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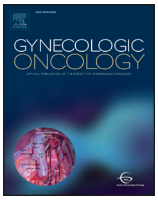

Symptom management in women with recurrent ovarian cancer: Do patients and clinicians agree on what symptoms are most important?

Casey M. Hay [a,*], Madeleine Courtney-Brooks [a], Carolyn Lefkowits [b], Teresa L. Hagan [c,d,1], Robert P. Edwards [a], Heidi S. Donovan [c]

[a] Division of Gynecologic Oncology, Department of Obstetrics, Gynecology and Reproductive Sciences, Magee-Womens Hospital of the University of Pittsburgh Medical Center, 300 Halket Street, Pittsburgh, PA 15213, USA
[b] Division of Gynecologic Oncology, University of Colorado Denver, 1665 Aurora Court, Aurora, CO 80045, USA
[c] School of Nursing, University of Pittsburgh, 415 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261, USA
[d] Massachusetts General Hospital, Harvard Medical School, 55 Fruit Street, Boston, MA 02114, USA

HIGHLIGHTS

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

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ABSTRACT

Objective. We sought to compare symptoms identified as a priority by patients with recurrent ovarian cancer to symptoms most frequently documented by their clinicians, and 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 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 ($p \le 0.0001$).

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.

1. Introduction

Ovarian cancer is diagnosed in approximately 20,000 women in the United States each year [1], with >70% diagnosed at an advanced stage [2]. While women diagnosed at advanced stages often respond to treatment initially, overall prognosis is poor, with <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

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[*] Corresponding author at: Department of Gynecologic Oncology, Magee-Womens Hospital of the University of Pittsburgh Medical Center, 300 Halket Street, Pittsburgh, PA 15213, USA.
E-mail address: haycm2@upmc.edu (C.M. Hay).

[1] Present address.

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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.

2. 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.

3. 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 ($n = 17$) (Fig. 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 ($n = 11$) (Fig. 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

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%)

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