a retrospective chart review of clinician documentation of symptoms reported by patients enrolled in a randomized controlled trial. The Written Representational Intervention to Ease (WRITE) Symptoms Study (NIH/NR010735; GOG 259) was a randomized controlled trial of the internet-based WRITE symptoms intervention, which was designed to facilitate ovarian cancer symptom management. The trial included 497 women with recurrent or persistent ovarian, fallopian tube or primary peritoneal cancer from 53 GOG sites. Patients were required to be experiencing three or more symptoms associated with ovarian cancer or its treatment, and could be at any point in their disease and treatment course. Active disease was not a requirement for participation. The objective was to compare the efficacy of standard oncology care, WRITE symptoms intervention facilitated by trained nurses, and WRITE symptoms intervention utilized as a self-directed interactive module. The intervention period was eight weeks and the study duration was one year. Results from the WRITE Symptoms Study (NIH/NR010735; GOG 259) have not yet been published, however further details of the WRITE Symptoms pilot intervention are available(13).

This analysis includes 50 women participating in the WRITE Symptoms Study from a single institution and was approved by the University of Pittsburgh Institutional Review Board. At the time of initial enrollment into the WRITE Symptoms Study women logged on to the study website and completed a baseline Symptom Representation Questionnaire (SRQ) rating the severity of 28 commonly experienced cancer and treatment-related symptoms. The SRQ has been previously validated in women with ovarian cancer(14). Patients identified their top 3 priority symptoms based on the three symptoms they “would like to get better control over”. Priority symptoms were established at the start of the study and were not re-queried. An automated report of the SRQ data was generated and forwarded to the clinical research assistant at each site; subsequent distribution of the reports to clinicians was at the discretion of the site primary investigators.

Electronic medical record (EMR) data for these 50 women were reviewed for clinician documentation of symptoms and interventions over the one year time period corresponding to study enrollment. Clinicians included physicians, nurse practitioners, and physician assistants. All oncology clinic visits during the period of study enrollment were reviewed, and any mention of any symptom by a clinician within the EMR visit was considered clinician documentation. Any action taken by a clinician to address a symptom and documented within the visit note was considered an intervention; these included prescribing medications, treatment plan changes due to symptoms, procedures directed at symptom relief, blood transfusions, specific recommendations for behavior change related to symptoms, and referral to other clinicians to address a specific symptom. If more than one clinician documented or intervened for a symptom during the same visit this was counted as

only one instance. Priority symptoms were identified on the SRQ using a dropdown menu of 28 symptoms and participants were not asked to provide more descriptive information on the symptom (e.g. type or location of pain). Any clinician documentation or intervention related to the priority symptom was counted (e.g. tiredness, exhaustion, no energy, were all considered documentation of fatigue).

Data analysis was performed using basic descriptive statistics and t-tests.

Results

Mean patient age was 58 years (range 28–77). All patients had recurrent or persistent disease. The majority of patients had stage 3 or 4 disease, had previously undergone surgery and chemotherapy, and were actively receiving chemotherapy at study initiation (Table 1).

When clinician-documented and patient-reported symptoms were combined, the most common symptoms were fatigue (n=39), neuropathy (n=34), musculoskeletal pain (n=28), bloating (n=18), and abdominal or pelvic pain (n=17) (Figure 1). When patient-reported priority symptoms (PS) were examined independently, the most commonly reported symptoms were fatigue (n=29), peripheral neuropathy (n=17), sleep disturbances (n=13), and pain (n=11) (Figure 2).

During the study time period clinicians documented at least one PS for at least one visit in 92% of patients; however, of the total 150 PS reported by patients 53% were never documented. The PS most often documented at least once were fatigue (n=21), peripheral neuropathy (n=12), pain (n=9), and sleep disturbances (n=5) (Figure 3). Clinicians never documented PS of memory problems, sexuality concerns, or hot flashes, which were reported by six, three, and three patients respectively. Conversely, symptoms not identified by patients as PS were frequently documented. The symptoms most frequently documented by clinicians but not identified as PS by patients were musculoskeletal pain (n=28), abdominal or pelvic pain/bloating (n=26), neuropathy (n=17), and nausea/vomiting (n=15) (Figure 3). While neuropathy was often a PS, these numbers indicate documentation of neuropathy in the chart of patients who did *not* identify this symptom as a PS.

The mean number of visits during the study period was 8.5 (SD=3.8). When documented, the mean number of visits in which a PS was documented was 2.3 (SD=1.6). An intervention for a PS was documented in 58% of patients. On average, PS intervened for were documented at 2.58 visits (range 1–7) versus 0.50 visits (range 0–5) for PS not receiving an intervention ($p = <0.0001$). The PS most frequently receiving an intervention were peripheral neuropathy (n=8/17), fatigue (n=7/29), pain (n=5/11), and sleep disturbances (n=4/13). The PS most consistently receiving interventions were lymphedema (2/2; 100%), depression (2/3; 75%), anxiety (2/4; 50%), peripheral neuropathy (8/17; 47%), and pain (5/11; 45%). The most common PS, fatigue, was documented 72% of the time (21/29) and intervened for 25% of the time (7/29).

Discussion

The four most common patient-reported priority symptoms (PS) were also the four PS most frequently documented by clinicians, showing that clinicians are identifying and documenting symptoms important to patients. However, 53% of symptoms identified as a priority by patients were never documented by a clinician. The prevalence of patient-reported symptoms never documented by a clinician illustrates a need for improvement in communication between patient and clinician, however it is possible that in some cases communication did occur but was not documented.

Interestingly, clinicians frequently documented symptoms that were not identified as a priority by patients. Symptoms documented by clinicians but not reported as PS by patients tended to relate to physiologic effects of disease and acute treatment toxicity. In particular, pain was much more frequently documented by clinicians versus reported by patients. This could be due to clinician emphasis on symptoms most likely to influence clinical decision-making, rather than symptoms most impacting patient quality of life.

PS reported by patients but not documented by clinicians tended to be less directly related to disease status or treatment toxicity. Possible reasons for this discordance are clinician de-emphasis on symptoms not directly related to therapeutic decisions, or clinician lack of training and discomfort with these symptoms. Clinicians never documented or intervened in sexuality concerns, hot flashes, or memory problems, perhaps due to the complexity of diagnosis, lack of familiarity with treatment options, and lack of referral systems to assist with these specific symptoms. Symptoms most consistently intervened for were depression, anxiety, peripheral neuropathy, and pain; this could be due to increased training in these areas and/or the availability of effective and affordable medications to treat these symptoms.

While cancer treatment is clearly a fundamental role of the gynecologic oncology team, it is vital that improvement be made in recognizing and treating symptoms important to patients, irrespective of the direct influence on cancer treatment. The Society of Gynecologic Oncologists states that “incorporation of palliative care principles is crucial to the delivery of quality care to women diagnosed with a gynecologic malignancy”(15) and identifies the alleviation of pain and distressing symptoms, both physical and emotional, as a principle of palliative care(16). We found that the number of visits documenting a PS correlated with intervention. This suggests that improving patient- clinician communication and clinician awareness of patient symptoms could increase documentation and intervention rates and improve symptom management and quality of life in women with recurrent ovarian cancer. However, it is possible that clinicians were more likely to document symptoms for which they provided an intervention.

Our study has several limitations. Priority symptoms were identified at study enrollment however symptoms may shift over time, thus some clinician documentation and intervention (or lack thereof) could reflect a change in patient symptomatology rather than discordance. Additionally, we describe the experiences of a small number of patients at a single academic institution, which may not be applicable to other environments and locations. We are also

unable to directly assess the frequency of patient- clinician communication or the consistency of clinician documentation.

Conclusion

This study compares patient-reported priority symptoms with clinician documentation of symptoms among women with recurrent ovarian cancer. Discordance was identified between the symptoms reported by patients as important and the symptoms documented by clinicians. The etiology of discordance between patient and clinician -report is likely multi-factorial and requires further exploration to help determine key areas to target for improvement. Our finding that more frequently documented symptoms more were more likely to receive an intervention illustrates the need to improve identification of symptoms important to patients, and suggests that improving communication between patients and clinicians could increase intervention rates to enhance quality of life in women with recurrent ovarian cancer.

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Highlights

- Discordance exists between patient-reported symptoms and those documented by clinicians
- Increased symptom documentation is associated with increased intervention
- Improving patient-clinician communication could increase documentation and intervention rates and enhance quality of life in women with recurrent ovarian cancer.

Figure 1.
Symptoms reported by patients and clinicians

Figure 2.

Number of patients reporting the four most common priority symptoms (PS), number of PS documented in the EMR, and number of PS for which an intervention was provided.

Figure 3.
Frequency of clinician documentation for patient-reported priority symptoms versus symptoms not identified as a priority by patients.

Table 1

Demographic Characteristics

	M (range)	N (%)
Mean age, years	58 (28–77)	
Median time since diagnosis, years	3.8 (1–20)	
Median time since recurrence, years	1.7 (<1–6)	
Stage 3 or 4		42 (84%)
Previous surgery		50 (100%)
Previous chemotherapy		50 (100%)
Active chemotherapy at study initiation		41 (82%)