

# Important Aspects of Health Care for Women With Gynecologic Cancer

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**Purpose/Objectives:** To describe what women diagnosed with primary gynecologic cancer reported to be important during their interaction with the healthcare system.

**Design:** Qualitative.

**Setting:** A specialized gynecologic cancer care unit in central Sweden.

**Sample:** 14 women diagnosed with primary gynecologic cancer were recruited. The women had been referred to the specialized care unit for radiation or cytostatic therapy.

**Methods:** Tape-recorded interviews were transcribed, coded, categorized, and analyzed.

**Main Research Variables:** Primary diagnosed women with cancer and their experience with quality of care during diagnosis and treatment.

**Findings:** Three partly overlapping categories (i.e., optimal care, good communication, and self-image and sexuality) were found to be of central importance in quality of health care. Participants stated that health care should be based on their own perceptions of the need for information and dialogue and how the disease and treatment would affect their health, self-image, and sexuality. Everyday conversations also were very important.

**Conclusions:** Central importance in health care for the women included both rational and human aspects. The primary need of participants was to achieve a rapid cure, which necessitated health care that was available, competent, and coordinated.

**Implications for Nursing:** Women with gynecologic cancer should be given individualized information and care to satisfy their individual needs and reinforce their self-image. Nurses have an important role in strengthening women's feelings of hope and supporting them in maintaining as positive a self-image as possible. Information and everyday conversation are of great significance. Sexuality should be an integral part of holistic care; to this end, inclusion of each woman's sexual partner may be helpful when discussions concerning sexuality occur.

A diagnosis of cancer is very stressful and frequently entails adjusting to new life conditions (Hellbom, Brandberg, Glimelius, & Sjöden, 1998; Hindley & Johnston, 1999; Wiggers, Donovan, Redman, & Sanson-Fisher, 1990). Individuals diagnosed with cancer often experience a loss of control over their lives (Given & Given, 1989), a feeling of helplessness (Hindley & Johnston), and worry about the future (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998). Cancer involving the female genitalia affects women in a unique way, both cognitively and emotionally, because the uterus, ovaries, and vagina are associated with femininity, motherhood, and sexuality (Capone, Good, Westie, & Jacobson, 1980; Krant, 1981). Studies also have

## Key Points . . .

- Although the women described that they more or less had to put their lives in the hands of their physicians, they nevertheless wanted to participate in healthcare decisions that affected them.
- The women felt they sometimes received too much technical information, which helped very little in managing their everyday lives.
- To obtain holistic care, the women should be given an opportunity for a sensitive and individual dialogue. They also want sufficient support from healthcare staff.

shown that women with gynecologic cancer worry more about their condition than patients with cancer in general (Corney, Everett, Howells, & Crowther, 1992) and that their sense of psychological well-being is poorer than that of patients with chronic illnesses and healthy individuals (Greimel & Freidl, 2000). They need information about therapeutic procedures and the disease process, as well as clarification of misunderstandings, and an opportunity to talk about their feelings (Good & Capone, 1980; Williamson, 1992).

The meaning an individual woman attaches to a diagnosis of cancer and how smooth her interaction is with the healthcare system affects her satisfaction with care, her everyday life (Cleary & McNeil, 1988; Wiggers et al., 1990), and her ability to cope (Rustoen, Wiklund, Hanestad, & Moum, 1998). What is important from the patient's perspective may not be perceived as being of the same central importance by caregivers and healthcare professionals (Larsson, von Essen, &

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Sjödén, 1998; Wiggers et al.). Good quality of care must be based on an understanding of the needs, desires, and expectations of patients (Nelson & Niederberger, 1990). Over time, interest has increased in assessing and assuring quality of care (Cleary & McNeil; Davies & Ware, 1988; Vuori, 1991) from the patient perspective (Larsson, Wilde & Udén, 1996). According to Donabedian (1988), patient satisfaction can be regarded as a component of health itself. Larsson et al. (1996) regarded patients' own ratings of a healthcare event as the most reliable information in the evaluation of quality of care. Wilde, Starrin, Larsson, and Larsson (1993) developed a theoretical model for understanding quality of care in which the rational and human aspects of health care are emphasized. The rational aspect involves the availability of competent medical personnel and medical facilities. The human aspect includes the availability of personnel with an identity-oriented approach and an environment that is favorable from the sociocultural point of view. An identity-oriented approach is based on the staff's ability to see and respect patients as unique individuals. Respecting patients' way of thinking is of central importance. According to Wiggers et al., this has not been stressed sufficiently in earlier studies describing satisfaction with the care of patients with cancer.

## Purpose

The purpose of this study was to describe what women diagnosed with primary gynecologic cancer reported to be important during their interaction within the healthcare system.

## Methods

### Setting and Sample

The study sample was located through the cancer registry of a specialized gynecologic oncology care unit at a university hospital in central Sweden. All women who had received radiation or cytostatic therapy on the care unit during the fall of 1996 or the spring of 1997, had no previous cancer diagnosis, and were able to speak Swedish were asked to participate in the study. A total of 17 women fulfilled these criteria. The women were contacted by one of the researchers 2–12 months after diagnosis ( $\bar{X}$  = 6.5 months). Fourteen women provided informed consent. With one exception, the women were diagnosed and had surgery at their local hospital. Four to six weeks after surgery, they were referred to the care unit for radiation or cytostatic therapy.

Two women had been diagnosed with cervical cancer, four with ovarian cancer, and eight with uterine cancer. The shortest treatment period was six days when brachytherapy was given, and the longest treatment series lasted 11 months. Elapsed time since the completion of treatment also varied. Two of the women were interviewed the day before their final treatment. The longest period of time between the end of treatment and the interview was three months ( $\bar{X}$  = 1.3 months). The women ranged in age from 33–80 years ( $\bar{X}$  = 57.5 years). All but two women lived with a partner.

### Study Design

The data were collected and analyzed using a qualitative approach (Patton, 1990). Semistructured interviews were carried out as dialogues with a minimum of interruption by the interviewer. The women were asked to relate their ex-

periences with the healthcare system when they received their diagnosis and treatment, and how the illness had affected their daily lives. In addition to their description of their experiences, supplementary questions were asked, such as "How did you feel then?" "What did you think then?" or "How did you act?" (Patton). The interviews were conducted in the hospital and lasted for an average of 60 minutes. The study was approved by the regional research ethics committee.

## Procedure and Analysis

All interviews were tape-recorded, transcribed, and analyzed using a qualitative content analysis. The content analysis was inspired by Patton (1990) and Burnard (1991) and was carried out inductively according to the following steps.

1. The interviews were read through repeatedly by the interviewer to get an overall sense of the whole.
2. During the reading, comments on the content of the interview were made in the margins.
3. These comments were analyzed and compared for each interview and among the interviews. Similarities and differences were identified and coding categories established. This process was completed when the data yielded no more contributions to the generated codes.
4. The final codes were compiled and abstracted into three main categories (see Table 1).
5. To detect any possible inconsistencies in the categorization process, a coexaminer undertook an independent categorization of the codes into the three main categories. When options differed, this was reviewed by the coexaminer until agreement was reached (Sahlberg-Blom, Ternstedt, & Johansson, 2000). This method of conducting analysis is a form of analytical triangulation (Patton, 1990).
6. The interviewer reread the interviews and compared the codes and categories to each interview and to the whole.

## Results

### Sample

All women were Swedish. Eight were treated with radiation, four with cytostatic therapy, and two with a combination of radiation and cytostatic therapy.

Analysis of the data revealed that the most urgent need for the women during their health care was to have the tumor removed quickly and thereby be cured of their cancer. In addition, the women felt that good communication and support were of central importance to maintaining as positive a self-image as possible. The results are described via three partially overlapping main categories (see Figure 1).

### Optimal Care

According to the women, optimal care meant that they could maintain the hope of a rapid cure and feel confident that they were getting the best care. Optimal care was characterized by rapid cure, availability and competence, and coordination.

**Rapid cure:** A common theme in the interviews was that the women experienced the tumor as being horrible and alien, something they wanted removed in the hope that life would return to normal.

I wanted to get well. I look at it like this. My cancer disappeared when they took out the tumor . . . and radiation

**Table 1. Examples of a Categorization Process**

Patient Statement	Code	Category
Get it out! I want to get well like I was before.	Rapid cure	Optimal care
He was supposed to be on vacation until August at the latest.	Availability	Optimal care
It's reassuring with staff who have experience with cancer care.	Competence	Optimal care
When I learned I was going to be transferred to the specialist care unit in the university hospital, it seemed like a gap opened up, there was a vacuum [in the communication].	Coordination	Optimal care
The doctor was amazingly understanding and straightforward, and I developed tremendous confidence in her. I got everything I needed there.	Confidence	Good communication
If something doesn't suit me, I can find out if there's any alternative.	Information and participation	Good communication
It's the simple things that are often so good.	Everyday conversation	Good communication
Sometimes, I think the staff nurse could do just as much.	Everyday conversation	Good communication
They've taken out everything, but there has been a sickness in my body—that's what makes me dislike my own body.	Openness	Self-image and sexuality
I haven't dared to ask why I feel totally dead inside. I believe I'm too much of a coward and the doctor might think that since I'm over 50 I should be content with what I've had. I'm so afraid of getting a stupid answer.	Openness	Self-image and sexuality

therapy and cytostatics are just safeguards. . . . I don't know if it's just a way of fooling myself. If I can get rid of it, as I hope I did, at a very early stage, then I can say that I've had cancer.

The time between when participants were informed of the diagnosis and when they received treatment was frequently very short, and the women often found it difficult to assess the benefits of suggested therapies. The women's conception of and knowledge concerning the tumor and what was adequate treatment greatly influenced their decisions. One woman described the situation in the following manner: "I either have to have an operation or let it keep growing in my body, and of course that's a very simple choice." For her, this was a choice between life and death.

Another woman declined radiation therapy prior to her surgery because she wanted the tumor to be removed immediately. "The surgeon hadn't operated on such a large tumor before—they usually remove the large ones by radiation therapy—but I wanted it to be removed surgically because it's my body and my life." Most of the women were confident about a cure, and surgery was considered the definitive treatment.

**Availability and competence:** Several women said that being able to go to the gynecologic care unit gave them a great sense of security. They felt very confident that the staff were

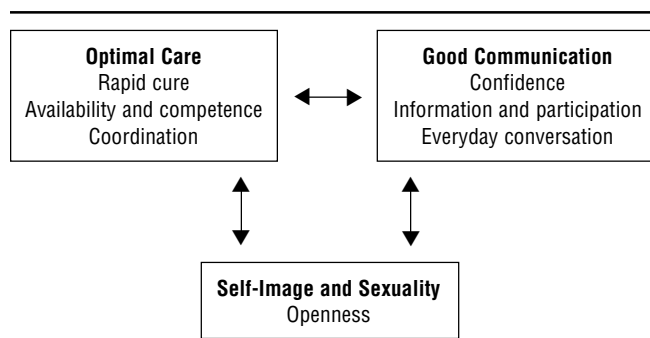
competent and knew what the best treatment was. One woman said, "When I finally got to the specialist clinic, we [the family] got answers to all our questions."

The women wanted a guarantee for year-round, rapid, and competent care. They thought it was important for health care to be available during vacations and holidays. A quick and uncomplicated diagnosis and treatment assuaged their worries. However, the interviews with the women were carried out during a period when cost-cutting in Swedish health care was being discussed in the media. Many women expressed concern that cutbacks in health care would affect both the availability of care and the competence of the staff.

**Coordination:** Study participants expressed views directly related to the organization of healthcare services. For example, they felt that a more explicit differentiation of professional responsibility should be available. This was especially the case when many doctors were involved in their care. Although oncology experts at the care unit were needed to achieve optimal care, the women nevertheless wanted to limit the number of individuals involved in their care. They wanted to be seen by the same doctor and know which clinical department was responsible for their care during the course of their illness. Because the women were referred from their local hospital to the care unit, they had experience with fragmentation of care. One woman said, "I'd just started the menopause and was sweating a lot, but the doctor said that the specialist would have to manage that when I got there." The woman did not feel that anyone had really taken responsibility for her total situation, and she emphasized the value of coordination among the various departments and among different health authorities.

## Good Communication

Good communication with healthcare staff helped the women feel more confident and participate more fully in their care. They felt that adequate time for talking with healthcare staff was an important aspect of healthcare quality. The point at which they received their diagnosis constituted a significant moment in the women's lives. In the course of a few minutes, their lives had been changed in a most shocking manner.



**Figure 1. Categories or Factors Affecting How Women Experienced the Healthcare System**

Despite that, the women said that they had been able to maintain a certain calmness. They felt that the staff sometimes expected them to react more strongly than they actually did.

They may have thought it was odd that I didn't react by becoming really depressed, which is what they were waiting for the whole time. They probably thought I was in a state of shock, but it can also be a way of working things through, looking ahead. How you react to something like this is very individual. In order to deal with them [the staff], you have to play by the rules or try to explain; otherwise, they won't let up.

**Confidence:** Being informed that they had cancer often caused the women to feel dependent on those around them and realize how important a trusting relationship was. The women described their dependence on their doctors, in particular, and how they had to place their life in the doctors' hands. "When it comes to diseases like this, you naturally have nobody but God and the doctors to trust in." Doctors were described as being the individuals with information of decisive importance about the disease and its treatment. The way in which the doctors handled this power had great impact on the feeling of confidence and well-being of the women. One woman said,

She [the doctor] understood how perfectly horrible I felt. So, we sat together and talked. She was the best person I could have met just then—unbelievably understanding and straightforward. I had great confidence in her even if she couldn't tell me that I was going to get well.

This woman felt acknowledged and respected in a difficult situation. This contributed to the development of a trusting relationship between the woman and the doctor.

**Information and participation:** Although the women described that they more or less had to put their lives in the hands of their physicians, they nevertheless wanted to participate in healthcare decisions that affected them. To be involved in their own care, they had to be given information on an ongoing basis. They reported that the least painful way of being informed of their cancer was to be given the information at a visit to a doctor they knew. Receiving such information, without prior warning, could be extremely traumatic. Some of the women wanted the information to be given in a straightforward manner, without embellishment.

If they [the doctors] try to avoid the subject too much, you'll understand that there is something they don't want to tell you. So, in a way, it is easier if they just tell you straight out. It has to come sometime anyway.

However, other women preferred to be informed more gradually. They were well aware of the difficulties involved in prognosticating and did not expect any guarantees about the future. Most of them understood and accepted the fact that no test was available to determine whether they would be free from cancer after the treatment. Nevertheless, most of them wanted to have all the information about the disease that was available to the doctor. Despite the uncertainty, they found this to be reassuring. The ideal doctor was sensitive to the women's present state and gave well-balanced information with some room for hope.

**Everyday conversation:** Everyday conversation with the nurses and assistant nurses often meant a lot to the women.

It was precisely the social aspect—not simply analyzing things—it was more than that. . . . "Those are really nice flowers you have." They can talk about this and that and not just go by the book. That really makes you perk up much more.

Being able to talk about "this and that" despite the gravity of the situation constituted an important safety valve for the women.

Communication with other patients could be beneficial to the women, provided they could decide when and how it occurred. They pointed out that they were especially sensitive recently after learning about their cancer diagnosis, and they did not want to be placed in the same room as "sick" patients. Seeing and listening to very sick patients made the women aware of what their own situation might be someday and could drastically diminish their hope of being cured. One woman said,

She [another patient] asked what I was here for. "I'm getting cytostatics," I said, "because I have ovarian cancer." "Oh, I see," she said. "I had that too, and after six months, I got the cancer back again in another place." Why did she have to say that to me?

Nevertheless, some of the women established beneficial contacts with other patients. They felt that only those who had been through the same thing could truly understand what it was like. They thought it was difficult for relatives and health-care personnel to understand what they were experiencing.

## Self-Image and Sexuality

The women appreciated the respect and support they received in their effort to maintain as positive a self-image as possible. An important aspect of this was being able to talk about their sexuality and bodies. They described how the disease had affected their daily lives, including their sexuality.

**Openness:** The women noted that the healthcare staff did not always address the issue of sexuality, and it was difficult to discuss it with the doctor. ". . . And then there's the matter of sexual intercourse that nobody has mentioned except to say when it will be appropriate." The women felt it would have been helpful if questions pertaining to sexuality had been asked. "Maybe it would be good if they asked about your sex life. If they just gave you a little opening, maybe you'd dare to ask them about it." One woman indicated that the information she received was of a biomedical character and did not increase her understanding or knowledge. This woman's doctor told her that her vagina was 10 centimeters in length, but not how this would affect her sex life. ". . . And at any rate, it [my vagina] was longer before. I want to know about any possible problems because of this and also if there might be changes in the mucous membranes and so forth."

Several conversations revealed that the women's desire for sexual intercourse had diminished.

I feel completely dead inside; the doctor took everything out. Since the operation, I haven't liked my own body because there are lumps everywhere. I imagine my vagina and then my empty abdomen. I tried to fake it the first time I had intercourse. It's something I've kept putting off. . . . It'll probably get better, but it hasn't yet.

The women noted that it did not necessarily have to be the doctor who gave them information and talked with them. The important thing was that the women's sexuality and sexual needs were not ignored.

## Discussion

One of the main categories identified in this study comprised wanting to receive optimal care to be cured rapidly of the cancer. Such optimal care required availability and competence of healthcare personnel and an organization that promoted coordination among various departments and healthcare authorities. This category has several points in common with what Wilde et al. (1993) deemed the rational aspect of health care. In the present study, the desire to be cured overshadowed everything else. The women felt that surgery was the treatment that was really curative. A similar finding was reported by O'Rourke and Germino (1998) in their study of the treatment choices of patients with prostate cancer. The researchers suggested that patients with prostate cancer preferred surgery because information about radiation therapy had not been adequately explained to them. Long (1993) found that women with breast cancer considered a radical mastectomy to be a more effective treatment than a combination of breast-preserving surgery and radiation therapy. Redelmeier, Rozin, and Kahneman (1993) indicated that patients' preferences for treatment sometimes seem to be irrational. According to Schaefer, Ladd, Gergits, and Gyauch (2001), women who participated in a breast cancer prevention trial made decisions to participate based on their experiences of the disease and its consequences for daily life. The decision-making process was described by the researchers as nonlinear and complex. This underscores the importance of respecting the way patients are thinking and basing information on their perception of the disease. According to Larsson et al. (1996), patients' perceptions of what is important can be regarded as an aspect of the quality of care. The unique experience of each patient should constitute the basis for health care (Hack, Degner, & Dyck, 1994) and should be the hub around which care revolves (Donabedian, 1988). According to Hack et al., patients' attitudes about participation in treatment can change over time.

The two other main categories, good communication and self-image and sexuality, are similar to what Wilde et al. (1993) described as the human aspect of health care and an identity-oriented approach. The women reported that the healthcare staff sometimes seemed to act in a stereotyped manner and that they gave them little individualized attention. This may be considered the opposite of an identity-oriented approach. This was particularly evident in the staff's expectations regarding the patients' reaction to the diagnosis and treatment and the fact that the staff seemed to ignore issues pertaining to sexuality and self-image.

The women stressed the necessity for information and good communication concerning how the disease and treatment could influence their quality of daily life. They wanted to know what the staff knew, even if it meant that they could not be given any guarantees about what would happen in the future with respect to their health. Brewin (1985) stated that patients never can be provided with too much information. However, most authors urge medical practitioners to let their patients control the amount of information that is given. This is supported by the present study. Healthcare professionals must respect the wishes of patients who do not want all the information that is available (Bennett & Alison, 1995; Friedrichsen, Strang, & Carlsson, 2000; Hack et al., 1994; Ptacek & Eberhardt, 1996; Sahlberg-Blom et al., 2000).

The women felt that they sometimes received too much technical information, which helped very little in managing their everyday lives. Medical terminology and the hierarchy of the healthcare system were obstacles to asking questions that were important to them. This was evident particularly when it came to sexuality. The women's accounts indicated that their disease negatively affected how they perceived their bodies and self-image. Foltz (1987) found that women with gynecologic cancer had a higher risk of developing a negative self-image than women who had other types of cancer. This finding is supported by other studies that demonstrated a negative association between gynecologic cancer and perceptions of femininity, motherhood, sexuality, and self-image (Adams, DeJesus, Trujillo, & Cole, 1997; Bruner & Boyd, 1998; Capone et al., 1980; Foltz; Krant, 1981). One study of patients who had undergone radiation therapy for cervical cancer showed that only 4 of 21 women had received information from their doctors on how the condition could affect their sex life (Krumm & Lamberti, 1993). Corney, Crowther, Everett, Howells, and Shepherd (1993) found that encouraging women to ask questions about their sexuality had a facilitating effect. Avoiding questions pertaining to sexuality may make patients think that sexual activity no longer is appropriate (Shell, 1990). A number of studies stress that sexuality deserves the same amount of attention as other aspects of cancer care (Adams et al.; Butler, Banfield, Sveinson, & Allen, 1998; Rice, 2000; Shell) and that each woman's partner should be involved in her care as early as possible (Lalos, 1997).

In one study, 178 questionnaires were sent to women who recently were diagnosed of gynecologic cancer or had been in clinical remission for two to five years and their families. They responded that information about cancer and how the disease and treatment affected them in their daily lives were of primary importance. Information about sexuality had a lower priority (Carlsson & Strang, 1996). The women in the current study described issues that were important to them in their interaction with the healthcare system. Based on the fact that the hope for rapid cure was the need that overshadowed all other needs, it is reasonable to assume that if they were to rank their needs, their priorities would be similar to those of the women in Carlsson and Strang's study. Clearly, the women in both studies sought knowledge about how their disease affected their bodies and daily lives. The women in the current study found it difficult to broach the subject of sexuality with their doctors. Despite cultural differences, this seems to be a worldwide problem (Corney et al., 1993; Flay & Matthews, 1995; Thranov & Klee, 1994; Weijmar-Schultz, Van De Wiel, Hahn, & Bouma, 1992; Yeo & Perera, 1995).

The women in the present study emphasized how important their contact with their doctors was. One of their most frequently stated wishes was to have continuity in contacts with doctors. Tishelman and Sachs (1992) reported that most women with cancer expressed the view that it was "important" or "very important" to see the same doctor at each visit. Similar results were reported by other researchers (Bennett & Alison, 1995; Genberg, Korpola, & Smedby, 1985; Ptacek & Eberhardt, 1996; Sardell & Trierweiler, 1993). The women did not explicitly mention the support they expected from nurses. This was seen indirectly, however, through the value the women placed on everyday conversations with nurses. Other studies have shown that nurses can play an important role in helping patients to get the information they need

(Bruner & Boyd, 1998; Corney et al., 1992; Greisinger, Lorimor, Aday, Winn, & Baile, 1997; Shell, 1990; Shell & Smith, 1994). Nurses' role in this phase of an illness must be described and discussed.

## Limitations

Limitations of this study include the small sample size and the fact that the women were only interviewed on one occasion. Also, the interviews took place at the university hospital when the women had their appointments with their doctors one month after treatment was completed. This could have affected the women's emotions and thereby the results; however, the results are confirmed by other studies.

Efforts were made to ascertain validity throughout the process by critically analyzing the data and continually questioning the findings (Patton, 1990; Strang & Strang, 2001). The results cannot be directly generalized to other groups but they could be transferable to similar domains of care. However, further studies must be conducted concerning how women experience their situations over time and their need for support, as well as how different interventions can strengthen the feeling of well-being in women with gynecologic cancer.

## Conclusions

The women in this study stressed that optimal care conditions and respect for the individual were important prerequi-

sites for achieving good quality health care. Both the rational and human aspects of the healthcare system were emphasized. Participants stated that health care should be based on their own perceptions of the need for information and dialogue and on how the disease and treatment would affect their self-image. An important part of this involves being able to talk about how the disease might affect the women's everyday lives and sexuality. Everyday conversation was an important safety valve for their well-being and optimized the women's satisfaction with their lives and with the care they received.


## Implications for Practice

Apart from the need for a rapid cure, women with gynecologic cancer need to receive individualized information and care. This means that the basis for care is the individual woman's way of looking at things and how she thinks and feels. Also, sexuality must be an integral part of holistic care. To this end, inclusion of each woman's sexual partner in discussions concerning this aspect may be helpful. The everyday conversation is of great significance here. Informative material about sexuality should be included in conversations with these women and their respective partners.

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## For more information . . .

- Women's Cancer Network  
[www.wcn.org](http://www.wcn.org)
- GynecologicalCancers.org  
[www.gynecologicalcancers.org](http://www.gynecologicalcancers.org)
- Fox Chase Cancer Center: Gynecologic and Ovarian Cancer  
[www.fccc.edu/clinical/gyn-ovarian](http://www.fccc.edu/clinical/gyn-ovarian)

Links can be found using ONS Online at [www.ons.org](http://www.ons.org).