

# Symptom Experience in Patients with Gynecological Cancers: The Development of Symptom Clusters through Patient Narratives

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**B**eing diagnosed with gynecological cancer is associated with high distress levels, particularly in younger patients and in advanced disease.<sup>1</sup> The residual effects of surgery and various treatments are known to have a profound and long-lasting impact on quality-of-life issues with significant and potentially detrimental change to women's self-esteem, mental health, sexual functioning, and fertility.<sup>2</sup> Although recent medical advances have increased survival rates, few investigations have been conducted to examine the interplay of physical and psychological symptoms on this group of patients. Moreover, previous studies have focused predominantly on gathering quantitative data such as the frequencies and types of symptoms, with little or no information about the gynecological cancer patients' symptom experiences.<sup>2,3</sup> This knowledge is important to gain if we are to understand the quality-of-life and supportive care issues that affect this group of patients. Thus, our current knowledge about gynecological cancer patients' experiences from a qualitative perspective remains limited.

**Abstract** The vast majority of the increasing cancer literature on physical and psychological symptom clusters is quantitative, attempting either to model clusters through statistical techniques or to test priori clusters for their strength of relationship. Narrative symptom clusters can be particularly sensitive outcomes that can generate conceptually meaningful hypotheses for symptom cluster research. We conducted a study to explore the explanation of patients about the development and coexistence of symptoms and how patients attempted to self-manage them. We collected 12-month qualitative longitudinal data over four assessment points consisting of 39 interview data sets from 10 participants with gynecological cancer. Participants' experiences highlighted the presence of physical and psychological symptom clusters, complicating the patients' symptom experience that often lasted 1 year. While some complementary and self-management approaches were used to manage symptoms, few options and interventions were discussed. The cancer care team may be able to develop strategies for a more thorough patient assessment of symptoms reported as the most bothersome and patient-centered sensitive interventions that encompass the physiological, psychological, sociocultural, and behavioral components of the symptom experience essential for effective symptom management.

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The physical effects on women after being diagnosed with gynecological cancer are often attributed not only to the symptoms arising from the disease itself but, most importantly, from the side effects of treatment such as surgery, chemotherapy, and radiotherapy.<sup>3-5</sup> Symptoms such as fatigue, frequency of urination, bleeding, weight loss, and ascites are commonly experienced by patients, particularly those with ovarian cancers.<sup>6</sup> Once diagnosed, gynecological cancer patients often go on to face a prolonged course of treatments which contribute to further symptoms such as chemotherapy-induced alopecia,<sup>7</sup> dermatolog-

ical toxicity,<sup>8</sup> fatigue, sleep disturbance,<sup>9</sup> nausea, vomiting, and sexual dysfunction.<sup>10</sup> Portenoy et al.<sup>11</sup> reported that ovarian cancer patients alone experienced a mean of 10.2 symptoms with a range of 0–25 concurrent symptoms. Similarly, 13.4 concurrent symptoms were reported in a study of 49 women undergoing chemotherapy, which caused disruption to the patients' quality of life.<sup>6</sup>

The psychological state of patients with gynecological cancers has also been investigated, particularly in association with increased risks of psychological morbidity such as anxiety and depression.<sup>2</sup> In a longitudinal study of women with ovarian cancer, Gonçalves et al.<sup>12</sup> found that neuroticism was associated with persistent psychological morbidity and suggested the need for routine and regular psychological screening for cancer patients. Newly diagnosed women with gynecological cancer also appeared to experience diverse psychological symptomatology that persisted over the first 6 weeks after the diagnosis.<sup>2</sup>

The relationship between symptom experience, distress produced, and quality of life has also been pursued, of particular interest being the direct correlation between improvement of symptoms and increased quality of life. Ferrell et al.<sup>3</sup> found that ovarian cancer patients not only experienced distress but often differently ordered the importance of symptoms at different phases of their illness. They also found that these patients utilized resourcefulness and innovative ideas to manage their symptoms. These authors suggested that symptom experience may be associated with, and can be mediated by, the influence of variables such as disease state, demographic and clinical characteristics, or individual and psychological factors.<sup>3</sup> It is therefore unsurprising that treatment-induced symptoms have been a major concern of most studies to gather information about symptoms arising from residual treatment or disease progression as well as frequency and types of symptoms.<sup>5</sup> To date, longitudinal studies have yet to be undertaken to gather information prospectively about gynecological cancer patients' symptom experiences. Consequently, the patients' personal experiences of physical and psychological symptoms, such as their concerns, perceptions, and responses to symptoms, remain largely unexplored. Such information is important in the development of interventions for symptom management and the provision of supportive care. Also, while some literature exists in relation to ovarian cancer symptoms, minimal related work has focused on other types of gynecological cancer, suggesting a gap in the literature.

The aim of our study was to explore the physical and psychological symptom experience in patients with gynecological cancer undergoing radiotherapy and/or chemotherapy over the first year from diagnosis. Specific objectives of the study were to (1) qualitatively assess the possible relationships among symptoms resulting from cancer treatments in patients with gynecological cancer, as understood by patients, and (2) explore how patients with gynecological cancer manage the symptoms they experience.

## Methods

A descriptive qualitative longitudinal design using face-to-face interviews was used in this study. Qualitative descriptive methods serve to provide descriptions of facts about a phenomenon.<sup>13</sup> Sandelowski<sup>14</sup> elucidates that qualitative descriptive research methods lend themselves to the data to produce comprehensively and accurately detailed summaries of different participants' experiences of the same event. Interviews were conducted by an experienced qualitative researcher. Interviews were conducted prospectively over four time periods: beginning of treatment (T1) and three (T2), six (T3), and 12 months (T4) later. This time frame was chosen as these are the critical times over which patients with cancer most commonly experience symptoms as a result of treatments or disease progression.<sup>15</sup> Leventhal and Johnson's<sup>16</sup> self-regulation theory was used as the study's theoretical framework, assisting us in developing the interview guide around symptom identification, exploration of meaning and consequence, and attempts to control or manage it. Their self-regulation theory suggests that symptoms activate a cognitive search process, which results in the construction or elaboration of illness representation. These representations then serve as standards against which new information is matched and evaluated. Comparisons of current sensations with cognitive representations allow for interpretation of new symptoms and for evaluation of the seriousness of current symptoms. Hence, fear behaviors (distress) or instrumental behaviors (coping) are the result of simultaneous parallel psychophysiological processes in response to the threatening experience. The response may be different from individual to individual, based on past experience and the cognitive processes involved, as may the strategies used to cope with the experience. Dodd et al.<sup>17</sup> simplified the symptom experience as including an individual's perception of a symptom, evaluation of the meaning of a symptom, and response to a symptom.

After approval from the ethics committee, patients were recruited from a large specialist oncology center in the UK a few weeks after diagnosis and prior to commencement of adjuvant treatment. Patients were provided with information about the study, and written consent was obtained. Ten patients were recruited from a list of consecutive newly diagnosed patients through purposeful sampling, and five declined participation, primarily due to the long-term commitment necessary for the study and being too upset with the diagnosis. Maximum variation was used<sup>13</sup> to capture core experiences and central, shared aspects or impacts of having a gynecological cancer rather than confining to specific aspects of different types of gynecological cancer. The sample included patients with any type of gynecological cancer and those receiving chemotherapy and/or radiotherapy. Patients with cognitive impairment, metastasis with central nervous system involvement, or life expectancy of less than 6 months at recruitment or who were unable to carry out the interview were excluded. Patients initially were provided with brief information from their oncologist; upon showing an interest,

potential participants were provided with a detailed information sheet and had a discussion with the research nurse. Upon agreement, patients signed a consent form and the first interview was scheduled. Participants were followed up for one year. Past experience, judgment on the quality of the data obtained, and data saturation were the key determinants in the decision to have a sample size of 10 over four times (=40 possible transcripts) with the possibility of recruiting more if data were not saturated with the initial sample, although in our study this did not need to take place.

An interview guide was used, starting with a broad question, such as “How have you been feeling physically this last week?” This was followed by questions relating to the psychological symptoms participants experienced, how these related to their physical symptom experience, what they thought when a symptom occurred, what impact the symptoms had on their life, and how they managed the symptoms. New issues identified in the early interviews were incorporated into the interview guide for subsequent interviews. Each interview lasted about an hour to an hour and a half. Interviews were conducted in the patients’ homes. Information about sociodemographic characteristics including age, education, and marital status was obtained from patients, who completed an initial sociodemographic form. Disease- and treatment-related information (diagnosis, treatment received, stage of cancer) was obtained from the patients’ medical notes. Interviews were recorded and transcribed verbatim.

Data were analyzed line by line using content analysis to code the content of each interview and to map major categories. Categories were compared by two of the researchers, the project lead investigator and another independent person. The analyzed categories were compared and discussed until agreement was reached. Symptoms that were expressed in T1 were grouped together if more than two participants spontaneously mentioned an association between at least two of the symptoms. In T2–T4 we continued this process, focusing primarily on changes in the initial cluster. Symptoms were grouped together as patients discussed them, and if patients reported the same symptom in different contexts, this was coded separately. No participant was asked for specific symptoms as the questions in the interview were broad to allow for important aspects of the symptom experience in each woman and each interview to surface. A final consensus was sought after comparisons and discussions for all categories.<sup>13</sup>

Credibility of the qualitative data was maintained by ensuring voluntary participation. Analyzed data were constantly discussed and checked by two independent persons, which acted as a constant peer-review process to ensure the analyzed data were true findings and free from potential bias. All interviews were audiotaped, and participants’ verbatim quotes were provided to represent categories and subcategories identified, which further ensured reliability by reducing the risk of selective data filtering by the investigators through recall or summation. Consistency was maintained by comparing initial categories within and across the data gathered from the participants to ensure repeatability of the categories. Field notes

were reviewed as a kind of inquiry audit to prevent potential bias and to ensure the stability of data.

## Results

### PATIENT CHARACTERISTICS

All 10 participants completed the interviews at the four time points, over the course of one year. One interview transcript (at T3) was subsequently found to be unusable, due to tape recorder malfunction, and was excluded from the analysis, thus leaving a total of 39 data sets of interviews over four time points. The mean age of the group was 62.8 years (SD = 7.7, range 51–72). Most were married (n = 6), two were separated, and two were widowed. The majority (n = 7) had secondary/high school education. Six were retired, two were homemakers, and two reported technical/manual work. Half of the participants (5/10) had ovarian cancer, while the rest had uterine (1/10), cervical (2/10), or endometrial (1/10) cancer and one had both uterine and cervical cancer. Seven participants had surgery. Of the 10 participants, six had chemotherapy, three had radiotherapy, and one had chemotherapy followed by radiotherapy. Chemotherapy included carboplatin (n = 2), carboplatin and paclitaxel (Taxol) (n = 5), and cisplatin (n = 1). Half the patients were at an early disease stage (stage 1 or 2, n = 5), three were at stage 3, one was at stage 4, and the stage was unknown in one patient.

### QUALITATIVE DATA

Patients identified symptoms in an interlinked manner rather than in isolation, suggesting some symptom clustering. There was always a key symptom mentioned together with several others that were reported as co-occurring or resulting symptoms. These associations and explanations helped patients to make sense of the symptoms and rationalize or legitimize the complexity of the symptom relationships and the difficulty in having control over the symptoms. Participants gave meaning to the physical symptoms experienced alongside psychological responses and how they managed to alleviate them. The meaning element was fairly stable across times as women discussed primarily the occurrence of symptoms, their impact on their lives, and their struggle to cope with them. What was an evident change in the perception, however, for most symptoms was the frustration from the “chronicity” of symptoms and the differential impact of symptoms at different times in their disease trajectory. Symptoms were described as co-occurring with one influencing others, giving an understanding of the formation of symptom clusters. Four major narrative symptom clusters emerged from the data.

*Tiredness, sleeplessness, pain, depression, and weakness.* The most common symptom experienced by all patients that persisted over the 12-month period was tiredness, which was also related with sleep disturbance associated with pain, tingling sensation of the hands and feet, and anxiety. Tiredness was experienced throughout the year as recounted by several participants:

“Basically, it’s after the effects of the treatment that I was feeling tired cos I’m having radiotherapy every day and chemotherapy once a week.” (GYP 01 at T1)

“Just me body felt tired, me body felt tired of it [radiotherapy]. I felt rotten. I couldn’t do anything. It’s depressing.” (GYP 12 at T2)

“Physically, I’m alright. I felt alright except I get tired easily, but other than that, I feel alright.” (GYP06 at T3)

“What I do find is that it’s depressing to feel physically tired all the time and I don’t know why.” (GYP04 at T4)

Difficulties with sleep were also associated with depression. For some (4/10) participants, feelings of depression occurred as they went through the treatment, as two participants described:

“I’ve actually felt quite depressed this last week and actually burst into tears, which is something I haven’t done before. But it was sort of overwhelming—these symptoms.” (GYP08 at T3)

“These symptoms are affecting my sleep. If I can’t sleep, I get tired and I can’t do anything the next day, then I get depressed.” (GYP06 at T3)

Depression was often the result of uncertainty and fear. Half of the participants expressed feelings of uncertainty lasting until the twelfth month, as highlighted by two of them:

“It’s very uncertain you know. It’s a very uncertain way of life. You don’t know . . . like I go and see . . . I go back every three months for check-up. You’re living your life for check-ups. So every four months you’re thinking . . . ‘Is everything alright?’ You live your life for those four months’ check-ups. The frightening bit is the uncertainty of it and it’s depressing just thinking of what will happen next.” (GYP04 at T3)

“I can’t sleep thinking about what will happen all the time. The uncertainty keeps you awake.” (GYP012 at T3)

However, this feeling seemed to subside by T4 as they became more in control and able to cope by not dwelling on it and just accepting the disease, its treatment, and symptoms. This marked shift in coping styles in T4 characterized the patients’ increased positive response to symptoms at this stage.

When participants were tired, they also complained of weakness. The expressions used included “muscle tone” and “muscle strength” weakness. However, a slight improvement in this symptom was observed from T3 onward. Tiredness and its related symptoms affected the participants’ ability to get on with usual routine housework; however, support from husbands, family, and friends helped the participants to cope with their symptoms:

“I’ve got such a strong group of friends and relatives and they all live around me . . . so all the family are around me and they’ll all come at least once a day.” (GYP11 at T4)

Very few management options were discussed. For both tiredness and weakness, participants used a variety of self-management approaches such as taking a rest even for half an

hour each day or doing some physical fitness like walking and pilates from the third month onward. To get their muscle tone back to normal, some participants expressed their desire to “get fit,” so they walked or went cycling. Two participants reported taking herbal medicines, such as echinacea, after surgery and before chemotherapy. They perceived this as helpful in building up their immune system. Pain was managed by taking painkillers, as prescribed by their doctors. Praying was also reported as a strategy used to combat the anxieties related to the illness.

Hair loss, ocular changes, body image, identity experience, and anxiety. Hair loss, including body hair such as eyebrows and eyelashes, was reported by four participants, all of whom had received chemotherapy. In the beginning, participants did not want to wear wigs and were anxious that it portrayed a symbol to others that they had cancer:

“I do not want my family to see me without hair as they will know I have cancer and then they will start to worry about me.” (GYP10 at T1)

Later on, they no longer cared whether they wore a wig or not, especially when they themselves and others accepted the situation. Such an experience was described as follows:

“I noticed my hair falling and got me a wig the first day.” (GYP11 at T1)

“I noticed that . . . the hairs in my nose, I think have all disappeared as well.” (GYP10 at T2)

“My hair came back like Shirley Temple, curly but it all came back slate gray and I didn’t like it.” (GYP11 at T4)

On a couple of occasions, negative feelings were externalized through talking about someone else, often a famous person. This may have facilitated the expression of difficult emotions. Such a transference is depicted below:

“My hair is more or less gone but this time my husband just shaved it all off. I bung my hat on and that’s it. I feel sorry for young girls. It must be horrendous cos I think of Kylie [Minogue, pop singer], for someone like her to lose her hair must have been terrible.” (GYP03 at T3)

Although participants understood that hair loss was an expected and common consequence of chemotherapy, its impact in some patients was more difficult to accept. Losing hair was seen as a realization that they had cancer or increased one’s identity as a cancer patient. The same patient also talked about hair loss and anxiety:

“I think one of the most difficult things is that you might be feeling alright physically and then you’ve got a bald head. When I put my wig on, I feel alright. But no hair is a big thing—even though people say you looked alright without it, you don’t.” (GYP03 at T3)

In some participants, hair loss, especially eyelashes, was connected with blurred vision as they believed that eyelashes protected their eyes, as reported by one (1/10) participant at T2 and three (3/9) participants at T3, around the end of their treatment.

*“My eyes seem as though they’re a bit blurred. I feel like I need eyeglasses. It’s a thing that annoyed me most. It just felt like there’s a film on your eyes. I wonder if it’s something to do with hair loss.”* (GYP10 at T2)

One participant was worried about her blurred vision being associated with other health problems:

*“I’ve had slightly sort of, not blurred vision but zig-zaggy vision that made me a bit . . . ‘Oh dear,’ you know . . . have I got a brain tumor? . . . a strange sort of thing that upsets my balance.”* (GYP08 at T3)

*Gastrointestinal problems: nausea, loss of appetite, taste changes, bowel function, weight changes, and distress.* Nausea, appetite changes, and changes in bowel function (diarrhea or constipation) were the most common symptoms reported in relation to gastrointestinal system problems that distressed patients. Patients who reported these occurrences received either chemotherapy or radiotherapy, and one received both. However, these symptoms were of limited extent as women reported them as mild or of less importance and perceived them as more manageable. Nausea was only reported by one participant at T1 and was relieved by prescribed medications. Another participant reported loss of taste throughout the year of the study. Loss of appetite was reported by one participant at T2 and T3. Weight loss, which three of the participants attributed to diarrhea, was also reported:

*“My tummy’s a bit off, had a bit of diarrhea, but that’s the norm.”* (GYP05 at T1)

*“I lost weight but then again, I don’t know if that’s down to eating then going to the toilet.”* (GYP04 at T3)

However, weight gain was reported by six participants at T3 and five participants at T4, which was the key distressing nutritional problem described, although for some it was seen in a more positive way:

*“I put on weight since the radium. But it’s a small price to pay isn’t it? A bit of weight for all that you’ve gone through.”* (GYP15 at T4)

*Numbness and tingling sensations in the hands and feet, restlessness, sleeplessness, and depression.* A common physical problem experienced by three of the participants who all received chemotherapy was tingling sensations of the hands and feet, which increased over time. At T4, three out of 10 participants still experienced numbness and tingling sensations as described by one participant:

*“I was worst after my last treatment, all sorts, my feet, my fingers were really bad . . . always tingly. My feet they’re numb and I get cramps. It’s weird, they get too cold. It’s depressing especially if I can’t sleep.”* (GYP10 at T3)

*“I still got funny toes and fingers. They feel fat and podgy. It’s depressing. It’s difficult to explain, it feels like because they’re not dead but . . . I know I’ve got them, if that makes any sense. I find it difficult to spread them.”* (GYP10 at T4)

Participants sometimes related the sensation to achy joint pains, as if they were getting the flu. This sensation also made them feel restless at night, contributing to sleeplessness. One participant related this to the side effect of paclitaxel (Taxol); therefore, her medication was changed to liposomal doxorubicin. Two participants tried to self-manage the feeling of coldness and numbness of their feet and fingers by soaking them in hot water. For those participants who experienced sleeplessness, due to feelings of numbness and tingling sensations in the hands and feet, wearing bed socks or soaking them in warm water, as well as using reiki and massage, were the management strategies described.

## Discussion

This study explored the explanations of patients about the development and coexistence of symptoms and how patients attempted to self-manage them. This is one of the few studies in the literature, and the only one in gynecological cancer, which has explored clusters of symptoms in a narrative manner. Its longitudinal nature, unusual in qualitative research due to the inherent issues in the analysis of such data, was another strength of the study as it allowed us to explore shifts in the symptom experience, perception, and meaning over time (although meaning was fairly stable and participants talked little about it). The vast majority of the increasing literature on symptom clusters is quantitative, attempting either to model clusters through statistical techniques or to test priori clusters for their strength of relationship. However, such clusters may be biased, not only from the technique used but also from the content of self-reports utilized to collect the data. The narrative symptom clusters could rectify problems with statistical measures as they reflect the unique patient experience in the patients’ own words and can assist in the development of (patient-centered rather than statistically based) symptom clusters that can then be tested quantitatively with larger samples. Hence, narrative symptom clusters can be particularly sensitive outcomes and can generate conceptually meaningful hypotheses for symptom cluster research.

Key symptoms experienced by the participants were tiredness, pain, body image changes, gastrointestinal changes, and peripheral neuropathy associated with chemotherapy, which concur with past studies of primarily ovarian cancer patients.<sup>9,10</sup> Out of the four clusters identified, one is applicable to all patients irrespective of treatment and two are clearly linked with chemotherapy. Symptoms varied in intensity but tended to subside in a year’s time for the majority of patients. Acceptance brought about self-management strategies to overcome both the physical and psychological effects of cancer and its treatment, but most important was the support they received from families and friends. In addition, the fact that some symptoms decreased over time may be due to some symptoms being linked to the time since the end of treatment; such symptoms could have naturally resolved after completion of treatment. However, we have limited information on the natural history of symptoms in patients with different types of gynecological cancer.

As with other studies, the most common symptom experienced by these participants was tiredness,<sup>3,9,18</sup> often associated with sleep disturbance due to pain, peripheral neuropathy, change in bowel function, and depression. Because these women complained of tiredness throughout the year, having social support from their husbands, families, friends, and neighbors helped them carry on with their usual household roles. This highlighted the important role caregivers play in supporting patients with cancer. Participants clearly differentiated between the symptom of tiredness/fatigue (a complex symptom involving physical, mental, and motivational aspects) from weakness (which is related more to muscle strength). This differentiation is evident in the literature,<sup>19</sup> and while they may be related symptoms, they should be assessed separately as they may necessitate different management strategies. Dodd et al<sup>20</sup> have shown the clustering of the symptoms of fatigue, sleep disturbance, pain, and depression in breast cancer patients, similarly to the work of Liu et al.<sup>21</sup> This quantitative work and our narrative cluster strongly support the existence and clinical relevance of this symptom cluster.

Loss of weight in the beginning was due to gastrointestinal disturbance including nausea, loss of taste, and change in bowel function. These findings concur with the literature, where such symptoms are prevalent up to one year posttreatment.<sup>22</sup> However, as time passed, the participants regained their weight, often above their prediagnosis level. Such a gastrointestinal symptom cluster has also been supported in the quantitative literature on symptom clusters, although the relevant items within the cluster very much depend on the items included in the data-collection scale.<sup>23</sup> Our own work with 143 patients over one year ( $n = 504$  symptom assessments) has also identified a gastrointestinal cluster, with the key symptom being weight loss, together with loss of appetite and difficulties swallowing, experienced by up to one-quarter of a heterogeneous sample of cancer patients at the one-year time point.<sup>24</sup> The attempts highlighted by the majority of participants to control their weight suggest that this is an important issue for these women. The inability to control weight may be frustrating and a key stressor in women with gynecological cancer. This assertion needs further investigation as the information we have about this topic to date derives almost exclusively from breast cancer patients. Weight control may be an important component of survivorship in these women, and it should be incorporated in the follow-up care of patients beyond breast cancer.<sup>25</sup> While the use of medication was mentioned with regard to the presence of gastrointestinal symptoms, no interventions have taken place with taste changes and other nutritional concerns. Interventions around the experience and enjoyment of eating and food should be an important research focus in the future, as should work around weight gain, for which we currently have limited information.

Concern about hair loss was mentioned by only four participants. They were concerned mainly that it identified them to others as a cancer patient as baldness became the main element of the cancer patients' everyday life and identity.<sup>7</sup> Participants were not concerned about their self-image but rather more concerned about protecting others (particularly family) and being treated differently. For these participants,

they accepted that loss of hair was a side effect of treatment and viewed regrowth of hair as a positive effect, which concurred with the study by Sun et al.<sup>10</sup> Ocular changes reported by three participants (out of 10) during treatment and up to six months later are an underreported issue in the literature. This is despite the established association between some types of chemotherapy (ie, cyclophosphamide, cisplatin) and ocular changes. More focus should be directed to this area, as well as to identifying reversible and irreversible ocular changes in the survivorship period. The narrative clustering of symptoms such as hair loss and ocular changes (connected with being "visible" cancer patients) with body image, identity, and anxiety is an interesting clustering of physical and psychological interrelated symptoms, with body image being the key symptom in this cluster. Our past work has highlighted the relationship between body image changes and "disliking" self in up to 20% of the sample, although these did not cluster together after the six-month assessment point (end of treatments) and were most visible during the chemotherapy period.<sup>24</sup> With the exception of using wigs, patients did not mention using any interventions regarding the multiple symptoms experienced within this symptom cluster, suggesting that this is an important area of research in the future.

Many of the physical symptoms reported were interrelated with descriptions of depression, uncertainty, body image, and identity as a cancer patient. While causal relationships cannot be ascertained from such a qualitative design, it is evident that there is a close relationship between the presence of physical symptoms, psychological status, and the impact of them in life. This is confirmed in a systematic review of studies with ovarian cancer patients<sup>26</sup> as well as other studies that support the association of symptoms of fatigue, pain, anxiety, and depression with quality of life.<sup>27</sup> A better understanding of these relationships is paramount in symptom-management efforts, particularly as it is recognized that interventions need to be multimodal and to target more than one concurrent symptom, a clear message that comes from the symptom cluster research.<sup>28</sup> For the majority of the participants, when symptoms were not managed well, they experienced psychological responses such as depression, commonly seen in the literature. Participants in our study accepted that they would experience these symptoms, although their occurrence and intensity differed from patient to patient. Some participants were able to tolerate treatment with little physical discomfort, while in others symptoms prevented them from resuming usual functional activities and social roles, thus leading to feelings of depression. It would be interesting to identify in future research the factors that allow some patients to live well with cancer, moving away from the current research model of ill-health to a model of "wellness."

Furthermore, a key distressing symptom that was associated with impairments in a variety of life areas was peripheral neuropathy in patients receiving chemotherapy. This cluster has some similarities with the tiredness cluster (i.e. the presence of sleep difficulties or depression), but women talked about it as a separate experience from tiredness. Peripheral

neuropathy is a difficult symptom to manage in practice and may necessitate dose reductions or chemotherapy discontinuation; therefore, the development of management strategies for this symptom is imperative. Women complained of sleeping difficulties when they experienced numbness and tingling sensations in their hands and feet, and it was a frustrating symptom that was also associated with depression. This is another symptom cluster that merits further research, and it is only emerging in the literature. Our past work on symptom clusters has also identified the presence of a “hand-foot” symptom cluster, which consistently increased over time and suggested a chronic nature, although not all symptoms identified in the present study were part of the latter quantitative evaluation.<sup>24</sup>

It was surprising to see the minimal range of interventions used to manage symptoms, both self-management and formal ones directed by the clinicians. The latter had minimal presence in the women’s descriptions, with the exception of pain management, antiemetics, and antidiarrheal medication. Specific physical responses to treatment were dealt with by changing the type of chemotherapy and resorting to the use of herbal medicine for symptom management, such as echinacea and red clover, or other simple self-management techniques, such as soaking the feet in warm water, eating healthy food, and carrying out regular exercise. The use of complementary therapies was also found in the study by Ferrell et al,<sup>3</sup> complementing the medical care provided to help control the symptoms.<sup>6</sup> However, all of these attempts seemed to be ad hoc, with no clear understanding of processes and possible outcomes or any guidance about their use from health-care professionals. Possible reasons for this ad hoc and unsatisfactory underutilization of symptom-management interventions may include the “acceptance” by patients that some symptoms are part of their treatment, the British cultural norm of not complaining, limited confidence from both clinicians and patients on nonpharmacological interventions with variable quality of evidence of effectiveness, distance from patients’ homes to the specialist service to provide supportive care, limited understanding from the clinicians of the impact of symptoms on patients’ lives, and clinician time constraints.

Although we purposely included women with a range of gynecological cancer diagnoses in order to gain an understanding of broadly applicable issues related to the physical and psychological symptom experiences of patients, the small

sample size limits the generalizability of the results. These symptom clusters will need further evaluation with statistical modeling. Also, the existence of symptom clusters in radiotherapy may not have surfaced well in our study with the inclusion of only three patients receiving radiotherapy, and this needs to be explored in future research. The length of treatment for each patient was variable, and knowledge of this would have enhanced the interpretability of the findings; however, this information was not available to us. Finally, although we wanted to focus on treatment-related symptoms, some of the symptoms (ie, anxiety and depression) may have multiple possible etiologies; and this needs to be considered in the interpretation of the findings.

## Conclusion

Our study provides information on symptom experiences from the patients’ perspective, which could lead to a better understanding of how patients perceive, assess, monitor, and manage their symptoms. This is particularly useful as the majority of the symptom literature focuses on the experience of patients with ovarian cancer. This is also important background information in developing strategies or interventions that are patient-centered and sensitive to the needs of patients that has relevance to the current policy framework. It also highlights the need for a more thorough patient assessment, to assess which symptoms are most bothersome and how symptoms are interrelated, and has implications for the physiological, psychological, sociocultural, and behavioral components of the symptom experience essential for effective symptom management. While we have identified the presence and experience of some well-documented symptoms, we have also highlighted areas of importance for patients and some underreported symptoms that merit further research in the future. Narrative symptom clusters, such as those identified in the present study, can provide a stronger conceptual basis in the symptom cluster modeling work and can assist in identifying patient-relevant and clinically meaningful groups of symptoms that can be the focus of future cluster research.

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