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## The Importance of Participation in Support Groups for Women With Ovarian Cancer

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**Purpose/Objectives:** To explore the experience of participation in support groups for women recently diagnosed with ovarian cancer.

**Research Approach:** Exploratory, qualitative.

**Setting:** Oncology department in a hospital in western Sweden.

**Participants:** 10 Swedish women, aged 42–76, who recently had been diagnosed with ovarian cancer and had participated in support groups.

**Methodologic Approach:** Data were collected by semistructured interviews and analyzed using grounded theory.

**Main Research Variables:** Ovarian cancer, support group experience.

**Findings:** Three categories emerged from the data analysis: sharing experiences and emotions, exchanging informational support, and exchanging emotional support. The core category was the experience of being in the same boat. Trust, openness, and willingness to create space for each other were experienced.

**Conclusions:** Support groups offer an opportunity to share experiences and emotions as well as exchange information. They are also a possible source of emotional support and therefore can contribute to quality of life of patients with ovarian cancer.

**Interpretation:** Knowing that others had similar symptoms and reactions, and that those experiences are normal, was very important for support group participants. Nurses can reduce patients' fears and uncertainties by confirming normality. Oncology nurses need to be aware that cancer support groups offer a unique opportunity to interact with others in a similar situation. Participation in support groups can be an important source of emotional and informational support for patients. The support program in this study may be used as a model when planning for extended emotional and informational support.

For the majority of patients with cancer, diagnosis of the disease causes emotional suffering (Bottomley, 1998b) and psychological distress (Bottomley, 1997a; Corney, Everett, Howells, & Crowther, 1992; Taylor, Falke, Shoptaw, & Lichtman, 1986). A variety of psychosocial problems often are reported among women with gynecologic cancer, including depression, anxiety, fear of dying (Corney et al.; Steniga & Dunn, 1997), hopelessness, concerns about the genetic inheritance of the disease, loss of femininity (Hamilton, 1999), fear of recurrence, and altered feelings about their bodies (Fitch, Gray, & Franssen, 2000a, 2000b). Physical side effects such as fatigue, pain (Steniga & Dunn), altered sexuality (Schultz & van de Wiel, 2003), and bowel difficulties (Fitch et al., 2000a, 2000b) also are common. Fitch et al. (2001) found that

### Key Points . . .

- Informational and emotional support is important for holistic, patient-centered care and is critical to improving quality of life for patients with ovarian cancer.
- Cancer support groups offer a possibility to meet patients' needs for sharing experiences and emotions, exchanging information, and receiving emotional support.
- Oncology nurses are in an ideal position to develop successful cancer support programs because they are aware of the consequences of diagnosis and subsequent treatment.

the most common problems for which women with ovarian cancer had not received adequate help were fear of dying and fear of recurrence. How to best help these patients has not yet been thoroughly explored. The aim of the present study was to investigate the experience of participation in support groups for women recently diagnosed with ovarian cancer.

### Literature Review

Anxiety and stress in patients with cancer can result directly from lack of preparation, information, and explanation regarding the type of treatment and the reason for its administration (Evans, 1995). For many patients, obtaining information is an important way to cope and to gain practical and emotional control over a threatening situation (Cunningham, 1995; McQuellon et al., 1998). Information, however, is often a substitute

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for emotional support. A rather desperate-seeming quest by patients ostensibly for facts can in reality be a need for reassurance (Cunningham).

Fitch et al. (2000a, 2000b) found that a majority of women with ovarian cancer had been informed accurately about the consequences of their treatment, but relatively few were satisfied with the information they received about nonmedical and psychosocial topics, emotional reactions, complementary and alternative therapies, and arrangements to speak with other women with ovarian cancer. Informational and psychosocial supports are important factors of holistic, patient-centered care (Jefferies, 2002; Veronesi et al., 1999) because they can have a positive effect on physical health, mental well-being, and social functioning (Carlsson & Hamrin, 1994). Psychosocial intervention also can prevent future treatment-related psychosocial morbidity (Hamilton, 1999) and decrease anxiety (Devine & Westlake, 1995; McQuellon et al., 1998) and diagnostic or treatment-related distress (Hamilton; Moorey et al., 1994).

## Support Groups

If patients receive limited psychosocial intervention, they will look for support from other sources, notably cancer support groups, to satisfy their needs (Evans, 1995). Group interventions can address cancer-related issues to enable patients to gain emotional support from other patients with similar experiences and to use the experiences of others to buffer the fear of the unknown future (Weis, 2003). Support groups have been shown to meet many psychosocial needs (Jefferies, 2002; Sivesind & Baile, 1997), to provide opportunities to gain mutual support (Cella & Yellen, 1993), and to introduce others who confirm progress or offer new perspectives on the diagnosis (Frymark & Mayer, 1993). A review of 26 group intervention studies suggested that structured interventions offer a greater potential for benefit than those of a purely supportive nature, especially for newly diagnosed patients with cancer. In a distressing time in patients' lives, structured approaches can add stability. Such approaches also can increase knowledge about cancer and its treatment and provide patients with coping skills that may be used when interventions end (Bottomley, 1997b).

Cain, Kohorn, Quinlan, Latimer, and Schwartz (1986) assessed women newly diagnosed with gynecologic cancer who had taken part in support groups. The women were found to be less depressed and less anxious. When compared with those who had not taken part in support groups, their knowledge about their illness and treatment had increased, their attitudes toward healthcare providers were more positive, and they had better adjusted to their illness. The women also had better sexual relationships and participated in more leisure activities. A study by Evans (1995) showed that a cancer support group helped enormously in giving support and providing confidence and direction for problem solving. Participants also benefited from being in a position to support others in similar situations. They needed to be accepted as normal and to be able to laugh at some of the more amusing phenomena associated with cancer without upsetting family or friends.

An article by Sivesind and Baile (1997) described a support group for patients with ovarian cancer whose members stated that participation meant that they had to face the realities of their disease and that they were able to compare their experiences with others. They felt less isolated because they were

able to validate each other's experiences and offer understanding, all of which resulted in a sense of belonging. Existential concerns were considered to be an important area of focus in the group. Fitch et al. (2000a) found that feelings of encouragement and the discovery that others feel the same way most frequently were indicated as helpful by patients with ovarian cancer who had participated in support groups. Feeling reinforcement, receiving information, being able to cope with pain and other symptoms, and having an opportunity to help others were reported as being most helpful in another study by the same authors (Fitch et al., 2001).

In Sweden, support groups are not a standard part of care but lately have been initiated in a few departments of oncology. In a survey of the potential interest in support groups among Swedish women newly diagnosed with gynecologic cancer, the interest was unexpectedly high (63%) (Carlsson & Strang, 1996). Educational support groups for Swedish patients with cancer and their families have been evaluated concerning perceived level of knowledge and effects on mood (Carlsson & Strang, 1998), experiences of coping patterns (Grahn & Danielsson, 1996), physical strength, and desire to conquer the disease (Berglund, Bolund, Gustafsson, & Sjoden, 1994). To the authors' knowledge, no qualitative studies of the experience of participation in support groups have been undertaken to provide realistic information on the need for, and experiences of participation in, support groups. Cumulatively, such studies can add to the knowledge of efficacy of support groups (Bottomley, 1997a, 1998a; Jefferies, 2002). To improve psychosocial support for Swedish women with ovarian cancer, the experience of participation in support groups needs to be explored.

## Theoretical Framework

Coping, a concept focusing on situational context and changes in that context, may be defined simply as the effort to manage stress (Lazarus 1999; Lazarus & Folkman 1984). According to White (1985), coping can be viewed as adaptation (i.e., routine modes of getting along under relatively difficult conditions). What a person experiences as stressful depends on the characteristics of the environment as well as the characteristics of the individual.

Antonovsky (1979) proposed a theoretical model designed to advance understanding of the relationships among stressors, coping, and health. The model later constituted the basis of a salutogenesis (i.e., the origins of health) orientation called sense of coherence (SOC). The SOC concept reflects the assumption that individuals have to cope with situations of distress and includes the following three components: comprehensibility, manageability, and meaningfulness. Antonovsky (1987) hypothesized that the stronger the SOC, the more likely it is that a person will cope successfully with life stressor situations. Theoretically, SOC is assumed to be consistent in adult life, and studies have empirically shown that SOC is a relatively stable characteristic (Langius, Bjorvell, & Antonovsky, 1992; Schnyder, Buchi, Sensky, & Klaghofer, 2000). On the other hand, a person's SOC can change quickly in a negative direction, for example in connection with a traumatic event such as admission to a hospital (Antonovsky, 1987; Schnyder et al.). SOC is defined by Antonovsky (1987) as "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that the stimuli deriving from one's internal and external environments in the course of

living are structured, predictable, and explicable; the resources are available to one meet the demands posed by these stimuli; and these demands are challenges, worthy of investment and engagement” (p. 123). SOC was used as the conceptual framework for the current study. Antonovsky’s salutogenetic model was chosen because of its multidimensional approach and because it may identify patients who are in need of psycho-oncology interventions.

The aim of this study was to explore the experience of participation in support groups for women recently diagnosed with ovarian cancer. Specifically, it sought to explain how women recently diagnosed with ovarian cancer experience participation in a support group.

## Methods

### The Support Group Program

Women recently diagnosed with ovarian cancer were invited to participate in a support group while in the hospital for their first chemotherapy treatments. The intervention aimed to allow patients the opportunity to acknowledge their experiences and express their emotions to others. The support group met six times, every other week, and each session lasted 1.5 hours. Each group had four to six members.

The group had two leaders: an oncology nurse specialist who was educated in sexology and had worked in a gynecologic oncology ward for several years and a psychotherapist with many years’ experience working with patients with cancer. She also had experience with leading support groups. The leaders’ roles were to provide structure and information, develop a safe climate, help support evolve, and promote group cohesion. A dietitian and a gynecologic oncologist each were invited to take part in one session.

The provision of support was combined with provision of information. Each session had a suggested theme for discussion. The sessions allowed time for patients to discuss experiences, emotions, problems, and problem solving. The themes for the six sessions were

- Receiving the diagnosis
- Diet and nutrition during treatment
- The concept of crisis and emotional reactions
- Physical changes caused by disease and treatment
- Impact of disease and treatment on body image and sexuality and the experience of fatigue
- Rehabilitation and how to go on with life.

### Participants and Setting

Thirteen adult patients who recently had been diagnosed with ovarian cancer and who had been members of three different support groups during fall 2002 or spring 2003 were invited to take part in the study. Ten patients accepted and were included in the study after giving informed consent. All participants spoke Swedish. The median age was 61. The study took place in the Department of Oncology at Sahlgrenska University Hospital, where patients from the city of Gothenburg as well as the western region of Sweden (population of 1.7 million) are referred.

### Procedure

All potential participants received verbal and written information about the study at the end of the final session of the support group program. Those who did not attend the final

session received the same written information by mail. The primary author called the patients one week later regarding their decisions to be included in the study. Two patients had been to only one session each and cited that as a reason for not wanting to take part in the study. One gave no reason for not wanting to participate.

An independent oncology nurse specialist collected data in semistructured interviews. All interviews except one were done during a single visit. Eight of the interviews were held five to nine weeks after the last session of the support group. Another interview was held 19 weeks after the last session, and the 10th participant’s interview was held 21 weeks after the last session. Participants were asked to describe important and useful experiences regarding participation in a support group, their expectations, and what they had experienced as supportive. Interviews were held at the hospital or in the participant’s home, depending on the participant’s preference. The interviews lasted an average of 50 minutes (range = 30–90 minutes) and were recorded on audiotape. The first five interviews were transcribed verbatim by the first author and the remaining five by a professional transcriber. The ethical committee at Goteborg University approved the study.

### Data Analysis

A qualitative approach using the constant comparison technique consistent with grounded theory (Glaser, 1978; Glaser & Strauss, 1967) was employed. Grounded theory was developed in the discipline of sociology and based on the theoretical framework of symbolic interactionism (Blumer, 1969). The purpose of a grounded theory study is to explore social processes with the goal of generating theory that is grounded in data (Carpenter, 1999; Glaser). Since the late 1990s, it has been an important research method in the study of nursing phenomena (Carpenter). In a grounded theory study, data collection and data analysis occur simultaneously. Data collected from interviews were simultaneously analyzed and continuously compared to categories that had been discovered in previous data (Glaser; Glaser & Strauss). Three levels of coding were used in the analysis. Initially, data were analyzed line by line, and substantive codes related to the content were identified. Subsequent analyses enabled the initial codes to represent more abstract groups of categories. In the third level of analysis, a higher level of abstraction resulted in a core category. At each stage of analysis, hypotheses were generated and tested against the data so that a core category and an explanatory theory arose. Data collection ended when no new information could be obtained (Schreiber, 2001).

### Evaluation Criteria

Grounded theory has specific criteria for judging the applicability of a theory: It must have fit and relevance, and it must work (Glaser, 1978). The criteria were achieved through openness, thoroughness in collecting the data, and consideration of all the data in the theory development phase. Also, the data were collected until theoretic saturation was obtained. To reduce possible bias during data collection and analysis, frequent discussions took place between the authors concerning the procedure for the interviews, the interviewer’s way of behaving toward the respondents, and the work with the analysis of the data. The analysis was done mainly by the primary author, although the second author confirmed the data analysis on a regular basis.



Memos were written regularly during the research process. They consisted of thoughts regarding the respondents' expressions, how the respondents' explanations fit together, and the researcher's experience of the interviews. The memos also included thoughts about patients' experiences to preserve hypotheses, hunches, and abstractions.

## Findings

Three categories of the experience of participation in support groups emerged from the data analysis: sharing experiences and emotions, exchanging informational support, and exchanging emotional support. The division into categories and dimensions is shown in Figure 1, and the statements that support the principles of division are shown in Table 1. The core category evolved to consist of an experience of being in the same boat.

### Being in the Same Boat

When joining the support group, the participants said that they felt frightened, anxious, lonely, sad, and insecure. They also had various physical symptoms. In the support group, they had an opportunity to share the cancer experience, to compare, to laugh, and to exchange knowledge and advice. They also had an opportunity to be supported emotionally. Supporting other members seemed to be nearly as important as receiving support. Sharing the cancer experience was of particular importance. Participants expressed that only those who are in a similar situation can personally appreciate and understand the experience of another patient with cancer. The group was a refuge where trust, openness, and a willingness to

create space for other participants were experienced. Feelings of trust and openness gave participants the freedom to express any emotions they wished.

### Sharing Experiences and Emotions

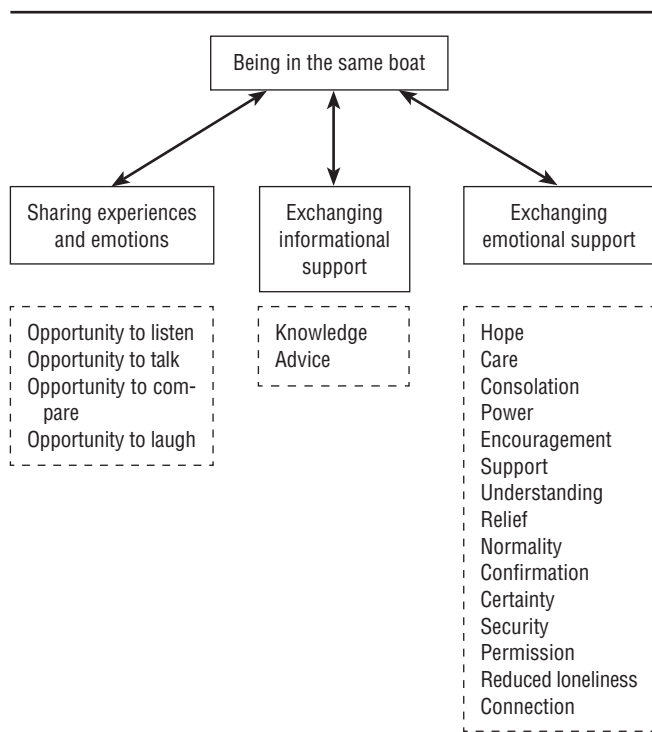
The experience of sharing experiences and emotions was divided into four dimensions: opportunities to listen, talk, compare, and laugh. Participants' descriptions of the opportunity to listen focused on the importance of listening to others telling their stories. A need to be listened to also was expressed. Listening to others was mainly positive but sometimes could be frightening when a member had gone through a difficult experience. Being able to talk and tell their stories was expressed as very important. Most participants felt free to talk about any subject while in the support group. They had a strong awareness of others' need to talk. A decision to stay silent and not take the opportunity to talk also was expressed. Participants experienced a need to compare symptoms, reactions, and emotions; they searched for commonalities. When symptoms or reactions differed, they had no cause for fear or worries. The last dimension of this category was the opportunity to laugh. Participants appreciated the support group as a place where they could laugh unexpectedly about the difficulties with which they were dealing.

### Exchanging Informational Support

The experience of exchanging informational support was divided into two dimensions: knowledge and advice. Most of the participants found that the knowledge exchanged in the support group was very positive. They wanted to know as much as possible about their diagnosis and treatment. Knowledge led to clarity and was experienced as supportive. For a few of the participants, some of the knowledge (e.g., information about cancer statistics) could be frightening. Giving and receiving advice constituted the second dimension of this category. Giving advice was described as helping others find their own way to handle the situation. Receiving advice was appreciated as support.

### Exchanging Emotional Support

The experience of exchanging emotional support was divided into 15 dimensions: hope, care, consolation, power, encouragement, support, understanding, relief, normality, confirmation, certainty, security, permission, reduced loneliness, and connection. Being in the support group gave participants feelings of hope that consisted of believing that they would have a future and that they could become well. The participants also expressed a feeling of being cared for, mainly by the group leaders. Participants received consolation from other members of the group and group leaders by sharing experiences and emotions. Many participants experienced feelings of power and strength to fight the disease as a result of being members of the group. Trying to give strength to each other was important. During group sessions, several participants felt encouraged or tried to encourage each other. A wish to support other group members was expressed. They wanted to do something to heal or help each other. The members had a feeling of understanding because they all had the same type of cancer. Sharing experiences and emotions with each other also resulted in a feeling of relief. Knowing that others had similar symptoms and reactions, which made them normal, was very important. Almost any



**Figure 1. Categories and Dimensions of Experiences of Participation in a Support Group for Women Recently Diagnosed With Ovarian Cancer**

**Table 1. Quotations That Support the Principles of Division**

Category	Quotations Supporting Categories and Dimensions
<b>Sharing experiences and emotions</b>	
Opportunity to listen	<p>You understand how important it is to listen to others. You may even have to calm down sometimes in order to listen to others.</p> <p>For me, the support group was more for listening. I feel that if I get this offer of help, even though I feel strong at the time, I still think that it's good to listen to what others say. Because I just don't know.</p>
Opportunity to talk	<p>Because it's like this: If you just came in to get your chemotherapy and then didn't talk to anyone, it wouldn't have been enough. It wouldn't have been enough. It's incredibly important to talk to everyone. For me, it's been incredibly important to talk and talk and talk and talk and talk. Permission to talk about this and that and the other thing. Incredibly important.</p> <p>Some people are always better at taking up space and better at talking. I would think so, though I didn't feel that. Of those who led this group such as [the group leader], she was good at getting others to talk by asking, "How are you feeling?" It's also about those leading the group, that they're good at it. But I did feel like I got space to talk.</p>
Opportunity to compare	<p>And then you get a bit of an "Aha!"—it can be like that; you learn there are people who are in a worse situation and that there can be others who experience things differently. . . . People believe that if you have cancer everyone reacts the same way, no matter what . . . and it really can be different.</p> <p>I thought that my situation wasn't so bad when I heard what it was like for others.</p>
Opportunity to laugh	<p>I probably hadn't understood how much it would mean for me to be able to sit and laugh at all these crazy things I did. . . . We sure did laugh a lot. We really did. I probably did not understand that it would mean so much just on that level.</p>
<b>Exchanging informational support</b>	
Knowledge	<p>In this support group, learning the facts is probably a positive thing. It doesn't create worry; rather, it creates understanding.</p> <p>Besides that, it was this knowledge that, in my opinion, I've probably appreciated most. Different phases, and what it can be like, and how it will be, or what it might be like. That they were all professionals then.</p>
Advice	<p>And then, of course, there was the good advice. You got loads of tips and advice from [the group leader] and from the doctor who was there. That was important.</p>
<b>Exchanging emotional support</b>	
Hope	<p>It's not just this hell, because going through chemotherapy is hell. It really is. That there's something afterwards. That you can get well. That's incredibly important. That's psychological. The group helps with that.</p>
Care	<p>But that I feel that they care about me, as well as about my children. [The group leader] could ask about how my children were doing and when I told about what happened with the dishes. . . . It was incredibly important. Really important. And just because it is an illness from which you can die. So it's important that there is someone who cares about you. So the group has many functions. It really does.</p> <p>And then there were the two group leaders. They were so nice, and they asked good questions. So you know that they remembered what we talked about last time. So it was nothing. . . . Yes, it was a little deep and you felt they were with you. And that was very good. That they cared about me or this or that particular person. And that . . . yes, that was good.</p>
Consolation	<p>But the heavy part, when you're in the middle of it all, those who are going through. . . . You can console each other there, and there is personnel like [the group leader] who came and could comfort you, that's incredibly important. That's incredibly important.</p> <p>So, I've never been afraid of dying, for example, and I've said that, too. I've been able to say that in the group, and if anyone found comfort in that, then it was good.</p> <p>It's comforting. It's comforting, because you need to hear that you are not the only one who feels so awful.</p>
Power	<p>This is about daring to give strength. It's about daring to give strength to each other and daring to say when you feel bad. You need strength, and it comes from the soul. It comes from the soul that you have the strength to believe, "I will get through this. This is not going to kill me. I'm going to kill it instead." That feeling, it comes from the soul. It comes from the soul and you get it. . . . You get power in the group.</p> <p>You get power, and you can give it back in some way. Because you've gone through something that you can give back. I can give strength back.</p>
Encouragement	<p>Cheering each other on. That's incredibly important for me. It's hard to say what's most important, because [the group] has many different functions that are important.</p>
Supportiveness	<p>But I feel that you should give as much as you can. Do as much as you can to help someone else to be able to handle things. I can only offer what I can. If that helps someone—if it helps someone just the slightest bit—then I can help, too.</p> <p>This part about self-healing, you get that in the group. For those who come to the group, despite everything, they want to give.</p>
Understanding	<p>The group is so important because they also have cancer. We have the same type of cancer. We could sit and talk about how it feels to have cancer, because no one else can do that. No one else can understand. Only those who have had cancer can understand.</p> <p>But then, no one knows what this means. The people in the support group know that. That's where the difference is. That they've experienced it themselves or are in the same, or about the same, situation.</p>

*(Continued on next page)*

**Table 1. Quotations That Support the Principles of Division (Continued)**

Category	Quotations Supporting Categories and Dimensions
Relief	<p>The part about healing. . . . For me, that's what you get in this group—understanding of each other's problems and that we are extremely little. We are all very little when it comes to this. Because it isn't just chemotherapy. It does its part. It does its part. You keep hoping that it will kill the cancer. But that isn't enough. That isn't enough. How you feel spiritually, that's at least as important. It is at least as important.</p> <p>I wouldn't go home and sit alone. . . . That would have smothered me. That would have smothered me. It would have drained me of my life energy. I have to talk things out; to talk about it to make it easier to bear. For me, it was easier to bear because I had the group.</p> <p>Yes, but with this you can get support and help, by sharing experiences. I think so. I mean that talking with someone, it makes it easier for the soul.</p>
Normality	<p>Now I can put up with this misery, because I know that it is normal.</p> <p>Like I said, you can have pain and you can have problems, as long as you know that it's normal and may even go away.</p> <p>That was the best part of it all. You came there, and maybe you had some new pain or symptom, and by the time you left and had everything explained, you realized that this is something we all have. All of us can have it. And it's completely normal. So it wasn't anything at all.</p>
Confirmation	<p>It was confirmation for me, and much of it was about confirmation. That's how it was for me, but I am not sure that's how it was for everyone.</p> <p>I think people want to have some kind of confirmation of how you've struggled, what good it's been, in some strange way. If someone says, "Of course, I feel sick every third day," or something like that, then you think, "Of course, okay. It's okay. I felt that way, too." Then you get a kind of confirmation.</p> <p>A large part was being able to process your sorrow together with the others, that feeling bad was allowed, and have this confirmed. A large part was getting confirmation, hearing that it is not just me.</p>
Certainty	<p>Because you're uncertain about a lot of things. You're really uncertain about why you feel the way you do. So there you could calm down. It's okay. Good. Now I know that this is how it is. Then you can calm down. But as long as you don't get confirmation that this really is the way it is, then you're just worried. And worrying is not good.</p> <p>If I were completely alone with my pain or whatever it was that I had, then I would become uncertain. A little nervous. Maybe a little afraid. Now I didn't have to be frightened because I knew that it was normal.</p>
Security	<p>You can have everything as long as you know that it will go away and that it's nothing out of the ordinary. Then you can stand anything at all. Because then it feels more secure. Then others have had it before me, and they've managed to survive. Then I'll manage, too.</p> <p>The support group, it was very, very good for us. Very good. A security. I went home calmer than when I arrived.</p>
Permission	<p>That it's permitted. That it's permitted. It's completely okay. It's completely okay to sit and cry and be like a dead person. Just don't be strong, because you can't be that. It's not possible.</p> <p>So it was allowed—it became allowed—to feel bad. You were allowed to cry. You were allowed to mourn. You were also allowed to say "death."</p> <p>Many things become permitted in the small group. . . . You can't just talk to anyone; you have to talk to someone who has had cancer. You know many. . . . There are some people who avoid you because they know that you have. . . . They don't have the strength to talk about it or whatever it is. But in that group, everything is permitted.</p>
Reduced loneliness	<p>It was probably the group's experiences of this, of treatments here, and the disease. It felt good to know that I wasn't alone.</p> <p>So then I thought, "Okay, those people thought the same way that I did" . . . and they had experienced this or that. And then you feel like you aren't as alone or anything.</p> <p>Because when you know that this is what it's like . . . when you can sit with the others and say, "Here's what it's like for me." And then they could say, "That's what it's like for me, too. This fourth day, it's just horrible. Sometimes this, sometimes that." And you think . . . "But that's good. I'm not the only one."</p>
Connection	<p>You become friends with the others. And we could sit and talk all together about each one's background.</p> <p>We were introduced to each other, and suddenly we felt like one big family.</p> <p>Yes, it was a bit like being in the same boat. It was more like that. You felt like you had extra contact.</p>

symptom or reaction could be accepted as long as they knew it was normal. For some of the participants, the main purpose of joining the group was to be confirmed or to be able to confirm others. Certainty, in this study, meant that participants felt less worried, frightened, and uncertain as they were participating in the support group. Being able to talk about their worries made them decrease. Being members of the group also made them feel more secure. Participants felt permitted to express any emotions, which in many cases could not be expressed anywhere else, and they also felt less lonely and isolated. The

last dimension of this category was connection. The group members experienced a connection that was expressed as a feeling of becoming like a big family. The connection happened only during group sessions. As soon as the group members left the session, the feeling diminished.

## Discussion

In the current study, participation in support groups was perceived as an opportunity to share the cancer experience and

emotions caused by the disease and to exchange information and emotional support. The support groups affirmed to the participants that they were sharing a special journey together. Sharing the same disease evolved to be a conditional prerequisite for sharing experiences, exchanging information, and experiencing emotional support in the group. Emotional support is important for most patients with cancer during illness and treatment and is reported to contribute to quality of life (Courtens, Stevens, Crebolder, & Philipsen, 1996). Courtens et al. showed that support groups are an important source of possible emotional support. The authors also suggested that support groups provide more information to patients with cancer.

The present study revealed that patients struggle for a sense of normality, which also has been found in other qualitative studies (Evans, 1995; Shaefer, Ladd, Lammers, & Echenberg, 1999). Participants often worried that their symptoms or reactions were abnormal. Worries about being abnormal as a consequence of their disease or treatment contributed to their fears and uncertainties. Confirming normality was of great importance. The support group was a refuge where trust, openness, and a willingness to create space for each other were experienced. Trust and openness enabled participants to express any emotions they wished. They were surprised at times at how easy it was to share personal experiences and emotions with the rest of the group. Cope (1995) found in her ethnographic study of the functions of a breast cancer support group that the participants had an unspoken understanding when they shared their personal feelings. Support groups seem to provide a nonthreatening atmosphere for discussing the cancer experience.

Understanding and supporting other members was very important for several participants in the study. Other authors have reported similar findings (Evans, 1995; Sivesind & Baile, 1997). According to the helper principle, the helper gains as much as the helped when dealing with a common problem (Killilea, 1976). The principle of self-help through helping others also is known from the numerous self-help groups in various countries around the world (Adamsen, 2002). Traditionally, self-help groups for patients with cancer have not had any professional involvement. Current empirical evidence has shown that nurses and other professionals have become an integral part of self-help groups, which provides new possibilities for a different and challenging professional function for oncology nurses (Adamsen & Rasmussen, 2003). Slevin et al. (1996) showed that most patients preferred professionally led support groups to self-help groups. Group leaders can have a significant influence on group efficacy (Bottomley, 1997b) and require many qualifications and specific knowledge on group facilitation.

According to Johnson and Lane (1993), healthcare professionals such as oncology nurses and oncology social workers are ideal for this position. In fact, the majority of support groups are led by these professionals (Presberg & Levenson, 1993). In the current study, the authors' different professions, backgrounds, and skills greatly helped to meet patients' needs. One advantage was that the authors could share the emotional burden as they set aside time to talk with each other after group sessions. This allowed them to support each other, assess the group process, and plan future group sessions. The psychotherapist's experience leading support groups was particularly beneficial to foster support among the group members. Several participants stated that they felt supported

and cared for, especially by the support group leaders. They believed that the group leaders confirmed every member of the group, were skilled at asking questions, gave good advice, and showed that they cared for each member of the group.

Effectively run cancer support groups have a potential therapeutic power (Johnson & Lane, 1993). The therapeutic process of support groups involves allowing patients to adjust to their diagnosis through sharing experiences, giving and receiving information, reducing social isolation, and improving relationships through better communication (Bottomley, 1997a). Unlike with psychotherapy groups, research on the psychotherapeutic dynamics in support groups has been limited so far. However, researchers believe that curative effects seen in traditional psychotherapy groups are similar to those in support groups (Cella & Yellen, 1993). According to Bottomley (1997a), cancer support groups are a potentially cost-effective way to help patients with cancer cope with their disease. Yet support groups generally have not been an integral part of cancer treatment; thus, only a small percentage of patients have attended them. However, with the increasing evidence of the benefits of group support, some can argue that it is unethical not to advocate and provide this kind of help for all patients who will accept it. Unfortunately, support groups often are short-lived. Hospitals often are reluctant to underwrite them (Pillon & Joannides, 1991), amounting to a cost-related barrier to incorporating support groups into standard cancer care (Cella & Yellen).

Coping is a process of self-regulation at emotional and behavioral levels (Weis, 2003). According to Weis, social support and the social environment of the patient directly influence the processes of emotional, cognitive, and behavioural coping strategies. Consistent with the concept of SOC, comprehensibility, manageability, and meaningfulness are the keys to patients' coping resources, necessary for dealing with situations of distress. The findings in the current study underscore that the importance of the feeling of "being in the same boat" as other patients, to share the cancer experience with people who may understand the situation, is central during cancer. The feeling of being in the same boat may be a tool that can help patients to reach higher levels of comprehensibility, manageability, and meaningfulness. The hypothesis will be tested in future studies.

Limited research has investigated support groups for women with ovarian cancer. The findings of the current study have provided an initial understanding of participation in support groups for women with this diagnosis. Further qualitative research is needed to obtain an understanding of the meaning of being in the same boat according to the concept of SOC and to explore, for example, if the feeling of hope is related to the experience of being in the same boat. Long-term effects of participation in support groups also need to be studied. Additional research into the needs of group support for women with recurrent ovarian cancer is also of great importance. Whether the intervention used in the current study could be used for other groups of patients with cancer (e.g., men with prostate cancer) also needs to be explored.

## Study Limitations

Data collected from interviews were analyzed simultaneously and compared continuously to categories that had emerged from previous data. The risk exists that interpretations of data were influenced by the fact that the first five interviews were



transcribed verbatim by the primary author and the remaining five by a professional transcriber. To minimize that risk, the primary author listened to the last five recorded interviews several times, following the manuscript, filling in missing words, and correcting indistinct passages. A process called "member checking," an invitation of respondents to assess whether the early analyses are accurate reflections, was not used. Instead, the authors will test their findings in a future study. The sample size in the present study is small; still, the study may have an impact as a background for further development of suggested theory.

## Implications for Nursing

The findings from the current study indicate that participation in a support group can be an important source of emotional and informational support for women recently diagnosed with ovarian cancer. Nurses should be aware of

the value of cancer support groups because they provide an opportunity for patients to share emotions and experiences and to exchange information and emotional support with others in a similar situation that are not found elsewhere.

Nursing interventions can make use of these results to show that patients benefit from confirmation that they experience normal symptoms or reactions. Nurses must be aware of patients' desires to be normal. Information and emotional support can reduce fear and uncertainty as well as help patients in their struggle for normality. Oncology nurses are in an ideal position to develop successful, ongoing support programs for patients with cancer because they are aware of the consequences of diagnosis and subsequent treatment. The cancer support program in this study can be used as a model when planning for extended emotional support and information.

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