ORIGINAL RESEARCH ARTICLE

"Lower abdominal pains, as if I was being squeezed…in a clamp": A Qualitative Analysis of Symptoms, Patient-Perceived Side Effects and Impacts of Ovarian Cancer

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Abstract

Background Understanding the patient's perception of their disease is vital for guiding care decisions. The current study aimed to identify the most predominant experiences in women diagnosed with, and treated for, ovarian cancer in terms of disease-related symptoms, treatment-attributed side effects and their impacts.

Methods Semi-structured qualitative interviews about disease-related symptoms, treatment-attributed side effects and their impacts were conducted with women who were being treated for ovarian cancer in Europe ($n = 55$) or in the USA ($n = 9$). The women were also asked to rate the bothersomeness of the symptoms, side effects and impacts that they mentioned during the interview. Symptoms, side effects and impacts were identified from coded interview transcripts using an iterative coding framework.

Results Bloating, abdominal pain, tiredness and frequent urination were the most frequently expressed symptoms, and were reported by 72%, 67%, 64% and 55% of women, respectively, which together constituted approximately 30% of all symptom expressions. The most bothersome symptoms were reported as bloating, abdominal pain, pain in the side, tiredness and fatigue. The most frequently expressed side effects were hair loss, neuropathy, tiredness and nausea, which were reported by 84%, 63%, 61% and 61% of women, respectively. The most bothersome reported side effects were constipation, nausea, diarrhoea, pain in general, fatigue, weakness, reduced sleep quality and hair loss. Feelings of anxiety, concerns about the future, physical functioning, work limitations and the adoption of coping strategies were the most frequently expressed impacts and were reported by 72–80% of women. Impacts reported as the most difficult to deal with were concerns about the future, emotional difficulties in general, physical functioning, sexual functioning, negative self-image, fatigue, sleep difficulties, financial burden and work limitations.

Conclusions In our qualitative study, the most common and most bothersome experiences reported by women treated for ovarian cancer were symptoms of bloating, abdominal pain and tiredness; side effects of hair loss, nausea and tiredness/fatigue; and impacts relating to concerns about the future, physical functioning and work limitations. We suggest that clinicians measure these experiences consistently and take them into consideration when making treatment decisions.

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Abbreviations

FDA	Food and Drug Administration
ICHOM	International Consortium for Health Outcomes Measurement
MOST	Measure of Ovarian Cancer Symptoms and Treatment
NC	not captured
SD	standard deviation

△ Adis

Key Points

Our qualitative interview study was conducted with women diagnosed with, and treated for, ovarian cancer.

The most common and most bothersome experiences reported were symptoms of bloating, abdominal pain and tiredness, treatment side effects of hair loss, nausea and tiredness/fatigue, and impacts relating to concerns about the future, physical functioning and work limitations.

When speaking to patients with ovarian cancer, we suggest that clinicians ask about and listen for mention of these experiences consistently and take them into consideration when making treatment decisions.

1 Background

Early symptoms of ovarian cancer are subtle and lack predictive value for identifying the disease [1]. Most women with ovarian cancer are first diagnosed with established disease, when the 5-year survival rate is less than 30% [2, 3]. In the USA, approximately 235,200 women are living with ovarian cancer [4]; it was estimated 22,240 women would be newly diagnosed and approximately 14,070 would die of the disease in 2018 [5]. The high rate of recurrent disease in women with ovarian cancer means that primary debulking surgery is almost always followed by multiple lines of chemotherapy [6–8].

Having a clear understanding of the patient's experience of their disease and treatment is vital for guiding evidence-based care decisions for women with ovarian cancer, for whom the generally poor prognosis for advanced disease makes achieving a balance between quality of life and quantity of life particularly pertinent. Understanding the patient perspective can help to identify the experiences that should be measured consistently to help monitor women's status regarding their ovarian cancer and its treatment. It is also a vital cornerstone of patient–physician communication and can be used to inform discussions about treatment options. The insights obtained from a better understanding of the patient perspective can be used to form the basis for developing patient-reported outcome instruments, thereby leading to improved assessments of patient-centred outcomes in clinical practice and clinical trials.

The high overall mortality of women with ovarian cancer and little new drug development and potential cures have recently prompted the US Food and Drug Administration (FDA) to position progression-free survival and overall response rate with sufficient response duration as potentially acceptable clinical trial endpoints for regulatory decisions [9]. Treatment-related toxicity also needs to be understood when defining the benefits and risks of new treatments [10]. The position of the FDA has affected clinical trial design, with patient-reported symptoms and impacts used to contextualize toxicity and progression-free survival [9]. Obtaining qualitative information directly from patients with ovarian cancer about living with the disease is essential for developing a valid and comprehensive patient-reported outcome strategy for clinical trials [11–13].

To the best of our knowledge, to date there have been no published qualitative interview studies involving women with ovarian cancer assessing disease-related and treatment-attributed symptoms and their bothersomeness and impacts that have used a rigorous methodology with an iterative coding framework to identify important concepts. The current study aimed to explore the patient perspective to identify the most predominant experiences in women diagnosed with, and treated for, ovarian cancer in terms of disease-related symptoms, treatment-attributed symptoms and their impacts.

2 Methods

2.1 Study Design and Participants

The current analysis uses data from a cross-sectional qualitative interview study conducted in 2014–2015 that recruited patients in France, Germany and the UK, with an additional arm added in the USA. The methodological orientation underpinning the study was a qualitative content analysis. In total, 64 adult women (18 years and older) were included in the study: 55 in Europe and nine in the USA. The study eligibility criteria were kept broad because recruitment for the larger part of the sample (55 in Europe) was by self-report, and patients were not aware of their diagnostic histology. The inclusion of at least one round of treatment added surety to the self-report patients having ovarian cancer. The study aimed to describe the patients' experience with their condition and within their healthcare system. Because clinical trial participation would have engendered an experience different from that in a typical healthcare system, women who had been treated with an investigational product in a clinical trial for ovarian cancer were excluded from the study.

In Europe, potential study participants were identified from local ovarian cancer support groups through the use of market research groups. Potential participants were first contacted by telephone and provided with information about the study to help them decide whether they would like to participate. In the USA, study participants were recruited from two clinical sites: one in North Carolina and one in Ohio. Potential participants were identified from clinic

databases, contacted by telephone and provided information about the study and eligibility for those willing to consider participation.

2.2 Semi-structured Interviews

All participants were interviewed using semi-structured interview guides with open-ended and prompted questions. Each interview lasted approximately 90 min. In Europe, the interviews were held in private interview suites with closed observation rooms or, at the patient's request, in the patient's home. In the US, interviews were held in a private room at their treatment clinic. Interviews were conducted in each participant's native language by professionally trained interviewers with several years of experience in qualitative research. All interviews were recorded. Non-English language interviews in France and Germany were audio-recorded both in the native language and in English via a simultaneous translator. All English recordings were transcribed for analysis.

The interview guides provided the participants with the opportunity to express information freely in response to open-ended questions about disease-related symptoms, treatment-attributed side effects and their impacts. For example, women were asked the following: "What symptoms were you experiencing when you were first diagnosed?" "What symptoms do you experience now that you feel are related to the ovarian cancer?" "What kind of side effects did you experience associated with your treatment?" "When you think about the side effects you experienced during and after your treatment, which one was the worst and why?" and "Where are the places in your life where the ovarian cancer or your treatment affects how you go about your daily life?" Interviewers used follow-up probes to explore symptoms, side effects and impacts that were initially either not offered freely or not elaborated on by participants in response to the open-ended questions.

After the open-ended questions and follow-up probes, women were asked to rate the level of bothersomeness of each of the symptoms and side effects that they described during the interview. They were also asked to rate the difficulty that they had experienced in coping with the impacts of their disease and treatment. All ratings were obtained verbally, using an 11-point numerical rating scale from zero (not at all bothersome/difficult) to 10 (extremely bothersome/difficult).

2.3 Data Analysis

The transcribed audio recordings of the interviews were coded by a total of five different coders. Concepts expressed by patients were identified in the transcripts and tagged with a code stem using ATLAS.ti™ software (version 5.0,

ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) to allow them to be grouped by similar content. Expressions were coded to describe symptoms, side effects and impacts of the cancer and its treatment. All clinical, demographic and rating data were entered into SPSS for Windows (version 11.5, SPSS, Chicago, USA), and were tabulated descriptively.

Two different methods were used to assess data quality. First, saturation of concept was evaluated to identify the point at which no new information was being derived from the interview process (i.e. the point at which further interviews would be unlikely to provide additional concepts). Transcripts were ordered chronologically based on interview completion date and divided into transcript groups of seven for the European interviews and three for the US interviews. The codes that arose in each subsequent group of interview transcripts were compared with those from the preceding group. Saturation of concept was considered to have been met when no new concept codes appeared.

Second, inter-rater agreement was assessed based on eight dual-coded transcripts (six from the European interviews and two from the US interviews). The dual-coded transcripts were compared and the percentage agreement was evaluated for both the presence of a concept and its assigned code.

Exercises were included in the interview process asking the patients to provide a rating (using a 0–10-point scale where zero was not severe/bothersome and 10 was extremely severe/bothersome) for the symptoms and side effects they experienced, and to rate, using the same type of numeric rating scale, the difficulty they had in coping with impacts of the disease and its treatment. Group means were described for the number of patients who provided ratings for each symptom or impact and are presented in descriptive tables.

Because of the differences in the recruitment of study participants and study settings, data from the US arm are analysed and reported separately from those of the European arm of the study.

3 Results

3.1 Study Participants

In total, 64 interviews were completed (55 in Europe [France, $n = 20$; Germany, $n = 15$; and UK, $n = 20$] and nine in the USA). Table 1 summarizes the demographic and clinical characteristics of the study participants. The mean age of the women in Europe was 53.9 years (standard deviation [SD] 14.1) and the mean age of the women in the USA was 62.4 years (SD 12.3). The mean time since first diagnosis of ovarian cancer was 4.4 years (SD 3.1) in the European group and 2.2 years (SD 1.1) in the US group.

Table 1 Patient demographic and clinical characteristics

Demographic and clinical characteristics	France, Germany, UK $N=55$	USA $N=9$
Age, years		
Mean (SD)	53.9 (14.1)	62.4 (12.3)
Range	18–82	42–80
Country, n (%)		
France	20 (36)	–
Germany	15 (27)	–
UK	20 (36)	–
Prior surgery for ovarian cancer, n (%)	31 (56)	7 (78)
Prior radiation therapy for ovarian cancer, n (%)	0 (0)	1 (11)
Prior chemotherapy for ovarian cancer, n (%)	55 (100)	9 (100)
Time since first diagnosis, years, mean (range)	4.4 (0.3 – 14.0)	2.2 (0.7 – 4.6)
Tested for *BRCA* mutations[a], n (%)	19 (35)	6 (67)

NC not captured, *SD* standard deviation

[a] Not known for two women (4%) in the European group

3.2 Data Quality

In total, 171 unique concepts were coded in the first six transcript groups in the European interviews, with no new concepts identified in the final transcript group, showing that concept saturation was reached. In the US interviews, 112 unique concepts were coded in the first two transcript groups and 20 in the third transcript group, meaning that saturation of concepts was not achieved; however, the number of new concepts identified decreased from 84 in the first transcript group to 28 and 20 for the second and third transcript groups, respectively, suggesting that most unique concepts were elicited. The concepts expressed were generally similar between the European and the US interviews, although the small US sample size meant that only broad comparisons could be made. High inter-rater agreement was demonstrated between coders (European interviews: 91−98%; US interviews: 93 − 100%).

3.3 Concepts Related to Women's Cancer Symptoms

At the start of each interview, women were asked to describe the events that led to the diagnosis of their ovarian cancer. Most of the descriptions were filled with frustration and negative experiences within the healthcare system. The difficulties with correct diagnosis of ovarian cancer at early stages were apparent, and the cancer was often quite advanced by the time it was finally diagnosed for most of the women interviewed. The immediacy and rigor of treatment, with no planning or adjustment time, left the women with varying degrees of shock and upset. For example, some women were whisked to surgery directly from their clinic visit before they were able to consult with their spouse.

The 64 women participating in interviews articulated a total of 1922 expressions related to cancer symptoms. Table 2 shows the symptom expressions that accounted for at least 2% of all coded symptoms in Europe and/or the USA, together with illustrative sample quotations from the interviewed women.

The most frequent symptom expressions were bloating and abdominal pain, which were talked about by 72% and 67% of the women, respectively, and which together constituted approximately 20% of all symptom expressions. The women spoke about bloating in relation to their clothing, such as struggling to close the zipper on their clothes or clothing cutting into their flesh because of bloating, or noticing their bloating most when wearing restrictive clothing such as work wear. Many women described their bloating as feeling like being pregnant. Abdominal pain was described by many women as being similar to menstruation-related pain. Quotations from participants included:

> "About 3 weeks prior to diagnosis in the evening, lying in bed, I noticed my belly is actually bloated",

> "...[I had] lower abdominal pains, as if I was being squeezed in some way, as if in a clamp".

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The next most frequent symptom expressions were about tiredness and frequent urination, which were talked about by 64% and 55% of women, respectively, and which together constituted approximately 10% of all symptom expressions. Example quotations included:

> "As soon as I do something, I get tired and so I go and sit down",

"I had to go to the bathroom much more often, especially at night".

Women also commonly talked about pain in the back, irregular menstruation, loss of appetite and shortness of breath; they said, for example:

"I couldn't be straight because I had back pain",

"I had haemorrhaging and lost a lot of blood",

"It was an alarming sign the fact that I didn't feel like eating",

"I couldn't breathe … almost getting to suffocation level".

The ovarian cancer symptoms commonly reported by women were broadly similar in Europe and in the USA (Table 2). There were some differences in the proportions of women mentioning particular symptoms, such as higher proportions of women in Europe than in the USA reporting abdominal pain, feeling full and shortness of breath, and higher proportions of women in the USA than in Europe reporting pain in the side and fatigue.

The most bothersome symptoms, each with a mean score of at least 7.0 (out of a possible maximum of 10.0) and rated by at least one-third of the women in Europe or in the USA, were bloating, abdominal pain, pain in the side, tiredness and fatigue (Table 2).

3.4 Concepts Related to Perceived Treatment Side Effects

The women attributed symptoms to their treatment based on the timing of a symptom in relation to therapy. When women were asked to talk about their initial treatment, which was usually surgery, the side effects mentioned were predominantly restricted to different types of post-surgical pain that resolved with healing from the surgery. When asked to talk about their experience with chemotherapy, the 64 women interviewed articulated a total of 1559 expressions related to perceived side effects of cancer treatment (Table 3). The most frequently expressed side effect was hair loss, which was talked about by 84% of women and which accounted for approximately 7% of all side effect expressions. Women talked about their feelings of shock and panic when losing their hair, about how they lost not just the hair from their scalp but also their eyelashes, eyebrows and body hair. The next most frequent side effects reported were neuropathy, tiredness and nausea, which were talked about by 63%, 61% and 61% of women, respectively. Many women described their neuropathy as a non-painful sensation of tingling or numbness, although several also mentioned it as being painful. Example quotations included:

"Three days afterwards, I sort of peeled my head like an ostrich",

"Had pain in my fingers, the ability of my hands to grab something gave in, I fell down the stairs",

"The first thing is tiredness, no energy at all, even for doing basic things",

"I am very sick during the 24 hours following the sessions".

Other commonly expressed treatment-attributed side effects were constipation, loss of appetite, vomiting, pain in general and fatigue, with example quotations including:

"Constipation after chemotherapy, four days I was unable to go to the restroom",

"I eat less … after chemotherapy, I don't eat",

"During the 24 hours following the [chemo] sessions, I have vomiting",

"I had chemotherapy, so I was all pain",

"You're feeling as if you are walking around with lead on your bones".

Most women did not know if they had received more than one type of chemotherapy or if their drug regimen had changed, because in Europe those decisions were left largely in the hands of the clinicians. Some comments from patients indicated their treatments were altered after having a reaction, but they were not able to name the prescribed drugs.

The most bothersome treatment-attributed side effects, each with a mean score of at least 7.0 (out of a possible maximum of 10.0) and rated by at least one-third of the women in the study sample, were constipation, nausea, diarrhoea, pain in general, fatigue, weakness, reduced sleep quality and hair loss (Table 3).

3.5 Concepts Related to Impacts

The women spoke about not being able to cope with work and other daily requirements, such as not being able to go shopping alone or prepare their own lunch, and talked about how their spouses and family members now had to work more and also take over much of the housework. There were 2847 concepts identified from the 64 transcripts that related to the impacts women experienced in relation to their disease and its symptoms and perceived treatment-related side effects (Table 4). The most frequently expressed impacts were feelings of anxiety, concerns about the future, physical functioning, work limitations and adoption of coping strategies, which were talked about by between 72% and 80% of women overall.

Table 2 Symptom expression frequencies and bothersomeness scores by concept group[a]

Concept group, symptom expression	Europe (N=55)			USA (N=9)			Example quotations
	% of 1667 symptom expressions	% of 55 transcripts contributing	Mean bothersomeness score (number of raters)	% of 255 symptom expressions	% of 9 transcripts contributing	Mean bothersomeness score (number of raters)	
Gastrointestinal	32.1	92.7		26.3	77.8		
Bloating	11.8	72.7	7.5 (40)	9.8	66.7	6.2 (5)	"Very bloated. I looked 6 or 7 months pregnant; that is how much it was bloated" "[L]ike a balloon, about to burst any moment"
Loss of appetite	3.5	34.5	6.5 (13)	2.0	22.2	3.0 (1)	"I lost my appetite and I had this feeling of having already eaten even though I hadn't eaten" "I wasn't interested in food whatsoever and would go the whole day without eating"
Feeling full	2.6	43.6	6.4 (19)	0.8	11.1	2.5 (2)	"[A] feeling of fullness, after three full fork loads of food I had to stop eating, totally saturated" "I couldn't eat properly because I just couldn't get it down; there was no room"
Gas	2.5	30.9	7.4 (12)	2.7	33.3	7.0 (2)	"I will have a lot of air in my belly with burping" "I have terrible wind"
Constipation	2.3	36.4	6.4 (19)	4.3	33.3	6.7 (3)	"I was constipated, I thought I had a problem with the colon" "[I]t was like having stones and it wouldn't move at all"
Pain and discomfort	23.8	87.3		31.4	88.9		
Abdominal pain	7.1	70.9	6.8 (28)	12.9	44.4	7.3 (3)	"[T]his pain like a cut with a knife in the lower abdominal area, felt like [I was] under labour" "[E]ach time [I] turn around in my bed, I could feel [abdominal] pain"
Pain in back	4.3	45.5	6.5 (20)	3.9	44.4	6.0 (3)	"I couldn't be straight because I had back pain" "I had back pain, I had a lot of back pain, like a belt around my back"
Cramping/ muscle pain	2.8	34.5	6.6 (14)	4.3	44.4	6.0 (2)	"[Y]our calf is knotted, that kind of leg cramp" "[M]y toes would be straight as though the joints were bending backwards [from cramping]"
Pain in side	2.6	30.9	6.6 (13)	5.1	55.6	7.5 (6)	"[L]ike a pulling sensation, something pulling on my sides, like a pinching pain" "[I]t started being painful on the right hand side, when I was kind of turning around"

Table 2 (continued)

Concept group, symptom expression	Europe (N=55)			USA (N=9)			Example quotations
	% of 1667 symptom expressions	% of 55 transcripts contributing	Mean bothersomeness score (number of raters)	% of 255 symptom expressions	% of 9 transcripts contributing	Mean bothersomeness score (number of raters)	
Sleep- and energy-related	13.6	80.0		14.1	88.9		
Tiredness	6.2	61.8	7.7 (17)	7.1	77.8	7.2 (6)	"[A]s soon as I do something I get tired and so I go and sit down" "I was tired. I just felt tired and thought you're getting old, and you feel tired"
Fatigue	2.0	27.3	7.6 (19)	2.4	55.6	2.0 (1)	"[F]atigue, it's like a psychological tiredness rather than a tiredness that's physical" "[T]hought I was suffering from burnout, had all of the symptoms of a burnout"
Genitourinary	7.4	67.2		7.5	66.7		
Frequent urination	4.4	56.4	6.5 (28)	4.3	44.4	4.0 (3)	"[E]very three quarters of an hour, I would need to urinate again" "I always want to go, I have to pee regularly, sometimes I've got to hold myself in"
Related to hormone changes	7.4	60.0		5.5	33.3		
Irregular menstruation	4.0	34.5	7.6 (18)	1.2	11.1	–	"I had my period and then about a week later I started a period again" "[H]ad one month without menstruation, then for several months had menstruations twice per month"
Bleeding	2.2	21.8	8.1 (7)	4.3	22.2	7.0 (1)	"I had bleeding, I'd gone past the age where you have periods" "[J]ust felt whoosh, all this liquid comes out, rush to toilet, watery blood"
Sensory	2.9	27.3		0.0	0.0		
Systemic	0.8	7.3		0.0	0.0		
Additional	11.9	76.4		15.3	77.8		
Shortness of breath	3.3	41.8	6.2 (21)	4.3	22.2	6.3 (4)	"I stand up, and I have to sit down, I am out of breath" "[W]hen I walk, I'm out of breath, when there's a little bit of effort involved"

[a]Symptom expressions accounting for ≥2% of all coded symptoms in Europe and/or the USA are shown

When talking about their anxiety, women mentioned the general fear associated with having cancer, anticipation of the next chemotherapy cycle and of test results, a feeling of not knowing what was going on, as well as symptoms and side effects, such as weight change, hair loss and bleeding.

Anxiety was described as one of the two key sources of sleep difficulty (e.g. "Sometimes found it hard to fall asleep – that was the anxiety."), with the other being pain (e.g. "I usually don't get up in the middle of the night, but the pain was

Table 3 Side effect expression frequencies and bothersomeness scores by concept group

Concept group	Europe (N=55)			USA (N=9)		
	% of 1327 side effect expressions	% of 55 transcripts contributing	Mean bothersomeness score (number of raters)	% of 232 side effect expressions	% of 9 transcripts contributing	Mean bothersomeness score (number of raters)
Gastrointestinal	21.4	98.2		17.7	88.9	
Bloating	1.2	18.2	6.6 (7)	3.0	33.3	–
Loss of appetite	3.3	41.8	7.0 (9)	1.3	11.1	–
Constipation	4.0	43.6	8.1 (25)	3.0	44.4	4.7 (3)
Vomiting	3.3	40.0	8.2 (14)	1.3	22.2	7.0 (2)
Nausea	5.3	60.0	8.1 (28)	6.0	66.7	5.5 (6)
Diarrhoea	2.1	36.4	7.1 (19)	2.2	22.2	6.3 (3)
Pain and discomfort	19.8	89.1		23.3	88.9	
Abdominal pain	2.4	38.2	8.2 (16)	3.0	55.6	6.7 (3)
Pain in back	0.6	9.1	8.6 (5)	2.2	22.2	–
Neuropathy	7.2	60.0	6.8 (30)	8.2	77.8	4.2 (5)
Pain in general	3.6	38.2	8.1 (21)	3.0	55.6	6.0 (2)
Bone/joint pain	2.2	25.5	–	0.9	22.2	4.5 (2)
Sleep- and energy-related	21.3	92.7		19.8	100.0	
Tiredness	6.3	61.8	7.0 (5)	3.9	55.6	10.0 (1)
Fatigue	3.1	47.3	8.4 (39)	2.2	33.3	6.4 (7)
Reduced sleep quality	2.8	40.0	7.8 (25)	1.3	22.2	2.0 (1)
Weakness	2.0	25.5	–	6.9	55.6	7.0 (3)
Low energy	2.2	29.1	–	4.3	44.4	6.0 (1)
Sensory	6.8	49.1		10.8	77.8	
Eye/vision problems	1.7	14.5	–	2.6	22.2	7.0 (1)
Mouth problems	1.0	12.7	–	2.2	22.2	4.0 (1)
Altered taste in mouth[a]	1.7	20.0	8.0 (10)	3.0	55.6	6.2 (5)
Systemic	1.1	16.4		4.3	66.7	
Additional	25.7	94.5		22.4	100.0	
Skin and nail problems	2.8	32.7	7.3 (12)	–	–	–
Allergic reaction	1.6	23.6	6.7 (10)	2.2	33.3	8.0 (1)
Hair loss	7.8	83.6	7.0 (48)	5.2	88.9	3.8 (8)
Cognitive dysfunction	–	–	–	5.2	22.2	7.5 (2)

Only side effect expressions accounting for ≥ 2% of all coded symptoms in Europe and/or the USA are shown

[a]USA group "Taste in mouth" only

so strong."). Concerns about the future were mostly about dying from cancer, with one woman saying:

"Every day I think I'll be dead tomorrow, I think about death constantly".

When talking about their impaired physical functioning, women described this mainly as an aftereffect of surgery. For example, one woman said:

"I couldn't pull too much on the scars so I was walking in small steps".

Work limitations were most frequently described by a lack of energy and reduced focus. Example quotations included:

"It was constant [tired], I had to be signed off work for 15 days",

"I got signed off from work from my GP because I was making mistakes and not realizing it".

Other explanations mentioned for work limitations included incontinence, bleeding, dizziness, pain, cramping and negative self-image. Time taken off work was the main contributing factor to the financial burden experienced by many of the women.

Examples of coping strategies adopted by women included religion/faith, a positive attitude, healthy behaviours and medication for symptoms. Example quotations included:

"I prayed and let God give me what I needed to do and I went through it that way",

"I just live one day at a time",

"I don't smoke anymore [since diagnosis and treatment]",

"I took the pills as the anti-nausea".

The most difficult-to-deal-with impacts, each with a mean score of at least 7.0 (out of a possible maximum of 10.0) and rated by at least one-third of the women in the study sample, were concerns about the future, emotional difficulties in general, physical functioning, sexual functioning, negative self-image, fatigue, sleep difficulties, financial burden and work limitations (Table 4). What made these impacts difficult to deal with was a general sense of powerlessness. For example, the women did not want to die from their disease, but knew that the very poor prognosis made long-term survival unlikely; the women suffered emotionally because of their disease and its treatment, but felt unable to do anything about this; and they no longer saw the point of looking after their body.

4 Discussion

Our qualitative interview study explored the patient experience and perspective of the most predominant and most bothersome experiences for women with ovarian cancer. The difficulty in diagnosing ovarian cancer was experienced in the storyline provided by most of the women interviewed, and the advanced state of the cancer by the time of the diagnosis and the immediacy and rigor of the treatment experience resulted in most women reporting very negative experiences with the healthcare system.

The most frequently reported and bothersome symptoms were bloating, abdominal pain and tiredness and, in terms of treatment-attributed side effects, hair loss, nausea and tiredness/fatigue. The most frequent and difficult-to-deal-with impacts for women with ovarian cancer were concerns about the future, physical functioning and work limitations. Role reversal issues within families were often cited as a result of these limitations, adversely affecting the burden on spouses and family due to loss of income and inability to maintain usual family care activities.

Understanding the patient perspective can help to identify the symptoms, treatment-related side effects and impacts of the disease on life quality that should be monitored in women with ovarian cancer to help to provide support and advice and to guide care decisions. In the American Cancer Society's Study of Cancer Survivors-I, symptom burden was identified as an important predictor of declining physical functioning in women diagnosed with ovarian cancer ($n = 284$) [14]. A survey of 95 women with advanced or recurrent ovarian cancer found that, although progression-free survival was considered the most important factor regarding preferences for treatment outcomes, women reported their willingness to forgo several months of progression-free survival to avoid severe treatment-related side effects, such as nausea and vomiting [15]. Results from the current study show some overlap between symptoms attributed to the disease and those perceived to be treatment side effects, which is likely in part to reflect actual overlap (e.g. tiredness/fatigue), as well as challenges around cause attribution that suggest a role for patient education in terms of being able to differentiate the two. The qualitative findings from the current study can be a framework against which to develop patient-centred quantitative measurement strategies to systematically and routinely capture the patients' perspective of the most important signs, symptoms and impacts in future clinical research and routine clinical practice. Initiatives to do this, such as the Measure of Ovarian Cancer Symptoms and Treatment (MOST) concerns or the International Consortium for Health Outcomes Measurement (ICHOM), should be considered in the context of the current study findings [16].

Although there have been other small qualitative studies that have provided important narratives of the experiences of women living with ovarian cancer [17–23], to the best of our knowledge, ours is the first interview study to offer both qualitative information and quantitative summaries that assess disease-related and treatment-attributed symptoms and the degree of bother and other impacts of these symptoms on the lives of women with ovarian cancer. The mean time between first diagnosis of ovarian cancer and the qualitative interviews in the current study (4 years and 2 years in Europe and USA, respectively) will have aided the broad collection of patient experiences during the disease and treatment trajectory. Recall bias is not usually an issue with major life impacts such as treatment for cancer, because it uses event-based memory. The women participating in this exploratory qualitative work had vividly memorable experiences of their condition, their diagnosis and their early treatment, which they recounted clearly.

Table 4 Impact concept code frequencies and mean impact difficulty scores by concept group

Concept group	Europe (*N*=55)			USA (*N*=9)		
	% of 2536 impact expressions	% of 55 transcripts contributing	Mean impact difficulty score (number of raters)	% of 311 impact expressions	% of 9 transcripts contributing	Mean impact difficulty score (number of raters)
Emotional health	26.5	98.2		24.1	88.9	
Feelings of anxiety	5.9	81.8	8.5 (12)	1.0	11.1	–
Concerns about the future	4.3	78.2	8.1 (35)	4.8	77.8	6.6 (5)
Concerns about fertility	1.9	29.1	8.5 (15)	0.6	11.1	–
Worry about treatment	1.1	38.2	–	0.6	11.1	5.5 (2)
Sadness/depression	4.3	61.8	8.3 (10)	2.6	55.6	5.5 (2)
Emotional difficulties in general[a]	0.8	21.8	7.7 (21)	1.0	33.3	6.0 (2)
Shock	1.9	38.2	10.0 (1)	2.3	44.4	–
Limitations to daily functioning	21.9	100.0		18.6	88.9	
Physical functioning	4.9	72.7	7.3 (34)	6.8	77.8	6.5 (4)
Exercise	1.3	32.7	6.8 (12)	0.3	11.1	–
Leisure activities	4.4	58.2	6.7 (30)	2.9	66.7	3.0 (3)
Dietary freedom	3.4	60.0	6.4 (32)	1.6	44.4	3.0 (2)
Housework/chores	3.1	63.6	6.8 (34)	1.3	33.3	4.0 (5)
General functioning	2.4	54.5	8.3 (4)	4.8	66.7	–
Self-care	1.2	32.7	6.8 (16)	0.3	11.1	5.0 (1)
Sleep- and energy-related difficulties	5.9	78.2		4.5	44.4	
Fatigue	0.6	18.2	7.3 (24)	–	–	6.0 (1)
Sleep difficulties[b]	1.5	49.1	8.0 (31)	1.0	22.2	2.0 (1)
Tiredness	1.5	34.5	7.5 (17)	1.0	33.3	6.5 (2)
Impacts on family/support network	14.2	90.9		15.1	100.0	
Work limitations	5.7	80.0	7.5 (33)	4.2	44.4	6.3 (4)
Given moral support	2.5	36.4	–	6.1	66.7	–
Financial burden	2.4	58.2	7.7 (29)	2.3	55.6	4.7 (3)
Altered self-perception	9.2	85.5		5.8	77.8	
Negative self-image	3.1	54.5	8.2 (28)	1.0	22.2	9.0 (1)
Shift in perspective	1.0	20.0	10.0 (1)	3.9	44.4	–
Altered relationships	8.6	83.6		6.1	77.8	
Relationships in general	1.1	27.3	6.8 (20)	1.0	22.2	2.0 (2)
Relationships with partner	2.5	40.0	8.0 (1)	1.3	33.3	–
Sexual functioning	2.1	50.9	7.8 (38)	1.9	33.3	7.0 (3)
Impacts on social functioning	5.9	76.4		1.3	44.4	
Reduced social activity	1.7	36.4	7.2 (25)	0.6	22.2	2.5 (2)
Social isolation	2.5	41.8	7.8 (4)	0.3	11.1	–
Attitude of others	2.1	40.0	6.9 (7)	0.3	11.1	–
Sleep- and energy-related difficulties	5.9	78.2		4.5	44.4	
Additional	7.8	76.4		24.4	100.0	
Coping strategies	7.8	76.4	3.0 (2)	24.4	100.0	–

Only impact expressions accounting for ≥ 2% of all coded impacts in Europe and/or the USA, and/or with a mean score of at least 7.0 (out of a possible maximum of 10.0) rated by ≥ 10 women in Europe and/or ≥ 2 women in the USA are reported. Note: impact difficulty rating exercises could be conducted only for impacts identified by interviewers during the interview

[a] 'Emotional health in general' in European interviews

[b] 'Reduced sleep quality' in US interviews

Our study had several key strengths. It used a rigorous methodology with a detailed coding framework to identify concepts expressed about disease-related symptoms, treatment-attributed symptoms and their impacts, and the most bothersome and difficult symptoms and impacts, in women diagnosed with and treated for ovarian cancer. This adds a methodological rigour in line with recommendations [11–13] compared with previous research. Saturation of concept was reached and high inter-rater agreement was demonstrated between coders. The use of open-ended questions as part of the semi-structured interviews gave participants the opportunity to express information freely about their experiences. The similar concepts expressed in the European and the US groups suggest the applicability of our findings across broad geographical regions. Limitations of our study include the low number of patients included in the study in the USA, the long period between diagnosis and study participation, which may have introduced recall bias, and that the study was not designed to capture individual treatment effects.

5 Conclusions

Our qualitative interview study shows that the most common and most bothersome experiences in women diagnosed with, and treated for, ovarian cancer were symptoms of bloating, abdominal pain and tiredness, treatment side effects of hair loss, nausea and tiredness/fatigue, and impacts relating to concerns about the future, physical functioning and work limitations. When speaking to patients with ovarian cancer, we suggest that clinicians might improve patient care and support by asking about and listening for mention of these experiences and taking them into consideration when making treatment decisions and offering guidance to their patients.

Compliance with Ethical Standards

Ethics approval and consent to participate The study was performed in accordance with the ethical standards of the institutional and/or national research committee and the principles of the Declaration of Helsinki and relevant approval bodies for research with human subjects. The protocol of the European arm was reviewed for compliance with exemption status by Quorum Review-Independent Review Board (IRB) for the UK and Germany and by the French Government. The US arm of the study was approved as low risk by Quorum Review-IRB for implementation in the USA. All participants provided written informed consent before their interview sessions.

Consent for publication Not applicable.

Availability of data and materials The datasets supporting the conclusions of this article are included within the article.

Conflict of interest KH and DE are employees of AstraZeneca. MLM is an employee of Health Research Associates, Seattle, WA, USA, which received funding for this project from AstraZeneca. At the time this study was conducted, MR was an employee of Electronic Research Technology, Peterborough, UK, which received funding for this project from AstraZeneca.

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