Living with ovarian cancer: Women's perspectives on treatment and treatment decision-making

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Abstract

In the year 2002, 2,500 women will have been diagnosed with ovarian cancer. Treatment for ovarian cancer is arduous, involving invasive surgery, chemotherapy, and/or radiation therapy. Studies have described the side effects of ovarian cancer treatment, but little has been written about women's perspectives on receiving that treatment.

This work was undertaken to describe women's perceptions of living with ovarian cancer and their experiences with treatment. Eighteen women who had been diagnosed with ovarian cancer were interviewed in depth and theme analysis was undertaken with their transcripts. Three prominent themes emerged during the analysis: 1) initial treatment plans were overwhelming, 2) involvement in treatment decision-making was minimal, and 3) treatment had many side effects and complications.

In 2002, 2,500 women were expected to face a diagnosis of ovarian cancer and as many as 1,550 may have died from this disease (NCIC, 2002). Ovarian cancer is the fourth most common cause of cancer-related death in women, preceded by lung, breast, and colorectal cancer. Half of those diagnosed with ovarian cancer are over the age of 65 and have advanced epithelial cancer (Moore, 1994).

Background information

Ovarian cancer is described as having four disease stages (Thompson, Szukiewicz-Nugent, & Walczak, 1996). In stage I, when the cancer is limited to the ovaries, surgical treatment is often deemed sufficient and adjuvant treatment may not be required. However, all other stages of the disease are treated with a combination of surgery, chemotherapy, and radiation. Stage II disease involves one or both ovaries and extends into the pelvic cavity. Stage III disease is present in one or both ovaries, peritoneal implants outside the pelvis, malignant cells in retroperitoneal or inguinal lymph nodes, or superficial liver metastasis. Stage IV disease involves one or both ovaries with distant metastases including positive pleural effusion or liver involvement. Seventy-five per cent of women are diagnosed with Stage III or IV disease.

Treatment for ovarian cancer usually includes surgery, chemotherapy, and/or radiotherapy. A total abdominal hysterectomy, bilateral salpingo-oophorectomy with omentectomy, and debulking of the tumour are done initially to stage the tumour, confirm diagnosis, and remove as much tumour as possible. Radiation treatments and various combinations of chemotherapy agents are given in an attempt to diminish symptoms, ward off a recurrence, and improve survival rates. To date, hormone treatment and immunotherapy offer little benefit over standard chemotherapy regimes. A combination platinum chemotherapy consisting of cisplatin and carboplatin and/or Taxol® is the first line chemotherapy of choice in Canada. Although the standard treatment for chemotherapy, platinum-based chemotherapy, provides a 70-80% response rate, long-term survival rates remain poor (Balat et al., 1996).

Chemotherapy, together with surgery and radiation, has side effects and the potential to impact upon the woman (Kornblith et al., 1995; Portenoy et al., 1994). The chemotherapy regimen, considered the 'big guns', is often physically overwhelming for women. Side effects from chemotherapy relate to the type of agent used. Cisplatin is associated

with moderate to severe nausea, hearing loss, and peripheral neuropathy. Carboplatin is generally better tolerated, but is limited by toxicity levels of thrombocytopenia (Miller, 1999). Although studies have described the incidence and prevalence of side effects (Portenoy et al.), little attention has been paid to describing women's perspectives about undergoing treatment for ovarian cancer (Schaefer, Ladd, Lammers, & Echenberg, 1999). A better understanding of women's experiences could help to provide insight regarding beneficial interventions.

Purpose of the study

The purpose of the study was to describe the experiences of women who had been diagnosed with ovarian cancer. This qualitative work explored the perspectives of women living with ovarian cancer. It was anticipated that by understanding their viewpoints regarding their experiences during diagnosis, treatment, and follow-up care, insight could be gained to help improve the delivery of care, as well as provide ideas for future research. The purpose of this paper is to describe a portion of the findings – women's experiences during treatment.

Method

The study sample consisted of 18 women who were invited to share their experiences regarding treatment for ovarian cancer. Women were identified in two ways: 1) by asking nurses and gynecologic oncologists in two major cancer centres to invite women diagnosed with ovarian cancer to participate in the interview, and 2) by a local ovarian cancer support group extending the same invitation to be interviewed. The criteria for participation included: 1) ovarian cancer diagnosis, 2) able to speak English, and 3) able to talk about their experiences. Potential participants were asked to give permission for the nurse researcher to receive their names and telephone numbers. The research nurse called interested women to explain the purpose of the study and to schedule an interview at a time convenient to them. Information about participation not affecting their care, ethical issues including confidentiality, and the reporting of aggregated data was given before a verbal consent was obtained from each woman. The study was approved by the ethics committee of Sunnybrook & Women's College Health Sciences Centre.

Interviews, lasting approximately one hour, were conducted over the telephone and audiotaped. They were conducted by a Masters-prepared nurse with expertise in qualitative data collection, and were guided by a semi-structured interview schedule. The interview schedule was designed for this study. It served as a stimulus to help women describe their experiences, and included open-ended questions related to women's experiences with diagnosis and treatment, making therapy choices, obtaining information, involvement in decisions,

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impact of illness, changes in lifestyle, and obtaining supportive care. The participants were asked at the start of the interview to talk about what had happened to them with regards to their ovarian cancer from the time they were first aware something was different about their bodies to the time of the interview. The interviewer listened as the woman shared her experiences and probed with the interview questions only if the woman did not volunteer the information. Demographic information (i.e., age, marital status, length of time since diagnosis, number of children, education, and current work status) was gathered to provide a description of the participants.

Interview data were transcribed verbatim and all 18 transcripts were read by the three authors independently (MF, KD, DH). Subsequently, working together and comparing impressions of each woman's story, the three authors designed a broad coding scheme for the data. This scheme facilitated the organization of the data into broad content categories according to the trajectory of illness experiences (i.e., peridiagnosis, diagnostic, treatment, rehabilitation, recurrence, etc.). Data were then coded by one author (KD) according to the categories developed by the three authors (MF, KD, DH). The overall scheme did not change during the course of the coding. Each category was then reviewed by the team and theme labels were generated to reflect the broad ideas women shared.

During the analysis, it became apparent that there was a wealth of information contained in the interviews. To do justice to the data, the team decided to write several articles from these findings. This article will focus on the perspectives women shared about the treatment period. Other articles by the authors will discuss the findings from this qualitative study concerning women's experiences during the peridiagnostic period, impact of the disease on the family, and dealing with recurrence.

Findings

Three themes related to women's experiences with treatment for ovarian cancer and dealing with side effects are described in this article. Pseudonyms are used in the text.

Sample

Eighteen women were interviewed about their experience with ovarian cancer. The mean age for the women was 53.2 years (range of 35-73). More than half of the women (n=12) had been diagnosed in the 12 months prior to being interviewed. The mode for the time since diagnosis was five months. Five women were longer-term survivors, having lived between 13 months and 12 years since diagnosis.

Twelve women in the sample were married and six were without a partner, being either single, separated, divorced, or widowed. Six women did not have any children while 12 had between one and four. Two women completed primary school education, six completed secondary school, seven attended university, and three attained college diplomas. Eight women did not work outside the home by choice or because of retirement. Six women were on long-term disability from their jobs. Four women had returned to work on a part-time or full-time basis after their diagnosis and initial treatment.

Theme one: Initial treatment plans were overwhelming

Women were stunned by the initial diagnosis of ovarian cancer and the treatment requirements for their disease. Although many had been experiencing symptoms such as bloating, fatigue, gastrointestinal symptoms, and pain, most had not considered ovarian cancer a possible cause of the symptoms. Hearing the diagnosis evoked shock and feelings of fear.

...And the doctor came to me and he told me that there was cancer all over all the insides...So that was rather shocking. [Maria]

This was, sort of, like completely out of the blue. It was diagnosed as primary ovarian cancer. I went bananas...It was to me the kiss of death. That was, our, very first reaction. [Ellen]

So then he (gynecologist) phoned me at home...I had to have surgery right away. And he said it would be in about a week. "Get your affairs in order, drop out of university. You're going to be off for six weeks at least after the surgery" ...and it also terrified me, you know, that I was going to be off for six weeks – giving me the impression that I was going to be in terrible pain. [Gail]

The majority of the women in this study were quite ill at the time of diagnosis, having endured arduous investigations prior to receiving a definitive diagnosis. Surgical treatment was often needed on an urgent basis. Decisions about this initial treatment were made quickly for the women, leaving many feeling as though they "were on an assembly line" and being rushed through treatment.

He sent me up to the hospital right away. I went and dropped my kids off and I went straight to the hospital...They had me in surgery the following morning. It didn't take 24 hours to get me in...my doctor came in the next morning and said it was a tumour. They had me down at the hospital in three weeks. The doctor there started my chemo two days later. And he booked me for more surgery five weeks later...And it's horrible. I would not wish this on my worst enemy. [Holly]

They felt they were being pushed along by events, and things were happening to them over which they had no control.

And then there were other tests that I have to take; the bowel test or something like that. But she is saying that I wouldn't wait for the result of the test. I still have to go for surgery tonight. It's like everything that's happening so fast. I couldn't even have time to look around for whatever, a second opinion or what I should do to ask around. I don't have any time...I don't, I can't even have the knowledge or what. I'm not even psychologically prepared to, to face this. To think of, what if it can't be cured? What if I'm going to die? ...when I look back I was so scared. [Jennie]

The severity of the disease and the urgency for treating it sometimes posed particular problems for younger women. Not only were there issues regarding child care to resolve, but personal goals such as having a child were interrupted by the urgency of the treatment need.

At that time (diagnosis) I wanted to have more children...finally my doctor said "it's time, we can't wait any longer...you're not pregnant yet so...we have to do the hysterectomy"...I had a hysterectomy and oophorectomy and also there was some bowel. It was a terrible hysterectomy. It was just awful. I had an anxiety attack on the operating table. [Mary]

The speed with which events unfolded allowed little time for planning. This was particularly an issue for mothers or single parent families.

Theme two: Involvement in treatment decision-making was minimal

Women in this study perceived they had minimal input into initial decision-making about their treatment. The women presented with severe symptoms. They were often very ill at the time of diagnosis and wanted something done to relieve their distress. They perceived that the initial treatment protocols were frequently determined by the surgeon and oncologist and, in large measure, they went along with the physician's recommendations. Few sought a second opinion.

Well, I guess with regards to the operation it (treatment decision) was made for me but I didn't complain about it, you know. I just figured it's (cancer) there and it has to come out. [Frances]
And when I went down to see (oncologist) at (cancer centre)...he checked me out and everything and he said "Okay, this is what we have to do... We have to remove the tumour"...And he explained that he had to give me a total

hysterectomy and he says “we’ll remove the tumour at the same time”. I felt relieved. Very relieved knowing that they could actually do something. [Holly]

They (doctors) made that (treatment) choice. I was very bewildered at the time. I really left myself in their care...when I was able to think a little bit more clearly I started asking them questions. [Betty]

Even when women were invited to participate in the treatment decision, they felt they were neither psychologically prepared nor equipped with adequate knowledge to contribute to the decision-making process.

We conjunctively [sic] made it (treatment decision). It’s one of those lovely doctor-patient decisions that is your decision to make! Well, I don’t know anything about it. So, I remember sitting there saying, “Well, are we dealing with a full army if we go in with just the Cisplatin?”, and he (oncologist) felt we were. So, I said, “Okay, fine; just do the Cisplatin,” which is what I had. Six sessions of that. [Ellen]

...I was told that I had this growth and if it didn’t get operated on it could explode and fill my system, you know, with cancer cells... the final diagnosis was made and seven days later I was in surgery so I hardly had time to digest that (diagnosis). To say that I participated actively in that decision is probably a stretch. I was carried away. It felt like there was no alternative and I didn’t know anything about cancer. Certainly didn’t know anything about ovarian cancer and so, you know, I got swept along. [Margaret]

...the primary treatment...it made sense to me. Now I had nothing to offer, sort of, I had no, you know, [questions to ask] how about this chemo? or how about that? or this is what they’re doing from somewhere else? I didn’t have any information about anything else happening in the world or, you know, next door to me. So what I did at that point was simply listen, ask questions, determine if it felt right for me and made sense to me. And it did so I went along with what they were doing. [Sally]

The women in this study also felt little or no involvement in decisions regarding adjuvant treatment because of the complex nature of the treatments as well as their capacity to confront the implications of the treatment. Still trying to come to terms with the diagnosis, the need for additional treatment was overwhelming.

And it (diagnosis) was Stage 3C because it had spread around my peritoneum. And grade 3 and so she (oncologist) said “we’ll do Taxol® and Cisplatin”; which is what I ended up having. ... because of the spread and the look of the cancer, because it was quite small nodules seeding, spread around my abdominal cavity, she felt that it would be better to do chemo first. Do four treatments of chemo to try and shrink the size of the cancer and then to do the surgery. Because, of course, as she said, it doesn’t matter how much she takes out, it matters how much she leaves in. And if there are all these seeds all around she’ll have to leave most of that in because she won’t be able to surgically remove them. So it’s best to get rid of as much as possible and then do the surgery. So that’s what we did. [Susan]

I had a terrible reaction after the surgery...I was really ill for several days. With nausea. I couldn’t seem to shake it. And then I started having anxiety attacks because I don’t do well with nausea. I thought that was the end of it because [the surgeons] told me they got all that they could see. And so things were

looking good when [my doctor] came back to me with the pathology report and said the next order of business was chemotherapy. I couldn’t believe it. I just didn’t. I had a hard time accepting that. [Margaret]

Women had to learn new terminology and understand the strategies for treating the cancer before feeling capable of participating in the decision-making process. The various treatment protocols were confusing for the women to sort out during a time of heightened anxiety. Many felt they did not have the necessary information.

Certainly nothing written! And very little verbal. In fact, they were telling me I would have the chemo, and I didn’t even know what the chemo involved. [Gail]

Frustration arose when the women did not receive support and understanding about their need to learn from health professionals. *I would come with a little list of questions and she’d (physician) roll her eyeballs. And I got tired of that. You know having to apologize for asking questions. [Margaret]*

...I had a list of about 20 questions to ask [doctor]. He just looked at us, like,...his first comment was...he sort of looked over his shoulder and said, “You expect me to answer all those questions?” ...I practically wanted to hit him in the face. [Ellen]

Many women talked about searching for information on their own or with the help of their family members or friends.

I had to search out a lot of the information on my own. I had to because a lot of, especially when I was first diagnosed, a lot of the answers to my questions were “I don’t know” from the medical profession. [Mary]

The following interpretation of the health care professionals’ response to questions was shared by many of the women.

I read up on most of it and if I had questions I would ask the oncologist or the nurse...sometimes I felt that [my questions] were being avoided. Or I didn’t get a direct answer, but perhaps I wasn’t asking the questions properly...So I’m being given evasive answers and that there was no answer to the question. They were trying to avoid, I think they just didn’t know how to answer the questions. [Jane]

The importance of information was described by many of the women. In the words of one individual, “I can’t imagine anyone going through this without knowing what the hell’s going on!” The women were clear that information could be useful, but that it also could be hurtful.

You know, once you hear that you have cancer, your life changes completely. It’s never the same again. Your whole life changes. Of course then I knew nothing about ovarian cancer. It’s just as well I didn’t know how lethal it was and how dangerous it was. [Diane]

In summary, women felt carried along by a tide of events where their input was not integral to the treatment decision. In the words of one woman, “The doctor said, ‘Well ultimately, it’s up to you; you can always say no’, but there wasn’t much choice.”

Theme three: Treatment had many side effects and complications

Seventeen women in this study underwent surgery consisting of a hysterectomy, bilateral oophorectomy, omentectomy, and sometimes bowel resection resulting in a colostomy. The surgery permitted appropriate staging of the ovarian cancer, allowed doctors to assess pre-surgical chemotherapy effects, and helped to determine if patients would need adjuvant treatment.

...I guess they can tell when they do the surgery, he (surgeon) said the chemo was working extremely well...and I think that's why since the surgery I've felt, and I mean, since I've recovered from the surgery I have felt better than I have felt in, like, probably a year and a half. [Holly]

Some patients endured repeated surgical procedures to relieve symptoms caused by the ovarian cancer.

My doctor went in at one point and did a laparoscopy; my bowel had stuck together...So that was one of the pains...and fortunately the laparoscopy actually fixed it. It unstuck the bowel. So that was fixed by that. And then the cyst, I guess it went off the nerve it was pressing on...they don't want to touch the cysts I have because they don't know if they're malignant or not. So in '95 however they took me in and they drained some fluid through ultrasound...And in January of '97, the tumour started getting a little smaller and it, that's how it remains. [Mary]

...the nurse phoned me and said, "You're scheduled for bowel restructure surgery"...and of course my first question was, "will I have a colostomy"? I was really worried about that. They said the chances are 5 to 10%. So I went into (hospital) on the 17th for bowel restructure surgery. It was four hours. And my first question to (surgeon) was do I have a colostomy? He said, "No and the results are very good. But I still want you to have three more treatments". So I was in hospital 11 days. I had to have blood, two units of blood. I was on antibiotics: My both arms got infected from IV. [Pam]

Side effects from radiation treatment caused major problems for the four women who received it. Side effects included fatigue, nausea, skin burns, bowel problems, and pain.

When I began (radiation treatment), that weekend I was feeling the terrible nausea. I just didn't think I could go through the whole six weeks if it was going to be like that. But they were able to control it (nausea) and it was pretty tiring – just the trips and...when I was going every day for treatments, you know, it seemed as if that was about all you had strength or time for...you'd come home and you'd have to get something to eat and then rest and get up and get going the next morning. Really, really I wasn't all that anxious during that time for company because...it seemed to take a lot out of me just to keep going. [Joan]

Some side effects subsided once treatment was completed, while others continued to plague these women.

Well, after the radiation...I began to have some pain...in my stomach. I guess it (radiation) sort of accumulates and burns and you feel the worst effects when it's come to the end. [Joan]

...I've had a terrible problem since diagnosis and since the radiation. Or at least not terrible but I had to be very careful. And it's just been in the last two months that I've started to notice that I can eat some things that I might not have been able to eat six months ago. I don't eat as much fruit and vegetables now because I know I can't. I can't drink coffee...I can't (drink), not any kind of colas or anything like that. They act as a laxative. [Dawn]

The printed information they have didn't say anything about burns to the skin. The only thing is the radiation technician, a young man who isn't there anymore, said to me, "You know, it's going to get worse." It was red, red, red, red! ...It was awful. It was like raw meat. I couldn't believe it one morning when I looked in the mirror...well it took two months to heal...There's nothing like the pain of burns. They were second degree burns...I shed like a snake. The whole top layer came off. It was awful! [Diane]

Seventeen of the women had chemotherapy. These women reported many difficulties with the heavy chemotherapy regimens, including nausea, vomiting, allergies, fatigue, alopecia, physical aches, and emotional burdens. They often experienced more than one side effect and found the whole situation draining.

So then I had six treatments of chemo...They were all day sessions too...Between the saline solution and all the different stuff they put into you. So I'd be there from eight in the morning until about six. Yeah, it was a long procedure. Then I'd feel really blah afterwards and then sort of at this point now, I felt nauseous. Well the very first chemotherapy I had in the hospital I got sick to my stomach...really badly. And I just felt like I was in another world. It was...paper really crinkled loud to me. Everything was just sort of thrown right off. After a few chemo treatments I seemed to level out, you know. I found my biggest effects seemed to come about a week after the treatment. [Maria]

The week after the chemo I wasn't at all well...I was told that I would get aches as if I had the flu. And I became very weak and...and I had no nausea. I forget the medication they gave me but it was very expensive medicine...You know, I didn't exactly know what I would have to go through...while they were giving me the chemo...I couldn't sit still...And I had to kind of walk the floor because as I said, I was very restless... [Frances]

For some women, losing their hair was particularly difficult. *That morning I was getting ready for church and my first hair fell out. So that was kind of emotional...But the nurses had advised me after my first chemo that within two weeks I should go and get a wig; which I did...And when my daughter and I went to buy my wig she was most helpful. I just wear my wig when I go out. I have several turbans, you know, the little soft turbans that I wear around the house. But when I go out I wear my wig. But that was one of my emotional moments. [Pam]*

Women learned to tolerate the side effects and take advantage of the times when they felt better between treatments. At these times, the women in the study tried to focus on engaging in pleasurable personal and family activities.

It (chemotherapy) takes everything out of me. It just zaps me. I finished on Friday. I know that Saturday and Sunday and Monday is just horrendous. Yesterday was better. Today I don't feel like I have any of the chemicals in me so I'm going to attempt to go out and enjoy myself. It's just that it (chemotherapy) tires me. Physically and mentally it tires me for a few days after that.

When I'm not feeling well, the first two days, I sleep a great deal. Not because I want to; it's (sleep) there. Then afterwards I can't sleep. I go from one extreme to the other but...when I have the surge of energy and I will get that at certain times during the day I can't sit. I will get up and I'll bake, or I'll start to cook or I'll tell my kids to come down for dinner or I will attack the house. I mean this is the way I am generally and that surge of energy is, is there and it's wonderful. It's a great feeling. [Betty]

Some women were fortunate to experience few side effects from chemotherapy treatment. What they experienced was managed by medications and resulted in minimal emotional toil.

It (chemotherapy) was a bit frightening but then after that I decided it wasn't as bad as all that. It was just a needle and it was going to make everything right. So after the first one (treatment) I was fine. I didn't have an awful lot of nausea. I had the anti-nausea medication that they give you these days

and I'm fortunate enough that my husband has a good plan (drug) so we could have what the doctor called the Cadillac of anti-nausea drugs. [Jane]

I was getting three hours of Taxol® and an hour and a half of Cisplatin; came through the first treatment okay. The first day after was great. I was back to my usual self and the next three or four or five days, I was not very, not very strong. But I took the medication (for nausea), and I didn't have any vomiting or anything. [Pam]

Discussion

This paper describes the perspectives of 18 women living with ovarian cancer about the initial treatment interval for their cancer. The findings provide insight into their views of the events surrounding treatment decision-making and their experiences receiving treatment. Two-thirds of those who participated were within one year of their initial diagnosis of cancer and had completed a first course of therapy.

The treatment regimens women with ovarian cancer undergo are arduous, taking a heavy toll both physically and emotionally. In this study, combined therapies were utilized, creating significant demands upon these women. Not only were demands made in terms of dealing with side effects and complications, but demands were also made around travelling for treatment, spending lengthy periods of time in the treatment facility, and not being able to engage in usual household and family responsibilities. The value of effective symptom management is highlighted in this study. When side effects were well managed, women described being able to carry on with daily activities. Those who had to struggle to control side effects found it used up what little energy they had and compromised their capacity to engage in desired activities/interactions. The types of symptoms and side effects these women described are similar to those reported in previous literature. The new insight emerging from this study is the description of the impact effective symptom management has on the women's capacity to cope and to engage in decision-making.

The women described minimal involvement in initial treatment decision-making. Most felt treatment decisions were made by the physician. As patients, they went along with the decision, primarily because they wanted help for the discomfort they were experiencing, or because they felt they did not know enough about either ovarian cancer or its treatment to make a contribution. Most felt caught up in a chain of events over which they had little control.

Additionally, women described little involvement in treatment decision-making following the initial surgical intervention. After recovery from the massive surgical procedure, women felt better, but still experienced difficulty participating in treatment decision-making. Similar perspectives regarding being caught in a chain of events and feeling little control have been reported by other cancer patients (Dollinger, Rosenbaum, & Cable, 1997). In particular, individuals who experience the need for rapid surgical intervention with resultant hospitalization (i.e., bowel obstruction) face the unexpected disruption caused by these events, as well as the implications of a malignant diagnosis. Hospitalization has the potential to disrupt family and work responsibilities. Surgery has the potential to disrupt normal body functions. The cancer diagnosis has the potential to disrupt future dreams, one's sense of mortality, and feelings of security. Adding to the sense of upheaval and uncertainty is a feeling of urgency about treating cancer that is voiced by health care professionals and perceived by the patient. Tension emerged between the urgency to get the treatment plan underway, the need to make appropriate arrangements about family and work responsibilities, and the need to come to terms with the diagnosis itself.

Another issue that may have increased the tension and inability to participate in treatment decision-making for women and their family

members was the lack of information about ovarian cancer and cancer treatment. The women in this study described how their own lack of knowledge influenced their ability to be engaged in decision-making about treatment and to cope with the side effects of treatment. Knowledge about the type of information that is most likely to help patients engage in treatment decision-making (i.e., the nature of the disease or medical reasons for initiating particular treatments, the medical procedures to be carried out, the expected side effects, and the strategies patients can use to cope with the upcoming threat) was described many years ago (Cohen & Lazarus, 1979; Derdiarian, 1987). It is disconcerting to learn that women are still facing difficulties accessing this information from their primary cancer care teams.

The literature has shown that patients with cancer in every age group want maximum amounts of information; however, not all patients want to be involved in the treatment decision-making to the same extent (Davison, Degner, & Morgan, 1995; Hack, Degner, & Dyck, 1994). Thus, there are likely differences in preferred decision-making involvement among the women in a group, but there also may be differences over the course of the treatment. It is of interest to observe how the women in this study seemingly "went along with" the decision made by the physician team. It is important to acknowledge that many of these women were seriously ill at the time of their diagnosis. Some had been experiencing symptoms for a period of time. Accepting a particular course of treatment was seen as the route to symptom relief without further waiting. Many also had limited information about ovarian cancer and its treatment at the beginning of their experience. It is of interest to note this seemingly passive stance around decision-making was not evident at the time of recurrent disease (Howell, Fitch, Deane, & Gray, 2002). By the time recurrent disease is evident, women reported having a vastly different knowledge about ovarian cancer and had experienced one course of treatment. For many, their participation in decision-making was considered more active than with the initial diagnosis.

The notion that cancer patients prefer their physicians to make a treatment decision has been reported by a number of authors (Davison et al., 1995; Degner & Sloane, 1992; Sutherland, Llewellyn-Thomas, Lockwood, Trichler, & Till, 1989). In particular, older (Blanchard, LaBreque, Ruckdeschel, & Blanchard, 1988; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Degner & Sloane), married (Blanchard et al.), and less educated (Cassileth et al.; Degner & Sloane) cancer patients prefer to delegate decision-making responsibility to physicians. However, controversy remains on this issue as other reports describe a desire by patients to participate in decision-making to varying degrees (Brandt, 1991; Degner & Sloan; Degner & Aquino-Russell, 1988; Hack et al., 1994).

Treatment decision-making occurs within the context of a social situation and, as a result, is influenced by that context, as opposed to being solely the product of the patient's medical condition and available treatment (Degner & Beaton, 1987). The central factor influencing the way in which treatment decisions are made appears to be "control over the design of treatment" or who actually selects the treatment. Four patterns of decision-making have been described whereby patients play different roles: provider controlled, patient controlled, family controlled, and jointly controlled (Degner & Beaton). That patients have preferences for the role they take or the control they assume is evident. Work with breast cancer patients revealed that 22% of women wanted to select their own cancer treatment, 44% wanted to select their treatment collaboratively with their physician, and 34% wanted to delegate this responsibility to their physician. Only 42% of the women believed they had achieved their preferred level of control in decision-making (Degner et al., 1997). Similar work has not yet emerged for women with ovarian cancer.

It should also be noted that several authors have emphasized that the desire for information is quite separate from the degree of willingness to use this information in making choices (Averill, 1973;

Degner & Beaton, 1987; Dennis, 1987). Sutherland and colleagues (1989) have noted that the need for information is likely related to the need to enhance psychological autonomy and not necessarily related to the desire to assume responsibility for treatment decisions. In other words, people may want a great deal of information, but may not want to be making choices about their medical care. Both preference for decision-making and desire for information should be assessed clinically if care is to be tailored to the individual patient.

Implications for oncology nurses

Several implications for oncology nurses emerge from this study. Nurses caring for women who have undergone surgical procedures where ovarian cancer was diagnosed must be sensitive to the individual woman's situation. Talking with each woman about the time before the diagnosis, how the diagnosis was made, the timing of the surgery, and her understanding of her disease will provide insight into that woman's experiences and the pressures she may be feeling. Providing an opportunity for her to voice any questions and concerns could facilitate the woman's access to information she considers relevant.

Nurses caring for women who are undergoing radiation therapy or chemotherapy treatment need to engage in astute symptom assessment and management throughout the course of the regimens. Symptoms that should be of primary importance to nurses include nausea and vomiting, pain, and fatigue. Nurses also need to provide the opportunity for women to voice any questions or concerns they might have about the side effects they may be experiencing. Together,

the nurse and the patient ought to determine the pattern of the woman's responses to the treatment regimens so that the woman can develop realistic expectations about when she will need to rest and when she can engage in some of her usual activities.

Throughout the illness continuum, the nurse must continually assess the patient's preference for involvement in decision-making. The patient may wish different degrees of involvement, depending upon the situation. For example, she may wish to leave overall treatment decisions to the physician, but wish to be highly involved in arranging appointment times for her chemotherapy.

Finally, nurses can play an important role in generating patient information tools. Given that individuals learn in various ways, several types of education tools may be of benefit (e.g., brochures, books, videos, etc.). Additionally, there would be value in ensuring women diagnosed with ovarian cancer are aware of local cancer support groups.

This study has provided a brief look at the perspectives of women diagnosed with ovarian cancer regarding their experiences with initial treatment for their disease. Issues have been identified regarding their involvement in decision-making, access to information, and need for astute symptom management. Additional research needs to be conducted to determine the magnitude of these issues in a larger sample and, eventually, to develop appropriate and effective interventions.

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