Perspectives on living with ovarian cancer: Young women's views

by Margaret Fitch, Ross E. Gray and Edmee Franssen

Abstract

Ovarian cancer is the fourth leading cause of cancer-related deaths in women. Ovarian cancer, and its treatment, has a considerable effect on the quality of life of women diagnosed with the disease. Young women diagnosed with ovarian cancer must confront life-threatening illness at a time when many are in the midst of raising children, maintaining a household, and actively engaging in work and career activities. Very little has been reported about the perspectives of young women regarding their experiences with ovarian cancer.

This article reports data from 39 women 45 years of age or less concerning the impact of ovarian cancer and its treatment as well as the availability of support. At the time of the study, the women were, on average, 38 years of age and approximately two-thirds were married and had children. About half of the women were working.

The most frequently identified problems included side effects (n=25), fear of recurrence (n=25), and difficulty sleeping (n=25). On average, women reported experiencing 10.4 problems since diagnosis. Of those who experienced problems, less than 50% perceived they had received adequate help. Approximately two-thirds of these women experienced a lifestyle change. Quality of life was rated significantly lower following their experience with ovarian cancer. Implications for oncology nurses emerge in areas of assessment, referral, and patient teaching.

Ovarian cancer is the fourth leading cause of cancer-related deaths in women. An estimated 2,500 women were diagnosed with ovarian cancer in Canada in 1998 and 1,400 died of the disease (NCIC, 1998). Prognosis is linked to the stage of disease and the grade of the tumour at diagnosis. If the disease is limited to the ovaries at the time of diagnosis, the five-year survival rate is 60% to 70% (Thompson, Szukiewicz-Nugent, & Walczak, 1996). Unfortunately, only 23% of women will be diagnosed when the disease is at the localized stage. For the majority of women, ovarian cancer is not detected until it is at an advanced stage (Teneriello & Park, 1995).

Ovarian cancer, and its treatment, has a considerable effect on the quality of life of women diagnosed with the disease. Several studies have described the impact of ovarian cancer treatment on quality of life (Ersek, Ferrell, Dow, & Melancon, 1997; Montazeri, McEwan, & Gillis, 1996; Zacharias, Gilag, & Foxall, 1994) and relatively consistent findings emerged: marked anxiety and depression have been observed in many women; sexuality is often negatively influenced; social functioning is impaired, especially as it relates to the ability to work; and physical functioning and disease progression are often predictive of quality of life. Symptoms which may be experienced with ovarian cancer have also been described (Portenoy, Kornblith, et al., 1994), including psychosocial distress (Kornblith et al., 1995). Symptoms such as fatigue, pain, and psychological distress were cited as the most prevalent among ovarian cancer patients (Portenoy, Thaler, & Kornblith, 1994). Payne (1992) reported that anxiety was highest in a group of young breast and ovarian cancer women (31-49 years) as compared to women 50 to 59 years and women 60 to 78 years.

Ovarian cancer is predominantly a disease of postmenopausal women (MacDonald, Rosenthal, & Jacobs, 1998). However, 10% to 15% of those diagnosed with the disease are premenopausal, younger women (Scully, 1979). These younger women must confront life-threatening illness at a time when many are in the midst of raising their children, maintaining a household, and actively engaging in work and career activities. Presently, very little has been reported about the perspectives of young women regarding their experiences living with ovarian cancer. The paucity of empirical work regarding the impact of ovarian cancer presents a limitation in designing and implementing appropriate nursing interventions for these young women.

The data reported in this paper were gathered as part of a nationwide survey investigation regarding the experiences of Canadian women diagnosed with ovarian cancer (Fitch, Gray, Deane, Franssen, & Howell, 1999). Questions were included in the survey regarding the difficulties women might confront across a broad range of potential problem areas, the impact they felt from any difficulties they experienced, and the help they received for those difficulties. This article reports the results for those questions as they were answered by respondents categorized as young women (45 years and younger). It was anticipated this work would provide increased understanding of the domains in which ovarian cancer and its treatment may have an impact on young women, and insight regarding possible areas for intervention. The results have relevance for the provision of nursing care to young women with ovarian cancer and point to areas where future work is needed.

Methods

Study design and sample

Twenty-six cancer programs across Canada agreed to distribute survey questionnaire packages to consecutive women meeting the eligibility criteria during a six-week period. The eligibility criteria included a diagnosis of ovarian cancer and ability to read either English or French. A single self-help group for ovarian cancer patients agreed to distribute the questionnaire at one meeting. The packages contained a cover letter, a copy of the survey questionnaire, and a prestamped return envelope, all in the language of choice for the potential respondent. The survey questionnaires were completed by the women at home and returned in the pre-addressed envelope. No follow-up reminders were used.

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A total of 1,068 surveys were distributed to women of all ages who met the eligibility criteria. A total of 315 were returned (29.5% response rate). Ninety-seven per cent of the survey questionnaires returned had been distributed by staff in a cancer program. This article reports the data from all of the respondents who indicated they were 45 years and younger (n=39).

Survey questionnaire

The survey instrument was developed by the investigating team to elicit data regarding important issues in ovarian cancer. The items were developed on the basis of indepth interviews with women living with ovarian cancer (Fitch, Gray, Deane, et al., 1999) and health care professionals who provide care for these women. The format of the survey questionnaire was based on earlier nationwide surveys of breast cancer patients (Health Canada, 1994) and prostate cancer patients (Gray et al., 1997). The items in the survey covered a wide range of topics including, among others, diagnostic and treatment issues, impact on quality of life, communication and satisfaction with information provided, and problems experienced and help received (Fitch, Gray, Deane, et al., 1999). The full survey contained 53 items. The majority of the questions were pre-coded, but opportunity was provided to respond to several open-ended questions. The survey was reviewed for clarity and readability with

three women living with ovarian cancer prior to its general distribution. Only minor editorial changes were made to the survey as a result of the pilot test.

The focus of this article is on the detailed results from young women regarding the survey items on the impact of illness and treatment as well as the availability of support.

Analysis

For the purposes of this analysis the responses from 39 women who indicated they were 45 years of age or less were considered. The database was set up in ORACLE and the analysis was completed using SAS, both on a UNIX platform. Medians, means, and frequencies for single items and cross tabulations for a limited number of theoretically related variables were calculated. Selected tests of differences (t-tests) were conducted, with a significance of $p < 0.05$, to compare 1) the number of problems women with recurrent disease experienced versus the number of problems women without recurrent disease experienced, and 2) quality of life before and after the diagnosis and treatment. The responses to the open-ended questions were subjected to a basic content analysis; all responses were reviewed, similar responses were grouped together and labelled to reflect the respondents' comments. Selected quotes will be utilized to illustrate the salient points made by the respondents.

Abrégé: Le vécu du cancer de l'ovaire: la perspective des jeunes femmes

Le cancer de l'ovaire est la quatrième cause de décès par cancer chez les femmes. Ce cancer et son traitement ont une incidence considérable sur la qualité de vie des femmes chez qui on le décèle. Les jeunes femmes diagnostiquées du cancer de l'ovaire doivent faire face à une maladie virtuellement mortelle à un âge où elles sont nombreuses à élever des enfants, à s'occuper d'un foyer et à s'engager dans des activités professionnelles. Jusqu'à présent, peu de publications se sont penchées sur la perspective des jeunes femmes relativement au vécu du cancer de l'ovaire.

Les données présentées dans cet article ont été recueillies dans le cadre d'une enquête d'envergure nationale axée sur le vécu des Canadiennes ayant reçu un diagnostic de cancer de l'ovaire. Au total, 1068 questionnaires ont été distribués à des femmes de tout âge satisfaisant aux critères de participation et 315 ont été retournés, soit un taux de réponse de 29,5 %. Les items du questionnaire portaient sur les difficultés que les femmes peuvent affronter dans un vaste éventail de domaines, sur l'incidence de toutes les difficultés qu'elles ont éprouvées et sur l'aide qu'elles ont reçue pour y faire face. Le questionnaire comportait un total de 53 items. Les items individuels couvraient une large gamme de sujets tels que le diagnostic et le traitement, les répercussions sur la qualité de vie, la communication et la satisfaction vis-à-vis de l'information fournie, les problèmes rencontrés et l'aide reçue. La majorité des items étaient précodés, mais les répondantes avaient l'opportunité de répondre à plusieurs questions ouvertes.

Cet article présente les résultats relatifs aux réponses données par les répondantes appartenant à la catégorie des jeunes femmes (45 ans et moins). On attendait de ces travaux qu'ils éclairaient sous un jour nouveau des domaines où le cancer de l'ovaire et son traitement peuvent exercer un impact important sur les jeunes femmes et mettre en évidence les domaines où des interventions seraient possibles. Les résultats sont d'une grande pertinence pour la prestation des soins

infirmiers aux jeunes femmes atteintes d'un cancer de l'ovaire et ils précisent les domaines sur lesquels les travaux pourraient porter à l'avenir.

La base de données a été élaborée sous Oracle tandis que l'analyse faisait appel au langage SAS, le tout sur un système UNIX. On a calculé les médianes, les moyennes et les fréquences des items individuels ainsi que les tabulations recoupées pour un nombre limité de variables théoriquement reliées. On a effectué une série de tests d'hypothèse (tests t), dont la signification était fixée à $p < 0.05$, en vue de comparer 1) le nombre de problèmes vécus par les femmes atteintes d'un cancer récidivant par rapport aux femmes touchées par un cancer non récidivant, et 2) la qualité de vie avant et après le diagnostic et le traitement. Les réponses données aux questions ouvertes ont fait l'objet d'une analyse fondamentale du contenu; toutes les réponses ont été examinées, et les réponses similaires ont été regroupées et annotées afin de refléter les commentaires des répondantes. On a choisi certains extraits pour illustrer les principaux points soulevés par ces dernières.

Lors de la tenue de l'enquête, les femmes (n=39) avaient une moyenne de 38 ans et environ les deux tiers étaient mariées et avaient des enfants. À peu près la moitié d'entre elles occupaient un emploi. Les problèmes les plus souvent dégagés comprenaient les effets secondaires (n=25), la crainte d'une récurrence (n=25) et le sommeil difficile (n=25). En moyenne, les répondantes éprouvaient 10,4 problèmes depuis le diagnostic. Parmi celles qui éprouvaient des problèmes, moins de 50 % estimaient qu'elles avaient reçu une aide adéquate. Environ deux tiers des femmes ont vu leur style de vie changer. Leur vécu du cancer de l'ovaire se traduisait par une détérioration significative de leur qualité de vie. Les répercussions d'importance pour les infirmières en oncologie se dégagent dans les domaines de l'évaluation, de l'aiguillage et de l'enseignement aux patientes.

Results

Sample characteristics

Thirty-nine women aged 45 years or less comprised the sample for this analysis. This represents 12% of the total survey respondents (n=315). Selected demographic characteristics are presented in Table One. All were Caucasian and approximately two-thirds were married and living with their partner. At the time of completing the survey, the women were, on average, 38 years old (range 21 to 45). Approximately two-thirds had children. The average number of children was 2.1 (range 1-4). Eighteen had children living with them at the time of completing the survey.

About half of the women were working at the time they completed the survey. Within the group, 15 reported there had been no change in their work status while 13 reported having to stop work completely because of their illness, nine reduced their work responsibilities, one stopped temporarily, and one went on disability. The women reflected a cross-section of household income levels and community sizes. The majority (n=22) had college or university education.

At the time of the survey, four women were less than a year from their original diagnosis, 28 were between one and five years, and six were more than five years. Thirty-six women reported having undergone an oophorectomy and 30 a hysterectomy. Thirty received chemotherapy, 13 received hormonal therapy, and five radiation therapy. Approximately one-third (n=12) reported experiencing recurrent disease, while six were uncertain if they had recurrent disease. At the time of the survey, 15 were receiving treatment.

Impact of disease and treatment

The impact of disease and treatment was determined by examining the problems and changes in lifestyle experienced by the women who responded, the help they received for the identified problems, and the

perceived impact on a number of life domains (e.g., relationships, role responsibilities). A list of potential problems was presented in the survey and respondents were asked to identify which problems had been experienced since diagnosis. Table Two presents the problems identified by more than one-third of the respondents. The most frequently identified problems included side effects from the treatment, fear of recurrence, and difficulty sleeping. All were identified by three-quarters of the group.

Only two women reported experiencing no problems since diagnosis. The remaining 37 reported experiencing, on average, 10.4 problems (range 1-23). Three women reported experiencing one problem: fear of recurrence. For the remaining 34 women, the combination of problems was different for each one of them. During the month prior to the survey, 31 (79.5%) of the women experienced, on average, 5.9 problems (range 1-14).

Women with recurrent disease reported experiencing an average of 11 problems (range 6-16) since diagnosis and 3.9 (range 0-10) in the past month. Those without recurrence reported an average of 10.1 problems (range 1-23) since diagnosis and 5.1 (range 0-14) in the past month. There were no significant differences between the women who had recurrent disease and those who did not in terms of the number of problems experienced since diagnosis ($t=0.4$, $p>0.6$) or the number of problems experienced in the last month ($t=0.8$, $p>0.4$).

For each problem which respondents indicated they had experienced, they were asked whether they felt they had received adequate help for that problem. Table Two presents the results from this question. The problems for which the largest proportion of women felt they received adequate help included side effects (41%), bowel difficulties (33%), menopause (33%), difficulty in sleeping (28%), getting around (28%), and pain (26%).

Approximately two-thirds (n=26) of these young women experienced a lifestyle change. The types of changes they experienced included living a healthier lifestyle (n=13), physical changes (n=10), having a positive attitude (n=6), and work changes (n=7). Some respondents experienced more than one type of change. Thirty-four women (87%) wrote comments about their lifestyle change following the diagnosis. Many of the comments reflected changes in diet, exercise, and relaxation:

Table One: Selected characteristics of sample (n=39)

Characteristic	Frequency
Marital status	
Married/common law	25
Never married/divorced/widowed	14
Have children	25
Caucasian	39
Working status (past year)	
Working	19
Unable to work	11
Highest level of education	
Primary	2
Secondary high school	15
College/university	22
Total household income (at time of survey)	
0-\$19,999	4
\$20,000-\$39,999	11
\$40,000-\$79,999	19
\$80,000+	5
Size of community	
<5,000	5
5,000-49,999	7
50,000-249,999	16
250,000-999,999	5
1,000,000+	6

Table Two: Problems identified by at least one-third of sample (n=39)

Problem cited	Number with problem since diagnosis	Number with problem in past month	Number who received adequate help
Side effects	25	10	16
Fear of recurrence	25	18	7
Difficulty sleeping	25	16	11
Fear of dying	23	14	5
Difficulty concentrating	23	15	4
Anger	21	12	6
How feel about body	21	15	8
Bowel difficulty	20	7	13
Sex issues	17	11	4
Menopause	17	10	13
Pain	16	5	10
Sexual function	15	5	2
Feeling isolated	14	4	2
Infertility	13	5	3
Getting around	13	3	11

...eat better foods, food supplements, especially vitamin C, vitamin E, and beta carotene, more exercise
 ...cut down on red meat consumption, get more exercise, read more about health, haven't opportunities or energy to work
 I try to eat better, exercise and understand and cope with my emotions
 I have learned to live one day at a time to the fullest
 ...more so than before try to enjoy each day and connect with friends and family each day; try to take care of myself and take more time for myself; I have physically slowed down although I still exercise. Eat more carefully. Need more rest.

Using a five-point Likert scale, respondents were asked to indicate the impact of their cancer diagnosis and treatment on a number of aspects of their lives. These aspects included relationships with partners, children, and friends; employment opportunities and worklife; financial status; leisure time; mental health; and household responsibilities. More than half of the women indicated their cancer diagnosis and treatment had a positive impact on their relationship with their partner and friends (see Table Three). Fewer experienced a positive impact on their relationship with their children, but still there were more indicating a positive impact than a negative one. For the rest of the life domains rated, more women experienced a negative impact than a positive impact. About half indicated a negative impact on their mental health and on their work life. Many of the comments contained poignant accounts of women feeling the impact of several changes occurring at the same time:

This disease has completely eroded almost all future dreams and hopes of mine. Due to the lack of adequate treatment for this disease, my life expectancy is extremely short. I will not see my children mature into adulthood. I will not share the years ahead with my husband. I am not able to do physically taxing activities with my family and friends. This is particularly difficult given that my children are still young. I am not able to work anymore which changes our financial picture somewhat. The most difficult aspect for me is knowing that my children won't have a mother for much longer
I can't make long-term plans; always thinking "cancer"; when I'm too ill to work, where is the money for paying for services if needed? We bought our home late – what if the insurance doesn't pay off when I die? My family will lose their home! Tire easily, skin rash, hands and feet swell (can't wear high heels), joints ache and crack, hearing off, sinus sometimes affects speech. Overall I'm less than I was before and now I worry if I'm doing or not doing the right thing.

When work life was an issue, it presented related difficulties for women:

...financial devastation due to loss of job and loss of supplementary health plan (drug plan, dental plan); constant fear for the future, fear of dying, negative impact and stress for me and my family members
...had to take less time at work, therefore less income – don't go out as much
...it was difficult not being as active as I had been used to being on a dairy farm. It left a lot of usually shared work on my husband and hired help, which made me feel guilty and a little useless. My husband was very helpful and supportive and without this I don't think my recovery would have been as fast.
...the biggest impact has been to put my life on hold, making employment plans difficult. My self-image suffered as my hair thinned, I gained weight and had no energy for my usual enjoyable activities. These have improved since my treatment finished and my health is returning.

The impact women observed was not only on themselves, but also on their family members. In the words of one woman:

It has completely changed my life. I was a totally independent person. Now I have to rely on people for help all the time. My children are older, so they have had trouble coping. One has turned to alcohol at 16 years of age. The other is quite withdrawn and they really don't want to talk about it. They want life to be the way it was.

For some women, issues concerning fertility were particularly difficult:

The major impact has been on my future plans. I was still in university when I was diagnosed and had treatment. And I was able to accommodate, finish school and get a job. However, I am now married and thinking about starting a family and I have a "now-or-never" feeling about getting pregnant because I have only about half of one ovary left. Having children has always been a priority for me and for my husband. So possible loss of fertility is our biggest concern.

No one ever talked to me about the emotional impact of losing my reproductive organs at the age of 37 and the further impact of now being unable to have children - to add insult to injury, when I was rehospitalized for chemo, I was put on the maternity ward with new, happy moms. This seems very insensitive. You also need counselling about fear of dying, grieving.

For women who had experienced recurrent disease, the event brought a unique kind of impact:

...first time, minimal change; recurrence, complete change, e.g., left work (disability), exercise, diet, vitamins tapes, herbs, etc., all must be done
...biggest problems are insomnia and pain; life has completely changed; I had to redefine who I was, deal with a lot of anger and had to give myself hope back after recurrence...
...the recurrence diagnosis had made immeasurable difference to my life – my original diagnosis carried a 90% cure – this time is totally different. I try to maintain a positive outlook and can finally look to a future longer than tomorrow. Will life ever be the same for me, my husband, children, parents, sisters, friends? Definitely never!

Finally, women also described feeling both negative and positive impacts from their illness situation:

...being so ill has made me realize that life may be short and you should live as best you can and also appreciate and enjoy what you have – try to become the best person I can be;

Table Three: Impact of cancer diagnosis and treatment (n=39)

Item	% reporting positive impact	% reporting negative impact
Relationship with partner	61.5	15.4
Relationship with friends	51.3	12.8
Relationship with children	28.2	12.8
Mental health	28.2	51.3
Leisure activities	28.2	38.5
Employment opportunities	7.7	30.8
Work life	12.8	51.3
Financial status	7.7	41.0
Household responsibilities	12.8	43.6

*negatively I don't have the energy to do what I used to. I seem not to remember as well as I used to
...physically it has had a negative impact. however, spiritually I feel that I have grown and am trying new experiences . My life is totally different – perhaps no better, no worse.*

Respondents were asked to rate their quality of life, before becoming ill and at the time the survey was completed, using a seven-point Likert scale where one equalled “very poor” and seven equalled “excellent.” On average, the women rated their quality of life before their illness at 6.0 (range 2-7) and at the time of the survey at 5.2 (range 2-7). The difference between these two observations was statistically significant ($t=3.9$, $p=0.0004$). During periods of treatment, women felt their quality of life was compromised:

Very difficult, sick all the time, I found it difficult to do the simplest things, i.e., cooking, dressing etc, suffered from depression

*during periods of treatment, quality of life is obviously low; during stable period after treatment or during a time of remission, quality of life good – the only limiting factor being a lower overall level of energy; at no time does this condition bring about mental/emotional difficulties since I find that that is more debilitating than the actual physical disease
I was very sick from chemotherapy – so for six months I stayed in bed. I couldn't do anything. I didn't have the energy. Now it's not so bad. But my capacity for doing stuff and working had minimized. I am angry sometimes
...the impact of the radical surgery and treatment, which I went through, has both mentally and physically changed the quality*

Table Four: Importance of, and satisfaction with, information (n=39)

Type of information	Number who rated information as important (4 or 5 on 5-point scale)	Number who were satisfied with information received
Medical condition	35	25
Possible side effects of cancer	36	26
Treatment choices available	35	26
Possible side effects of treatment	34	30
Possible emotional reactions	32	18
What to do to relieve physical discomfort	30	25
Diet/nutrition	31	23
Supplies/equipment	22	25
Counselling services available	25	20
Arrangements to speak with another woman with ovarian cancer	23	14
Complementary therapies	24	10
Alternative therapies	23	9
Self-help groups	20	14

of life, such as not always feeling physically able to do certain activities due to early fatigue. Mentally it is something you always carry with you – if not the memories of treatment, the ever going concern that it could return at any time.

Some women anticipated the poor quality of life they experienced during treatment would be regained following treatment. In the words of one woman:

fatigue has affected the quantity of time I have in a day to complete household tasks or participate in leisure activities. Chemotherapy was extremely difficult. However, I feel extremely happy to still be living and to have the drugs work so effectively for me. I will resume a good quality of life once my energy increases.

For those who had completed their treatment, quality of life varied depending upon what circumstances had unfolded for them. Some felt their quality had deteriorated:

*...no longer employed, partner left me, daughter angry with me. Very sedate lifestyle
I cannot go out as much. I am not left alone very much. I really feel trapped and have no life at all now
...had to deal with mental/physical issues. Strained long-term friendships, will now have to pay money to have children (if I live long enough), put a huge financial burden on my family
...had to slow down and put off my wedding
I no longer work outside the home and I am more dependent on others
I feel as if my life is completely over. I cannot do a lot of the things I want to do. I no longer can afford to do some of the things I wanted to do which would have made my life easier. People avoid me now and do not want to give me a job.*

Other women perceived they had gained in terms of their quality of life and learned valuable lessons:

*...brought me closer to friends, family, spouse – sounds trite but I try to savour the moment.
I have gone part-time and I relax now without worry about all the things that need to be done.
I take more care of me and try to get as much rest as possible
...relationships with some friends and most family became closer. Social life greatly reduced. Otherwise not a great deal of change except in my own attitudes.
I look at life in a more positive way and appreciate things and life more. Our spiritual life has truly grown.
I take time to smell the roses. The small things that seemed so important are no longer so.
The dishes can sit in the sink, while I go for a walk...my life is more relaxed, not so rushed to get everything done.*

Availability of support

Availability of support was determined by examining responses to items concerning communication, talking with others about cancer, use of complementary therapies, participation in support groups, and how helpful others had been.

When asked about the desire to talk with someone about their difficulties with cancer, 27 women indicated they had wanted to talk. Of this group 22 had someone with whom they could talk. Most of these women ($n=18$) cited family members and friends as their confidantes. Additionally, 11 had seen a mental health professional about their cancer-related difficulties. Of note, 11 of the 12 individuals with recurrent disease indicated they had experienced the need to talk about difficulties with their cancer compared to 12 out of the 20 without recurrent disease.

The majority of the women ($n=31$) indicated they had been informed accurately about the consequences of their treatment.

Respondents were also asked to rate their satisfaction with the various types of information they received (see Table Four). The majority of women rated all types of information as important. However, the number of women who were satisfied with the information they received diminished concerning non-medical and psychosocial topics. Relatively few women were satisfied with the information they received about complementary and alternative therapies, self-help groups, speaking with another woman with ovarian cancer, and possible emotional reactions.

Nineteen of the women had sought complementary or alternative therapies since their diagnosis. The types of therapies they most frequently reported using included vitamins (n=13) and herbal medicines (n=11).

Only six of the women had had the opportunity to participate in support groups for women with ovarian cancer. An additional 15 expressed an interest in doing so. When asked about the benefits of either attending a support group or talking with someone about their cancer experience, the women cited several. The benefits they saw included the chance to find out that others felt the same way they did (n=11), learning about alternative therapies (n=9), encouragement and reinforcement (n=8), getting more information about ovarian cancer and its treatment (n=7), opportunities to help others (n=7), and coping with pain and symptoms (n=7).

Respondents were asked to rate, on a five-point scale, how helpful others had been to them since their diagnosis. Other family members, doctors, partners, friends, and nurses were identified most frequently (see Table Five).

Discussion

This nation-wide study was mounted to provide insight into Canadian women's experiences of living with ovarian cancer. The findings presented in this article focus on the perspectives of women 45 years and younger. Their viewpoints concerning the impact of ovarian cancer on lifestyle and the availability of support have particular relevance to oncology nurses. Implications exist for nursing assessment, patient education, and information provision.

There are several limitations in this work which need to be kept in mind in looking at the results. As is the case with all mailed surveys, those who returned the completed forms are likely those with an interest in the topic and may reflect women who are, overall, coping relatively well. Women who are coping less effectively are likely under-represented in this study. The sample is also a well-educated, Caucasian sample and does not reflect the diversity of cultures which exist in Canada. The majority of the sample enjoy a relatively comfortable socioeconomic status. Finally, the sample of 39 is small and further work with a larger sample would be needed to validate the findings reported here. Despite the limitations, the work provides interesting observations and ideas for future work.

Clearly, the younger women who responded to this survey experienced problems in both physical and psychosocial realms. Given the nature of the treatment protocols these women were undergoing, it is not surprising that they experienced significant side effects and symptom discomfort. It is important to note when interpreting these data that the question in the survey asked the respondents whether or not they experienced a problem, as opposed to whether or not they had experienced a symptom or event. The respondents may have experienced a particular symptom (i.e., pain) or event (i.e., menopause) but did not perceive it was a problem. It is possible the frequencies reported for this sample under-represent the actual number of women who actually experience particular symptoms or events.

Of particular interest, however, is the high average number of problems reported by the young women in this sample and the high prevalence of specific problems. The prevalence of problems cited is in marked contrast to a similar study with women 61 years and older living with ovarian cancer (Fitch, Gray, & Franssen, 1999). The older women cited, on average, experiencing only 5.2 problems and only four types of problems were experienced by more than one-third of the older women [side effects (54%), bowel difficulties (45%), fear of recurrence (43%), and difficulty sleeping (36%)]. Although young women also experienced these types of problems, the incidence for younger women was higher. Such differences may relate to the perceptions of what constitutes a problem or the actual reporting of concerns related to health. As health care consumers, younger women may have more comfort in identifying and reporting health-related concerns.

The young women in this sample are also in the midst of raising young children and, in many cases, working outside the home. They are juggling many roles and responsibilities. Physical illness can disrupt one's ability to function in those roles and fulfil one's expected responsibilities (Cain et al., 1983). For young women who undergo treatment for ovarian cancer, the physical strain from the protocols is daunting and, for a period of time, they may be unable to carry out their mothering or work-related roles. This, in turn, adds to the distress a young woman feels when she is ill (Fitch, Bunston, & Elliot, 1999).

Finally, the difficulties with menopause, infertility, and sexual issues/functioning were cited as problems by the young women in this sample. This, too, is in contrast to a sample of older women living with ovarian cancer (Fitch, Gray, & Franssen, 1999). These issues reflect developmental, life-stage related concerns, expected for women in this age grouping. Caring for young women diagnosed with ovarian cancer requires sensitivity to these issues.

Of particular concern is the number of women who reported they had not received adequate help for the problems they experienced. It is unclear from the data whether they did not receive any help whatsoever, or received help that was not useful. Nevertheless, the finding of such unmet need raises several questions: Are the patients' problems being identified by the cancer care team? Are appropriate referrals being made when an issue is identified? Are appropriate services available to provide the required assistance? Are actual interventions provided to resolve the problem effectively? In work with breast

Table Five: Helpfulness of others since cancer diagnosis (n=39)

Sources of help	% who rated helpfulness as 4 or 5 on 5-point scale	Mean rating of helpfulness
Other family	84.6	4.5
Partner	74.4	4.6
Friends	74.4	4.4
Children	46.2	4.2
Doctors	84.6	4.3
Nurses	74.4	4.3
Counsellors	25.6	3.6
Literature	51.3	3.7
Media	33.3	3.0

cancer patients, many of the young women find that services are targeted to the needs of older women. Finding services that are sensitive to the needs of young women has been a challenge (OBCIEP, 1998).

It is noteworthy that the problems for which more women found they received adequate help were physical in nature (i.e., side effects, menopause, bowels, pain, difficulty sleeping) or practical (getting around). Less help was received for the problems of a more psychosocial nature, such as fear of recurrence, feeling isolated, infertility, and sexual issues. This same pattern of less attention to psychosocial problems was evident for older women reporting on the areas where they did not receive adequate help (Fitch, Gray, & Franssen, 1999), although their problems were somewhat different. These psychosocial issues may be difficult to identify and respond to appropriately within the context of a busy clinical setting. Often, routine clinical assessment is geared toward a physical/body system assessment rather than a whole body/mind assessment. There are implications for the role of nurses in conducting comprehensive clinical assessment with these patients as well as making referrals to appropriate services. Additionally, there are implications for interdisciplinary team collaboration to ensure access to a full range of expertise for these women.

With the high prevalence of problems and the level of inadequate assistance, it is not surprising that so many women experienced lifestyle and quality of life changes. The women in this sample, and their families, were dealing with many changes simultaneously, especially those on active treatment and those dealing with advanced disease. Women who move beyond the active therapy and recover some measure of physical health are able to see a shift upward in their quality of life. Recent work about quality of life with ovarian cancer patients described a similar shift in patients' perspectives about their quality of life (Guidozzi, 1993). The shift is often linked to the number of symptoms a person is experiencing and the ability to engage in activities of importance to the individual (Portenoy, Thaler, & Kornblith, 1994). The findings concerning quality of life and the patterns of problems the young women in this study cited emphasize the need for astute problem identification with the individual woman and interventions targeted to the constellation of problems she is experiencing. The findings serve as a reminder that quality of life is subjective and care providers need to understand the individual woman's perspective.

Despite the difficulties many women reported, it is interesting to note the number who experienced a positive impact following their diagnosis and treatment. This notion of positive effects following a cancer diagnosis is a seldom evaluated area (Anderson, 1994). However, cancer survivors often describe increased enjoyment of and appreciation for life and good times, spiritual enrichment, and increased closeness of significant relationships (Danoff, Kramer, Irwin, & Gottlieb, 1983). Brickman (1978) also reported that traumatic events (i.e., serious illness, accident) can lead to a relatively higher level of perceived well-being in the victim after the event. In a qualitative study of quality of life by Ersek et al. (1997), cancer patients described both positive and negative influences.

The negative impact upon employment, work life, and financial status has been reported for ovarian cancer patients (Guidozzi, 1993). The physical impact of the treatment protocols means that many individuals are not able to maintain the level of productivity they could prior to their diagnosis. Care providers need to be cognizant of the financial difficulties young women may be facing as a result of reducing their work hours or stopping work altogether. Referral may be needed to assist with the strain these matters produce.

That only half of these young women reported a negative impact on their mental health is somewhat surprising. Faced with the gravity of their illness, the uncertainty regarding recurrence, and their fear of dying, it was anticipated more women would have reported experiencing a negative impact on mental health. One possible explanation is that these women may be trying to carry on in the face of adversity and not wanting to openly acknowledge the dire situation in which they find themselves. They may be coping by trying to maintain a positive attitude and a sense of hope that things will be fine. Maintaining a positive attitude and a strong sense of hope have been cited by cancer survivors as important to them (Gray et al., 1998). The challenge for health care providers is to identify those women who are experiencing a negative impact following their cancer diagnosis and would like assistance in coping with that impact.

It is of interest that approximately a third of the women in this sample did not feel the need to talk with someone about difficulties regarding the cancer. Within the group who experienced recurrent disease, the proportion was much smaller. However, the observation emphasizes the variation in coping among individuals and the importance of recognizing that different individuals will benefit from different types of intervention. Also, about 20% of those who wanted to talk did not have someone with whom they could talk. Clearly, health care professionals need to be able to identify those who want to talk and do not have a confidante.

Many women in this study reported a range of benefits in talking with others about their cancer. Few, however, were able to access self-help groups which have been such an important source of support and information for women with breast cancer (Gray et al., 1997). Presently, the development and growth of self-help groups for women with ovarian cancer has lagged behind those for breast cancer patients. This is likely because of the lower prevalence of women living with ovarian cancer as well as the morbidity and mortality associated with ovarian cancer. There are simply fewer women available to provide peer leadership in ovarian cancer groups. This raises the question of whether health care professionals or well-women volunteers ought to assume a more active role in helping to organize and facilitate self-help groups for women with ovarian cancer. Additionally, young women may not be able to attend groups because of child care, work responsibilities, and not having sufficient energy to add another activity into their schedules. This suggests the need to find innovative methods to provide access to support for this group. Telephone peer support or use of the Internet may be helpful for women with ovarian cancer.

The young women in this study were clear about all types of information being important to them. However, a sizable proportion of the sample was not satisfied about the information they had received. It is unclear from the survey data whether these women did not receive information in the first place or they did not like the implications of the information that was provided. It is also unclear whether the dissatisfaction was a result of communication that was insensitive. Findings from a recent qualitative study of living with ovarian cancer indicate that sensitivity to the individual women's needs is of paramount importance (Fitch, Gray, Deane, et al., 1999). Finally, many topics for which women indicated dissatisfaction are areas where nurses could be intervening. These areas include information about emotional responses to cancer, community resources, how to get in touch with another woman with ovarian cancer, and complementary and alternative therapies.

Implications for nurses

The findings from this study indicate that young women living with ovarian cancer experience a wide range of problems and are not receiving what they perceive to be adequate help. Many are

dissatisfied with information they are receiving. Many see nurses as being helpful to them. Nursing interventions ought to include limiting the impact of side effects and assisting women with ovarian cancer to cope with the myriad of changes they may be experiencing as a result of their disease and its treatment. Based on this imperative, there are several implications for practice emerging from this study.

Nursing assessment with a young woman who has ovarian cancer must be comprehensive and include both physical and psychosocial elements. A comprehensive approach must be applied in the assessment regardless of the woman's stage of illness or the setting in which the nurse interacts with the woman. The communication needs to be sensitive to the woman as an individual and pinpoint the issues which are of concern to her, not simply the ones with which the nurse is concerned.

Nurses need to be particularly alert to the situation of a woman learning about recurrent disease. Treatment options and likelihood of cure narrow considerably at this point in time. In a recent qualitative study of ovarian cancer, women described substantial changes in the support they felt from health care professionals at the time of recurrence (Fitch, Gray, Deane, et al., 1999).

For women who are experiencing difficulties, referral to appropriate services or agencies is important. Nurses need to tell women about the types of services that are available. The

information ought to include both what types of problems the service can help resolve and how to access the service. Nurses can also play a part in helping women understand the emotional responses that accompany life-threatening illness and its inherent losses. Particularly with young women diagnosed with ovarian cancer, losses related to infertility and menopause need to be anticipated. Nurses need to be informed about topics such as child-bearing options and hormone-replacement therapies if they are caring for young women with ovarian cancer. Nurses need to offer young women the opportunity to talk about their feelings and to ask any questions they may have.

With the growing interest in complementary and alternative therapies (Gray et al., 1997), nurses are often the health care provider with whom women talk about such therapies. Nurses need to be able to talk about these therapies in an open and non-judgmental manner. Finally, nurses need to be able to inform women about the availability of self-help groups and the benefits some individuals derive from such groups (Sivesind & Baile, 1997).

In terms of research, this study provides an initial examination of the issues young women diagnosed with ovarian cancer may experience. Further research is needed with larger samples to explore the issues in greater depth and to identify interventions that are effective with this group of women.

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