

A Qualitative Study of an Internet-Based Support Group for Women with Sexual Distress Due to Gynecologic Cancer

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Abstract Internet-based support groups for cancer patients have been studied extensively; very few have focused on gynecologic cancer. We pilot-tested a web-based support group for gynecologic cancer patients and assessed women's perceptions of the intervention. Twenty-seven gynecologic cancer patients were randomized to an immediate intervention or a waitlist control group. Women participated in a 12-week, web-based support group focusing on sexuality-related topics. Semi-structured interviews were conducted to investigate the feasibility and efficacy of the intervention. Women reported benefits to participating in the intervention, including receiving support from group members and moderators, increased emotional well-being, improved feelings of body image and sexuality, and comfort in discussing sexuality online. Web-based support groups are both feasible and accepted by gynecologic cancer

patients with psychosexual distress. The online format provided women with easy access to the support group and anonymity in discussing psychosexual concerns. Women with gynecologic cancer may benefit from participating in online support groups which provide an environment of relative anonymity to discuss psychosexual concerns.

Keywords Gynecologic cancer · Internet support groups · Psychosexual concerns

Introduction

Gynecologic cancer is the fourth most common cancer in women [1], estimating 8,400 new cases of gynecologic cancer diagnosed in Canada during 2010 [2]. Although the

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psychosocial and psychosexual problems of gynecologic cancer patients have been well documented [3–9], the associated psychosocial interventions for this population are rarely described [10–17].

Internet groups for cancer patients are readily available and widely used [18], but few focus on gynecologic cancer. Empirical evaluations of Internet cancer support groups have also emerged [19, 20], including a randomized clinical trial, which found that a professionally led, web-based, support group reduced distress in breast cancer patients [20]. Whether similar benefits will be found for gynecologic cancer patients is unknown. Distressed cancer patients may be more likely to participate in Internet support groups than face-to-face groups [21], possibly due to their anonymity, which makes it easier to discuss highly personal issues [22]. Given the sensitive nature of psychosexual concerns among gynecologic cancer patients and the relative anonymity of an online support group, an Internet-based support group may be especially appealing to gynecologic cancer patients with psychosexual distress.

The purpose of the study was to pilot-test a web-based support group for women with psychosexual distress due to gynecologic cancer. The web-based support group intervention was professionally moderated, addressing weekly topics related to gynecologic cancer: its treatment and side effects, managing the impact on intimate relationships, self and body image, and sexual functioning. Participants were also provided with information on each weekly topic as well as recommended websites. Here, we focus on the qualitative component of the study investigating participants' experiences with the intervention and their perceptions of its efficacy. The details of the primary quantitative measures, survey instruments, analysis, and outcomes will be published in another manuscript.

Methods

This study is a qualitative investigation using semi-structured interviews to examine the feasibility and efficacy of a structured, online support group for women with gynecologic cancers experiencing sexual distress post treatment.

Participants

Women who were treated with surgery, chemotherapy, and/or radiation for gynecologic cancer and were not receiving active treatment were eligible for this study. Other inclusion criteria were as follows: cancer-free for a minimum of 3 months; no more than 5 years post-diagnosis; willing to discuss psychosexual concerns; at

least 18 years of age; having access to the Internet; speak, read, and write in English; have a score of >24 on the Revised Female Sexual Distress Scale (FSDS-R); and provide informed consent. Participants were not excluded based on computer literacy, and private instruction was provided when necessary.

Participants were recruited from gynecologic oncology outpatient clinics at the Princess Margaret Hospital and the Odette Cancer Center, two tertiary care cancer centers in Toronto, Ontario, Canada. Twenty-seven women were randomly assigned to receive immediate ($n=13$) or waitlist intervention ($n=14$). Women assigned to the waitlist condition received the intervention approximately 4 months following baseline assessment.

Intervention

The intervention was a 12-week, web-based support group called *GyneGals*, consisting of an asynchronous support group (e.g., bulletin board format or forum) with discussion centered on specific topics each week. Participants could also spontaneously raise topics of importance to them. The intervention was based on the supportive–expressive group therapy model [23], which encourages open and honest expression of thoughts and emotions, receiving and offering support, and learning new ways to cope. The intervention was facilitated by two clinical psychologists with expertise in facilitating psycho-oncology and sexuality groups. Forum content was monitored daily, and discussions relevant to the weekly topic were encouraged. Daily monitoring of postings enabled facilitators to ensure that any potentially non-productive discussions or crises were quickly attended to and that the appropriate actions were taken. Participants were asked to keep all group discussions confidential.

The program introduced a new topic weekly. The themes were adapted from Spiegel and Classen's book on support groups for cancer patients [23] and Schover's book "Sexuality and Fertility After Cancer" [24]. Web pages were developed to present materials on gynecologic cancer and sexuality. Materials addressed the concerns of heterosexual and lesbian women and women with and without sexual partners. The intervention also included one scheduled, 90-min synchronous, live chat session during week 10 with a gynecologic oncologist, a radiation oncologist and the forum facilitators. Discussions on *GyneGals* covered the following topics: information on types of gynecologic cancer, emotional challenges, sexuality and body image issues, communicating with family members and friends about cancer, dealing with early menopause, self-identity issues, and management of symptoms such as pain, fatigue, vaginal changes, and incontinence. An enhanced description and discussion of

the specific weekly discussion topics will be reported elsewhere.

The two platforms that were used to conduct the study were Caring Voices (www.CaringVoices.ca) and Women's Health Matters (www.womenshealthmatters.ca) websites. Caring Voices is a social networking platform that hosted the private forums and the live chat. The Women's Health Matters website provided the education content to support the asynchronous discussion groups.

Semi-Structured Interviews

Participants were invited to participate in a semi-structured interview at the end of the intervention period. The formal, semi-structured debriefing interviews were conducted by a member of the research team to explore the study participants' experiences with the intervention. Interviews were audio-recorded and transcribed. Participants were asked a series of 12 open-ended questions which were meant to elicit feedback on participants' experiences with website registration and ease of usage, program topics, usefulness of the information provided, helpfulness of forum moderators and support group members, and benefits and satisfaction with the study intervention. Interviews were conducted over the telephone and lasted approximately 30 min.

Data Analysis

The text from the transcribed participant interviews was coded (by key terms and phrases) and sorted by theme (parent and sub-theme). Qualitative data analysis was completed independently by two different members of the research team (MT and DW). Emerging themes from the two analyses were compared and contrasted and reviewers worked to achieve consensus. A total of seven parent themes and several sub-themes were agreed upon. NVivo 8 software was used to facilitate the coding and sorting process.

Results

Twelve (44%) women participated in the debriefing interviews. Three women were in the treatment condition, and nine women were in the waitlist condition; all women were interviewed after participating in the intervention. The majority of women (83%) who participated in the debriefing interviews were Caucasian, in a relationship, and had secondary school education (Table 1). The mean age of interviewees was 45.4, ranging from 37 to 58 years old.

The seven major themes identified through from participant transcripts included: (1) general delivery of the

intervention; (2) perceived helpfulness of a supportive environment; (3) improved feelings about body image and sexuality; (4) comfort and anonymity in discussing sexual issues; (5) information needs; (6) barriers to participation; and (7) enhanced quality of life.

General Delivery of Intervention

Registration and Usage

Accessing and using the online components of *GyneGals* was not difficult. Participation usage varied from logging on at least once a week to logging in multiple times a day. Frequent users were excited to view responses from the group and checked regularly to view these, "it was a nice thing that it was there on a daily basis if I wanted to post anything." Participants also found it easy to access and navigate the resources on the *Women's Health Matters* website and to post questions in the forum.

Program Topics

Participants reported that the most helpful topic was, "Has treatment changed your body image?" (week 6 topic) as it was relevant to their current situation, "It pertains to my case, specifically. It... it just gave me some information about menopause and body image that I didn't really... I wasn't really dealing with properly. Or wasn't aware of. So it helped me." Other helpful topics included: "Did cancer treatment change your sex life?," "Let's talk," "Coping with sudden menopause," "Finding a new normal, who am I now," and "Enhancing intimacy and sexuality in your relationships." For participants who were not in a sexual relationship, the topics pertaining to sexuality and intimacy were perceived as less helpful.

Live Chat

Participants had mixed reactions to the live chat sessions. For those for whom synchronous computer mediated communication was a new skill, the experience was "interesting," and there was an expressed desire for more or longer live chat sessions. The fast pace of the chats was a challenge; for some "...it [was] a bit difficult to keep up" which impacted on the perceived helpfulness of the session.

Intervention Format

Women were generally satisfied with the online forums. It was suggested that a more "conversational" approach could have improved the experience, and this could be supported through "live interface via conference call."

Table 1 Participant demographics

Participant demographics	Number of patients*
Highest level of education	
Secondary school	1
Some college	5
Trade school	1
Bachelor's degree	4
Some graduate school	1
Relationship status	
Never married	1
Common law partner	3
Married or in a relationship similar to marriage	8
Racial/ethnic background	
White/European	10
South American	1
Filipino	1
Primary site of disease	
Endometrium/Uterus	4
Cervix	6
Ovary	2
Disease stage	
I	7
II	3
III	2

Other suggestions to improve accessibility of the content included increasing the font size of the forums and using more visual aids such as body diagrams.

Timing

It was commonly believed that 12 weeks was “just right” for the length of the intervention. The benefits of extending the length and timing of the intervention were explored by participants. It was suggested that the intervention could be most beneficial when survivors were just finishing active treatment. Participating in this type of support group closer to the treatment period could give women “more of an idea of what is ahead of them and that might help them get through their relationships and how they feel about themselves.” The notion of having a “permanent chat forum” so that group members could log in anytime was also suggested.

Overall Satisfaction

Participants were satisfied or “very satisfied” with their experience with *GyneGals*. Participation in the group was very well received: “I was 150% glad” to participate. There was a willingness to recommend the support group to others and participate again if given the opportunity.

Perceived Helpfulness of a Supportive Environment

Perceived Support from Group Members

The supportive online community was perceived as helpful by the participants. Specific group members helped to “define” the experience for others through their responsiveness and willingness to participate in the group. The variety of personal experiences shared by the group enriched the interactions and participants were able to get “different experiences and suggestions, not only to hear from the administrators, but people who are dealing with it everyday.” Although the level of participation from the group was not uniform, and there was a desire for increased participation from some group members, participants expressed high regard for their group and described the others as “helpful” and “supportive.”

Connecting with others and sharing experiences was a dominant theme expressed by participants. Participants came to understand that they were not alone in dealing with cancer-related issues and felt that their concerns were validated by other group members who shared similar experiences. “[I]t was more just knowing that ... I’m not unusual in this particular situation. That this is normal given what I’ve gone through, so that’s the big thing to learn.” Or, “it just kind of opened my eyes and [I] realize

that there are other people going through the same thing.” Women felt that the experience was beneficial because they could talk with people who could relate to them: “they [referring to those without cancer] don’t get the fear and everything, whereas the women [online], they’ve really got that.” Women also appreciated the willingness of other participants to talk about the challenges they had experienced.

Group members also helped each other cope with their emotions. Participants appreciated hearing different perspectives on similar issues and coping strategies. The emotional support helped group members to open up and communicate with others which enhanced their ability to cope. Women gained insights on self-acceptance, dealing with problems, and moving on. “This is how it is and you sort of move on because I still have the rest of my life to live. So this is my new normal.” Specific areas for emotional support were lacking, such as the emotional aspects of dealing with infertility.

Role of the Moderators

Moderators were well received by the participants. They were found to be both very supportive and knowledgeable. Participants valued the moderators as they were able to “frame things and make things ... that you can’t make sense of ... clarified.” They found that they “made you think more deeply about some things or think about things a little bit differently or point out maybe something that you’d said, what that might have meant, or what did you mean.” They were experienced as “help(ing) to keep us on track” and they appreciated knowing “they were there and listening but they didn’t get in the way of anything.”

Benefits of Non-Active Participation (Lurking)

Participants found value in reading what others had posted even without posting themselves. When asked “And what did you primarily use the forum for? Was it to post information or to read postings by other members?” several participants admitted to posting only a few times while primarily using *GyneGals* for reading other people’s posts. One participant disclosed that she was not sure how to post so she was only “reading those things, but not posting anything.” Although there were participants who posted only a few times, getting a response to their posts helped them to feel supported in problem solving. When asked about the helpfulness and relevance of the information posted by others in the group, one participant said “Some of it was and some of it wasn’t relevant to me. But there were some instances where I could...whatever that person had posted, I could kind of understand. So in that term, it kind of helped.”

Improvements in Emotional Well-Being and Quality of Life

Women shared how the group helped them to gain confidence in themselves: it was beneficial in that it helped them to “gain some courage, and feel less lonely.” There was a shared experience of an enhanced quality of life that related to “acceptance of” and “confidence in” themselves. Participants reported the ability to “... get some things off my chest because up until then I wasn’t able to. I didn’t have that avenue.” Having feelings and experiences validated was also beneficial, “[it] helped me validate my feelings and my experiences.” There was, however, a counterpoint theme that the group itself could not influence quality of life because improvements in quality of life have to come from within the individual; as one participant said, “a group isn’t going to enhance my quality of life. I have to do that myself.”

Improved Feelings About Body Image and Sexuality

Participants felt that it was good that the topic of sexuality was discussed and felt that the web-based support group improved how they felt about their body and their feelings about being a sexual person. “I think I’ve been a lot more gentle with myself... not expecting it all to be better right away and just concentrating on trying to make little changes rather than feeling that I should be a totally different sexual person at this point in my life.” By participating in the support group, women who did not currently see themselves as sexual beings also came to realize that this was “okay.” Participants said that they would recommend the support group to other women who were dealing with body image and sexuality issues.

Comfort and Anonymity in Discussing Sexual Issues

Women generally felt comfortable talking about sexual issues online. “It was fine because it’s not like I knew these people or would ever see them so I didn’t really have to be embarrassed. So it was kind of like, this is how it is, this is what I’m going through and I felt totally comfortable.” The online format allowed participants to protect their anonymity: this was viewed as a benefit over face-to-face communication. This anonymity also made it easier to ask questions. “I think in the beginning, it’s easier ... over the Internet... it’s an easy forum to just ask your questions.” For those who were very comfortable discussing sexuality, they felt they would be just as comfortable discussing these issues in person as they were online. Sexuality did remain a difficult topic for participants to speak about: “it’s just a difficult thing for me to talk about...it’s outside of my comfort zone.” Being able to learn from others’ experiences was

comforting and helpful to those who remained uncomfortable discussing sex.

Information Needs

Participants found information presented on the support group relevant, useful, interesting, and abundant. Participants commented on the comprehensiveness of the information; it “touched on everything that had ever been going through my head.” Despite the perceived abundance of information, women still wanted more information about the effects of radiation, diet-related issues, psychological aspects of survivorship, such as handling the loss of fertility, and long-term issues related to complications and procedures. One woman suggested that there should be more discussion about the “anticipation of going in for follow-up exams, the fears and concerns around that and how to make best use of the time.” Another woman saw the support group as “a place to contact each other” rather than as a place to gather information.

Barriers to Participation

The main reason participants gave for not accessing the online intervention as much as they wanted to was being occupied with other activities such as checking personal emails, taking care of their family or other life responsibilities (e.g., new job). Fatigue was also raised as a reason why women did not participate on the support group as much as they would have liked to.

Discussion

Web-based support groups can be helpful in addressing the psychosexual concerns of women post-treatment for gynecologic cancers. Results of this study suggest that there are benefits to participating in a moderated virtual group. The most striking benefit was the importance of the peer-to-peer support and the mutual validation and support that was shared by members of the group. This was enhanced by the presence of the professional moderators who were able to bring credibility and guidance to the group when needed. Other benefits included access to easy-to-understand resources that were relevant to participants. As a result of participating in this intervention, participants reported an enhanced emotional well-being and quality-of-life. This overall feeling of improvement in well-being could be related to the increased exposure to emotional support, new knowledge, and coping strategies acquired from other group members, and the expressed improvements in their perceptions of body image, sexuality, and intimate relationships. It has been well documented that involvement in

support groups by people with cancer has psychosocial benefit [25]. The benefits of the shared experience expressed in this study and realization that others have experienced similar feelings is consistent with the findings of a previous study in breast cancer. Results from that study suggest that participating in an Internet-based support group can help survivors realize that others were facing similar circumstances to their own. The group experience helped participants to cope with emotional challenges [20]; this is consistent with the small body of literature on online cancer support groups. A review of the literature on online cancer support groups in 2003 found that nine of the 10 studies reviewed concluded that online cancer support groups were successful in helping people cope with their disease [26].

There were mixed levels of involvement from participants in both *GyneGals* groups, with the waitlist group being far more active than the intervention group. Although not all participants were actively engaged in posting during the 12-week intervention period, they did still benefit from the more passive participation through “lurking.” This behavior is not uncommon in online communities [27]. Lurkers who do not post to online communities do seek answers to their questions through these communities [27]. The literature suggests that the most common explanations for not posting include not needing to post, wanting to know more about the group before actively participating, a belief that they are more helpful by not posting, poor usability, and not being comfortable with the group dynamic [27]. In this intervention, usability was stated as one of the reasons for not posting. However, during the intervention period, there was enough active participation that the active and responsive interaction helped to contribute to building a supportive online atmosphere. This ongoing dialog was beneficial to those participants who chose to be more passive participants through their “lurking.” The lack of a unified level of participation was acknowledged by participants who expressed a desire to see more participation from other group members and indicated that the experience would have been more beneficial if members of their group had participated more regularly. These findings suggest that group participation rates have an impact on satisfaction with an online support group. This is supported by the literature that suggests that overall satisfaction with online communities is higher for active participants than for lurkers [27].

There are clear benefits of offering this type of support group online. The asynchronous approach was advantageous because it allowed women to participate at their leisure and according to their individual and life schedules. Although participating in a web-based support group was a new experience for many women, the majority of participants did not have trouble accessing the forum or live chat. In addition, they enjoyed the experience and described

aspects such as the live chat as an important component of the intervention. For some, the opportunity to try something new helped to improve how they felt about themselves because they were able to express themselves in a different way. There still were, however, acknowledged barriers to participating in this type of intervention. Usability was raised as a concern, and participation was influenced by competing responsibilities and obligations.

In general, participants felt comfortable discussing sexual issues online, consistent with a previous study where breast cancer survivors felt comfortable in discussing sexual concerns [20]. Participants who would not normally discuss or ask questions related to sexuality found it easier to do so through the web-based support group. Most women also felt more open to discussing sexual issues online rather than in a face-to-face setting, similar to research reporting that distressed cancer patients are more likely to participate in Internet support groups rather than face-to-face groups [21]. It is likely that women were more comfortable discussing sexual issues online because it provided more anonymity than a face-to-face support group, consistent with a previous study in which cancer patients perceived the anonymity available on web-based support groups to be advantageous [28]. The anonymity of an online-based group also appears to give participants the comfort to ask what they really want to know without worrying about what others may think of them.

Limitations

There are several limitations to this study. A small number of women participated in the debriefing interviews (<50% of study participants), raising the possibility that only those who felt positively about the forum chose to participate in the debriefing interviews. There was a higher rate of participation in the debriefing interviews from the second intervention group, which had more actively participating women. The intermittent nature of forum postings was difficult for some participants to keep track of. Participants' experiences may also be highly dependent on the willingness of other group members to share their experiences.

Conclusion

The present study highlights the potential benefits of a web-based intervention for gynecologic cancer patients coping with concerns related to body image and sexuality. This online intervention has been demonstrated to be feasible and appears to provide participants a safe environment to discuss sensitive issues and to discuss issues that they might not explore in a face-to-face environment. The active participation rate affected women's experience and perceived value of the

intervention. Several barriers to participation were identified including competing priorities, fatigue, and the strain of reading materials on a computer screen. Participants did perceive an improved quality of life and support gained through this online intervention. The next phase of research will focus on a randomized control study to explore the effectiveness of the intervention in a larger group of survivors of gynecologic cancers.

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