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Qualitative Exploration of Healthcare Relationships Following Delayed Diagnosis of Ovarian Cancer and Subsequent Participation in Supportive-Expressive Group Therapy

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Patients with ovarian cancer frequently present to a general practitioner with initial symptoms (e.g., abdominal pain, bloating, incontinence, constipation) that are attributed to more common disorders (Koldjeski, Kirkpatrick, Swanson, Everett, & Brown, 2003; Smith et al., 2005; Wikborn, Pettersson, Silfversward, & Moberg, 1993). Koldjeski et al. (2005) asserted that primary physicians misdiagnose the early symptoms associated with ovarian cancer in 70%–75% of cases. Early diagnosis of the disease is crucial; if diagnosis is delayed and the cancer has metastasized, survival rates drop below 25% (Johns Hopkins Medical Institute, 2008). Only 19% of cases are diagnosed early, but almost 94% of these women survive for an average of five years (American Cancer Society [ACS], 2008). Diagnostic delay frequently is attributed to the vagueness of the general symptoms experienced in ovarian cancer; however, Goff, Mandel, Muntz, and Melancon (2000) found that 21% of patients attributed their diagnostic delay to physician attitude. As diagnostic delay increased, the proportion of women with this opinion rose to about 50%. Therefore, diagnostic delay may engender frustration, which, in turn, may affect patients' psychological well-being, navigation of the healthcare system, and willingness to engage in certain treatment processes.

Supportive-expressive group therapy (SEGT) was designed originally to facilitate coping with an advanced breast cancer diagnosis (Goodwin et al., 2001; Kissane et al., 2007; Spiegel et al., 2007). However, SEGT has been adapted for other patient groups, including those with ovarian cancer or multiple sclerosis (Bischoff, 2006; Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001). SEGT emphasizes the enhancement of patients' quality of life by providing an outlet to discuss emotionally charged

Purpose/Objectives: To explore the role of supportive-expressive group therapy (SEGT) in facilitating the development and quality of healthcare relationships in patients with ovarian cancer.

Research Approach: Qualitative, grounded theory, and comparative approach.

Setting: Tertiary care cancer center.

Sample: 6 patients with advanced ovarian cancer and 3 healthcare professionals.

Methodologic Approach: Patients participated in semistructured interviews that examined the nature of their healthcare relationships, diagnoses, and SEGT experience. The primary gynecologic oncologist and two nurses responsible for the care of the patients also were interviewed. Analysis of this qualitative study employed a grounded theory technique.

Main Research Variables: Patients' and healthcare professionals' perceptions of healthcare relationships.

Findings: Patients' negative diagnostic experiences were found to influence the quality of relationships with healthcare providers. However, the process appears to benefit from patient participation in SEGT. Patients perceived that SEGT helped facilitate communication between patients and professionals. Patients also indicated that SEGT led them to participate more actively in the treatment process. Professionals viewed patient participation in SEGT as a positive outlet for emotional expression, a source of psychological healing, and a tool that facilitated communication, collaboration, and understanding of medical treatment.

Conclusions: Participation in SEGT can advance communication and collaboration in medical care and provide opportunity and resources for psychological healing.

Interpretation: SEGT provides a vehicle to enhance the quality of life of patients with ovarian cancer by breaking down the common feeling of isolation, addressing women's frustration and resentment regarding delayed diagnosis, and enhancing relationships with healthcare providers to promote collaborative care in this patient population.

topics associated with cancer diagnoses and treatments with others who have similar experiences (Spiegel & Spira, 1991). Following SEGT, patients have reported reduced anxiety, stress, and interpersonal conflict (Fobair et al., 2002). In addition, participants reported improved mood, sleep, quality of life, and ability to cope with their cancer diagnoses (Edwards, Hailey, & Maxwell, 2004; Fobair et al.).

Researchers have found that support groups can influence healthcare relationships. Kissane et al. (2004) reported an increase in compliance with physician requests and treatment plans in patients who were participating in SEGT. Hitch, Fielding, and Llewelyn (1994) also noted that support groups involving collaboration with healthcare professionals resulted in improved communication with professionals and more positive orientations toward the healthcare system. Given the frustration that is likely to occur in individuals with a delayed ovarian cancer diagnosis, SEGT potentially heals damaged healthcare relationships and restores trust in the healthcare system. Another complicating factor is that women in this population typically are presented with the prognosis that they will die of their advanced ovarian cancer within a few months or years. SEGT processes can help to prepare these women by giving them an outlet to discuss death and dying as well as access to resources that may mend damaged healthcare relationships. As a result, the current study aimed to explore how diagnosis experiences and subsequent participation in SEGT affects the quality of healthcare relationships in patients with ovarian cancer.

Method

Participants

A minimum of six patient interviews from a homogeneous sample were necessary to ensure saturation of initial themes (Guest, Bunce, & Johnson, 2006). Eligibility criterion was attending four consecutive SEGT sessions. The sessions were facilitated by two registered clinical psychologists and were offered weekly in an open-ended format. Nine women actively participating in SEGT were approached by the study researchers after a weekly SEGT session. Six women consented to participate; three declined participation because they were too ill. The patients' healthcare professionals also were contacted to participate in the study to balance the patient perspective on the healthcare relationships. A gynecologic oncologist and two oncology nurses were approached directly. The healthcare professionals were responsible for the medical care of the women and were not participants in the SEGT group. Informed consent was obtained from patients and healthcare professionals.

Procedure

One-hour interviews were conducted with each SEGT participant and transcribed verbatim. Interview length was determined to be adequate for retrieving rich data while not being too onerous for patients who were undergoing treatment. Discussion explored patients' diagnostic experiences, SEGT involvement, and healthcare relationships. Example questions included, "Describe your diagnostic experience," and "How have you been impacted by your SEGT participation?" Specific questions relating to healthcare relationships included, "Describe your current healthcare relationships," "Can you think of ways in which your healthcare relationships and encounters with the healthcare system could be improved?" "In what ways are you satisfied with your relationships?" and "What have you learned about your role in your healthcare relationships?" After the patient interviews were completed, the relevant healthcare professionals were approached to participate in the study. Each healthcare professional also participated in a one-hour interview that explored their perceptions of SEGT as well as patient participation in SEGT. Interview questions included, "What is your understanding of the purpose of SEGT?" "Do you know when one of your patients is involved in the group?" "Are there any defining characteristics you notice about those patients who attend SEGT?" and "Do you think that SEGT is helpful or unhelpful in meeting the psychosocial needs of your patients?" All interviews were completed during a one-month period.

Analysis

Grounded theory analysis of interview data was conducted. Grounded theory often is used to explore the processes involved in healthcare patients' experiences (Strauss & Corbin, 1998). The constant comparative method of grounded theory emphasizes ongoing analysis and data collection; therefore, themes that emerged during the analysis of initial interviews were further explored in subsequent interviews, increasing the likelihood of saturation (Charmaz, 2006). In addition, initial interviews were compared to the new themes as they emerged in the analysis. Patients were encouraged to keep contact with the interviewer and had the opportunity to review the study findings; however, no participants commented on the analysis. Analysis was done by one investigator to maintain consistency but was discussed with the other investigator. Collected data also were compared with existing literature for discrepancies and consistencies, which is consistent with the comparative method. Themes were gleaned from the interviews, coded, and then organized hierarchically. Relationships among themes were determined and used to construct a theory about the

development of healthcare relationships in relation to the unique diagnosis processes and SEGT experiences of these participants (Charmaz; Strauss & Corbin).

Results

Participant Characteristics

Participants' mean age was 53 years; mean age at onset of ovarian cancer was 50 years. Four patients had experienced cancer recurrence at the time of the interview. Referral to SEGT was through direct approach by the group facilitators (i.e., psychologists) rather than the oncology professionals. Because of the maturity of this particular SEGT group, all participants had been attending the group for at least one year. Demographic details are not reported for the three healthcare professionals to protect anonymity.

Findings

A model of relationship development among participants is shown in Figure 1. Each category in the model is outlined in the following sections.

Relationship With General Practitioner

A patient's relationship with a general practitioner (either positive or negative) sets the stage for the diagnostic experience and, therefore, the emotional reaction to the experience. Diagnostic experiences may be perceived as positive or negative. Patients also identified that the experiences influenced their future interactions with the healthcare system and healthcare professionals.

Diagnostic Experience and Emotional Reaction to Diagnostic Experience

For participants whose cancer was detected coincidentally during another procedure, trust in their general practitioners was more likely to be retained. These women eventually understood that ovarian cancer, referred to as "the silent killer," often eludes accurate diagnosis. They realized that they were fortunate to have the disease diagnosed coincidentally. Although all participants indicated that they trusted their general practitioners initially, the trust often deteriorated in patients who experienced

misdiagnosis. Several patients changed general practitioners after they were misdiagnosed. The diagnostic delay and series of misdiagnoses led patients to question their general practitioners' methods. A patient commented, "I was frustrated with the things that were happening that my doctor didn't see." Another reported a similar mixture of emotions: "I was frustrated, worried, and stressed." One patient expressed losing respect for the professional who misdiagnosed her and neglected to take her concerns seriously. Another patient reported, "I still to this day can't figure out why they didn't call for a CAT [computed axial tomography] scan or something more major, even an MRI [magnetic resonance imaging] . . . anything." The notion extended beyond the general practitioner to other individuals involved in the diagnostic process.

[I had an] emergency room doctor who palpated this increasingly growing stomach, and I remember [him] saying, "Well, it's definitely gas; it's not fluid so that's a good thing." [Then] the gastrointestinal specialist palpated my abdomen, and just three taps and he said, "This is not gas, it's fluid, and it's serious."

The patients who had negative diagnostic experiences were more likely to react with mistrust, frustration, and anger. After changing physicians, one participant sought out her previous physician and expressed her concerns directly to the clinic. She reported her feelings after she sought out a new doctor. "I was pleased because I was so mad at [my general practitioner], I wanted to show up with my bald head and say, 'You screwed up.'"

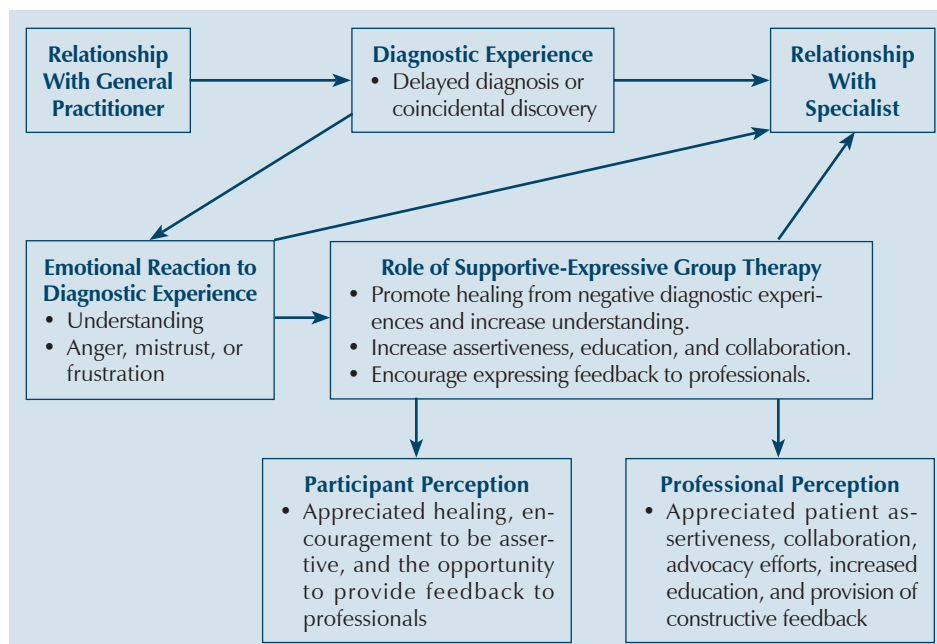


Figure 1. Model of Relationship Development

Identified Roles of Supportive-Expressive Group Therapy

Promotion of healing from negative diagnostic experience and increased understanding: All study participants eventually understood that ovarian cancer is very hard to diagnose. Although some women initially retained their anger and frustration about the diagnostic process, they were able to manage them in the SEGT group by discussing their stories with others, thus facilitating emotional healing. One participant came to a new understanding: "That's why they call it a 'practice,' because it's like they don't really know. They're educated guessers." Another woman had a particularly challenging time getting over the resentment she had toward her physician, stating, "Most of all, I had to take a while to become really charitable and be forgiving and understand that they are trying to do the best that they can do with the knowledge that they have." She mentioned how helpful it was for her to hear the stories of the other women's diagnoses in processing her opinion about her physician. She recalled,

In the support group, you hear how many more women . . . didn't have the cancer detected right away. And so then I thought, well, this is a cancer that is really tough and there is not enough knowledge about it.

Increased assertiveness, education, and collaboration: All participants acknowledged that they were much less assertive in their treatment before they began participating in the SEGT group. One woman said that the group was the impetus for her confidence and assertiveness: "I don't know if I would have done that without going to the support group, generally . . . I'm so unconditionally accepting of things." The following exemplars show similar experiences.

I don't feel I have ever been a very assertive person . . . but I have found my experience with the [group has] definitely helped me to be more assertive, especially because it's my life, it's my body, and you have to fight for what you want done.

I'd just said to him, because I felt confident from the group, "I just told you, it is different," and I said, "I'm not leaving here until I see Dr. X." And I, I think I might not have felt that confident to do that without having support of the group. Something . . . we talk about a lot is you've got to learn how to squeak. If there is something wrong, you squeak—you make noise until somebody hears. . . . The group has taught me how to squeak and given me boldness, and even showed me *where* to squeak. So that's invaluable and that's another one of the reasons why I just really think that if you

have ovarian cancer you have to go to this group. I don't think it's an option.

One patient commented on the novelty of her new opinion on her cancer care: "This business that you go in and see yourself as a partner with the doctors is fairly new. [The group facilitator] introduced us to the term being an 'im-patient' and not an 'inpatient.'" The concept refers to the idea that patients need to speak up about issues that are important to them rather than do nothing about them. The approach encouraged patients to listen intently, process more information, and provide valuable insight into their treatment process. In addition, the women were more aware and proactive in preventing instances in which patients may "slip through cracks." For example, a patient reported, "Communication issues [have] just been terrible . . . that's why I'm phoning all the time to find out. I'm just going to start bugging people." One woman described her frustration about staff sending her the wrong information and being unable to find her medication: "If this was my first time, if I had just been diagnosed, I would think, 'I would die in this place and they won't even notice.'"

All participants were able to describe their assertive behavior by citing examples in which they asked questions, researched alternative treatment ideas to bring to their physicians, or expressed concern about the quality of their cancer treatment. Despite becoming actively involved and collaborating in their treatment, some patients interestingly found a way to blame themselves for treatment problems by saying they should or could have asked more questions. Even complex medical procedures were considered something that the patient might have been able to influence had she asked more questions. For example, one patient took partial ownership for the incorrect establishment of a particular type of central line through which to deliver chemotherapy.

Healthcare professionals perceived that patients who attended SEGT were more assertive than most other patients. One professional commented on how patients with ovarian cancer "have every right to be demanding . . . [because] a lot of them have been left to late stage cancer." The healthcare professionals reported that SEGT participants came to appointments armed with more information and were able to ask more educated and thorough questions than patients who did not participate.

Another professional reported that patients with ovarian cancer are "realistic. I think they have a very good understanding of their cancers, especially the ones that participate in this supportive group." The characteristics were perceived positively by the gynecology-oncology staff, as treatment often was more collaborative in nature.

Professionals indicated that they appreciated patients who made a collaborative effort to advocate for ovarian cancer issues. Issues included limited public awareness of ovarian cancer symptoms, restricted availability of treatment and testing options, and lobbying for funding. Almost all members of the SEGT group had become active in advocacy issues in some capacity. Participating in such activities gave the women the feeling that they were active members of a team fighting for patients with ovarian cancer, acting as advocates for themselves and others and making a great contribution to the treatment of the disease. One professional reported that the participants have “a real . . . passion for what is happening, and for people, [saying], ‘What can I do to help the person behind me go through this?’” Therefore, the increase in advocacy also was perceived as collaborative.

Encouraged expression of feedback to professionals: Some participants expressed concerns about the way they may be perceived by their healthcare professionals and, in turn, about the quality of their treatment. Several women reported that they believed their physicians must “like” them and that they must be “good” to be provided the best care. One patient commented,

I think I am being a pretty good patient. I think I’m doing what I am supposed to be doing . . . whatever they tell me [laughs].

Another woman reported,

Sometimes there’s stuff you hold back on. When your life is in people’s hands you don’t want to piss them off. There is this irrational fear . . . and I think it’s a gender thing, that you have to be a good girl. . . . I know other people who have felt like this, too, that if they like you they’ll take better care of you. And that’s a very scary feeling. If you think, “Somehow, they’ve got to like me.” Often around my irritations about things, it will take a lot before I say [anything]. I am getting better at it, and I’m getting to trust that they won’t let me die just because I complain.

Consistent with the reluctance to share feedback, several participants felt that they should not complain about their symptoms unless the symptoms were potentially life threatening. In hindsight, the women commented that their reluctance to report was unwise because experiencing symptoms indicated a life-threatening situation.

[I had] terrible side effects. [I] didn’t know whether they were really more out of the ordinary, and there was reluctance on my part, I think, to question more of the symptoms, and I sort of downplayed it to some of the nurses just how bad I was feeling . . . perhaps some denial on my part.

I didn’t want to bother them. . . . And someone said, “Just phone [the nurse]. She’ll get things done for you.” And I thought, well, I don’t want to bother her, she’s so busy, but that was kind of just me. I don’t like to bother people about things.

As part of the SEGT group’s overall goal of improving healthcare relationships, group members were encouraged to overcome their fears and provide feedback to their healthcare professionals. Through group participation, the women found the courage to express their treatment concerns, despite a desire to be liked and perceived as “good” patients. Many participants approached the professional personally, whereas others felt more comfortable using the group facilitators as a resource to provide feedback. One woman commented on expressing feedback about her concerns to her physician. “It was my responsibility [to] the people that came after me. The group just helped me figure out what to do.” She felt that she must try to change the system so that the wrong doing would not recur for the next group of patients. Another woman commented on the group’s role in her ability to express her concerns.

It’s just a reminder that I can do this, I can bring this up, and that’s legitimate. To listen to how people have approached these things with doctors, trying to put things assertively rather than aggressively, therefore, I’m more likely to get a more open conversation going.

The healthcare professionals initially expressed concern that participants might use the group as an opportunity for nonconstructive gossip; however, patients continually reported that their conversations within and outside the group were progressive and improvement focused. Specific comments from healthcare professionals included, “The supportive group is very useful because I think it allows these women to talk to each other. It allows them to see how well others are doing,” and, “The support group allows people to express some of their misgivings [and] anger [but] also talk about the positive.”

Healthcare professionals appreciated the SEGT participants’ willingness to share constructive feedback with them. One professional stated,

If you don’t tell us, we can’t change it. I don’t *want* or *like* to hear it . . . that we’re not doing things right . . . but I must hear it for the sake of not only her, but everybody else.

Another professional refuted patients’ fears that they might receive differential quality of care for expressing concerns.

Whether a patient is demanding or irritating or rude, I don’t think it disrupts the care, it’s just that maybe we’re not as happy to see them when they come in, but they still get the same treatment.

Discussion

A patient's healthcare relationship in the specialist setting is influenced by his or her emotional reaction to and ability to process the diagnostic experience. Participants felt that patients with ovarian cancer uniquely experience under-recognition within the healthcare system and, often, significant diagnostic delay (ACS, 2008; Goff et al., 2000; Johns Hopkins Medical Institute, 2008). As a result, survival times for patients are significantly reduced, which can engender intense frustration in patients. Participation in SEGT improves a patient's navigation through the healthcare system by advancing communication between patients and professionals and providing opportunities and resources to deal with psychological and emotional issues surrounding diagnosis and treatment. Specifically, SEGT provides the opportunity to work toward emotional healing by encouraging the patient to develop a new sense of understanding regarding the challenges of diagnosing ovarian cancer. SEGT participants become more educated, assertive, and interested in collaborating on treatment decisions, and healthcare professionals appreciate the patients' increased assertiveness and collaborative attitudes. Professionals commented on the helpfulness of the group at informing and educating participants and appreciated constructive feedback and efforts toward patient advocacy. Therefore, participation in SEGT facilitates the development of successful relationships and allows patients to heal from negative diagnostic experiences.

Consistent with previous research, relevant mediators of successful healthcare relationships were found to include communication, trust, patient assertiveness, and collaboration (Anderson & Urban, 1997; Bell, Kravitz, Thom, Krupat, & Azari, 2002; Shaw et al., 2007; Shenolikar, Blakrishnan, & Hall, 2004; Street, Gordon, Ward, Krupat, & Kravitz, 2005). However, the relationships are complicated by patients' previous negative diagnostic experiences. The ideal relationship, as supported by SEGT, includes healing from the previous diagnostic experience, is open and collaborative, and is composed of patients who are educated and encouraged to be assertive.

Patients who participate in SEGT are likely to have good healthcare relationships. In the future, solutions must be implemented with regard to detecting ovarian cancer at earlier stages. Until detection improves, the diagnostic delay likely will continue to burden the development of successful healthcare relationships. SEGT was found to be effective at improving such relationships and, therefore, should be applied to other groups of patients with ovarian cancer who are at risk for strained healthcare relationships. Future patients with ovarian cancer also should benefit from the experience of SEGT participation.

Limitations and Direction for Future Research

Biases may have existed in the study sample. The sample size was small; only six patients were eligible to participate in the interviews. Given that the current study used the only known SEGT group specific to ovarian cancer, the group processes of future SEGT groups should be studied. Although the depth of discussion was enriched by the fact that all patients were seen by the same group of healthcare professionals, the range of discussion was limited. This study explored the nature of how SEGT processes affect relationships; therefore, future evaluative studies should assess other outcomes beyond healthcare relationships or compare SEGT with other forms of psychotherapy. Lastly, in regard to diagnostic delay, promising advances have been reported in the early detection of ovarian cancer (Evans, Ziebland, & McPherson, 2007). As a result, the relationship development of individuals who avoid diagnostic delay should be studied.

Several efforts were made to establish the validity of the current study's data. Because the study's principal investigator also was an SEGT facilitator, a coinvestigator conducted and analyzed the interviews to help decrease any potential biases in patient reporting. Of note, participants provided a balanced account of the positive and negative aspects of their healthcare relationships and SEGT experiences. Patients were encouraged to keep contact with the interviewer, and one participant followed up with the researchers to share additional information. The data collected also were compared with the existing literature for discrepancies and consistencies.

Implications for Practice

Researchers, therapists, and healthcare professionals should seek to increase patients' quality of life in ovarian cancer. SEGT clearly is effective at breaking down the sense of isolation that often accompanies the experience of illness and suffering. By aligning a support group of women who have had similar experiences, providing necessary education, and working to improve the maintenance of healthcare relationships, SEGT can enhance the healthcare experience of patients with ovarian cancer.

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