

Perceptions regarding online support, illness, information, and awareness of women with cancer

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ABSTRACT

The purpose of the study was to examine the perceptions of women diagnosed with gynecologic cancers or pre-cancers regarding online support, illness, information and awareness. The study contributed to the literature regarding online support for women with gynecologic cancers and pre-cancers. The data were analyzed using the descriptive univariate analysis method of frequency distribution presented in percentages. Out of a population of 472 members of an online support group for women with gynecologic cancers and pre-cancers, 379 (80%) participated in the study. The results indicated that the experiences, both physical and emotional, of the women in these groups were more similar than different. Conclusions and recommendations based on the findings in this study indicated online support groups offer the advantage of having many ongoing conversations at one time, and women participating in groups can choose which conversation is applicable to them. In doing so, many needs are met by having multiple topics of discussion encompassing a variety of experiences, stages of disease and recovery, and a wide range of emotional needs.

Keywords: Online support groups, perceptions regarding online support, cancer groups

INTRODUCTION

According to Klemm (2012) social support has been found to have a positive effect on cancer patients' health. In fact, in their study on why Finnish cancer patients choose the Internet as a source of social support, Yli-uotila, Rantanen, & Suominen (2013), indicated that the "initial stimuli to use the Internet as a source of social support were the ease of communication and access to information as well as the need for emotional and informational support" (p. 264).

Internet users in North America totaled 246,402,574 [in 2008], representing 74% of the total population, and worldwide users exceeded 1,407,724,920 (Sutton & Raines, 2008). Sutton and Raines (2008) have argued that the Internet is increasingly becoming a routine part of daily life in the United States, and the influence of the Internet, regarding how people manage health and illness experiences, cannot be ignored. According to the Pew Internet and American Life Project (as cited in Sutton & Raines, 2008) daily use of the Internet in the U.S. increased from 52 million in 2000 to 70 million in 2004 (a 37% increase) and that in 2005, 93 million Americans sought health-related information on the Internet and 36 million joined online support groups.

The van Uden-Kraan, Drossaert, and Taal (as cited in Sutton & Raines, 2008) qualitative study (N=32) found that participation in an online support group was an empowering process for the participants. The Eo and Chee study (as cited in Sutton & Raines, 2008) with cancer patients found that Internet support group participants were more seriously ill than traditional support group participants. The Aslam study (as cited in Sutton & Raines, 2008) also found that over 60% of the participants knew of health-related websites and 68% reported that home was the most common place to access the Internet.

Ford-Martin (2008) concluded that there are benefits to online self-help groups such as anonymity, personal empowerment, the break down of any barriers caused by race, cultural differences, physical disabilities and age differences, the lack of dues or fees, relief from emotional isolation, and promotion of self-esteem. Moreover, she asserted that one of the most attractive features of online support is accessibility, which is available 24/7. Additionally, she concluded that an essential feature of many self-help groups is introspection, which may be beneficial to those who are struggling to come to terms with difficult thoughts and emotions. As such "the use of online resources promotes personal empowerment because informed cancer survivors with good social support are more active and optimistic in their treatment and recovery" (Hong, Pena-Purcell, & Ory, 2012, p. 289).

As noted by several authors, women with gynecologic cancers and pre-cancers have concerns unique to their conditions, such as sexual dysfunction morbidity or mortality; infertility; premature menopause and aging; and even shame stemming from the stigma associated with female reproductive cancer (Pearman, 2003; Woman to Woman, 2008). Other concerns for survivors of female cancers are physical alterations, gender identity issues, and body image changes that can result from surgery and other treatments (Anderson & Lutgendorf, 1997).

Because of the physical, social, and life maintenance issues, researchers have been prompted to investigate the quality of life (QOL) aspects of cancer survivors, which led to the study of the emotional aspects of dealing with gynecologic cancer by several

researchers (Anderson & Lutgendorf, 1997; Barnett, 2007; Gotheridge & Dresner, 2002; Pearman, 2003; Puccio, 2007; Woman to Woman, 2008). As described by Cella and Cherin (1988), the patients' appraisal of, and satisfaction with, their current level of functioning as compared with what they perceive to be possible or ideal is the working definition of QOL for cancer patients (Anderson & Lutgendorf, 1997).

Notably, Pearman (2003) reported that his search of the literature in MEDLINE produced relatively few research studies on QOL in the gynecologic cancer patient and that the conclusions were conflicting. Pearman also concluded, as did Anderson and Lutgendorf (1997), that the reasons for many of the conflicting results in the literature might be too many possible variables for which to account in any given study. These variables include the wide range of gynecologic conditions and degrees of disease, the numerous treatment options and the varying severity, the range of demographics, such as age, location, and educational levels, and the patient's degree of social support. However, these authors concluded that attention to the physical and emotional conditions was important for the overall health and well-being of cancer patients and survivors. Moreover, several researchers have suggested that support and support groups are important, even vital, to a woman's coping with all stages of disease and recovery (Boscaglia & Clarke, 2007; Butow, Kirsten, Ussher, Wain, Sandoval, Hobbs, & Stenlake, 2007; Hodgkinson, Butow, Fuchs, Hunt, Stenlake, Hobbs, & Wain, 2007; Steginga & Dunn, 1997).

Davison, Pennebaker, & Dickerson, 2000 and Meier, Lyons, Frydman, Forlenza, & Rimer (2007) indicated that not a lot of attention has been given to online support groups. However, neither of the researchers spoke directly to participants asking why they joined, what benefits they received, why they continued to participate, or what other factors may or may not be advantageous to them. Both monitored posts and drew conclusions from what they read. Davison et al. (2000) chose 20 newsgroups from the 40,000 they identified. Meier et al. (2007) chose a systematic 9% sample to read that were posted during a five-month period from the 10 groups they chose from lists hosted by ACOR. Rimer, Lyons, Ribisl, Bowling, Golin, Forlenza & Meir (2005), also using 10 groups from ACOR, invited new members to participate in their study, which focused on why the members joined. Consequently, there been little or virtually no information found that has directly addressed women dealing with gynecologic cancers and pre-cancers in a private, listserv environment. Therefore a study to examine the perceptions of women diagnosed with gynecologic cancers or pre-cancers regarding online support, illness, information and awareness in a private, listserv environment seemed timely.

JUSTIFICATION OF THE STUDY

Prior research identified and confirmed the need for attention to both the physical and emotional health of women with gynecologic cancers and pre-cancers (Anderson & Lutgendorf, 1997; Barnett, 2007; Beesley et al., 2005; Chan et al., 2001; Corney et al., 1992; Gotheridge & Dresner, 2002; IOM Committee, 2007; Pearman, 2003; Puccio, 2007; Yaker, 2008). Face-to-face group support has been championed by many (Boscaglia & Clarke, 2007; Butow et al., 2007; Hodgkinson et al., 2007; Steginga & Dunn, 1997).

Online support for women with gynecologic cancers and pre-cancers has not been sufficiently researched or reported. Two (Davison et al., 2000; Meier et al., 2007) of the three (Rimer et al., 2005) studies found that investigated online support for illness, monitored the posts to the respective chosen groups and neither directly engaged participants. Only one (Meier et. al., 2007) of the two included a gynecologic cancer (ovarian) and neither included a gynecologic pre-cancer group. Rimer et al. (2005) did not specify the groups chosen.

From the Chinese there is an aphorism that states, “To know the road ahead, ask those coming back” (Woman to Woman, 2008, p. 1). This study asked participants to speak directly to online support and was designed to define, describe, and report their first-hand experiences.

The results of this study will provide information to, and raise the awareness of, people in general, and specifically, women diagnosed with a gynecologic cancer or pre-cancer and the medical personnel who treat them. These study results will also increase the base of information and knowledge for those who seek online cancer support and resources.

Definitions

For the purposes of the study, perceptions were defined as a participant's personal opinions, views, observations, and experiences. Online support refers to support groups meeting in gathering places created, and facilitated, by the technology of computers and the Internet instead of meeting in physical locations. Illness was confined to gynecologic cancers (cancers of the cervix, uterine corpus, endometrium, ovaries, fallopian tubes, vulva, and vagina); female anal and perianal (peri means “around”) cancers; and dysplastic (pre-cancerous) conditions (CIN, VIN, VaIN, AIN, and PaIN). Information was defined as knowledge, facts, details, and/or specifics of and about these illnesses and the situations, conditions, and problems—both physical and emotional—created by these illnesses. Awareness was defined as familiarity, consciousness, realization, and/or a state of knowing.

REVIEW OF LITERATURE

Support Groups

Support groups for cancer patients can enhance self-esteem, reduce depression, decrease anxiety and improve relationships with family and friends (Rochman, 2007). Additionally, they help patients cope better with diagnoses and increase patient knowledge of cancer and its treatment. Moreover, support groups have greatly improved the QOL of many people who have been diagnosed with cancer, and the emotional benefits these groups can provide are significant. The best support group is the one that works for you (Rochman, 2007).

Support groups help to validate one’s experiences and complement the medical aspect of treatment and recovery (Schimmel, 2003). She argued that they help patients to cope, provide a safe place to share innermost feelings, and allow patients to be with others who know what you are experiencing. Schimmel (2003) concluded that cancer

patients who attend support groups lead good lives and survive longer than those just receiving medical treatment alone.

Jefferies (2002) suggested that support groups, where patients with a similar diagnosis meet together, provide some needed support. She argued that these groups can reduce patients' sense of isolation, loneliness, and fear. Lang and Path (1994) suggested that group participation empowers patients through the sharing of their own experiences and feelings with others, aids them in bolstering their fighting spirit, and assists in regaining a sense of control over their illness. Heilman (2003) also concluded that it is enormously validating when you find a whole room full of people who feel exactly as you do.

Moran (2001) argued that the patient support group movement has been fueled by the idea that no one can understand better than someone that has experienced it. He reported that groups giving social, emotional, and educational assistance to patients and their families are meeting around the country. He suggested that generally support groups are not replacing the support of families and friends, but instead, they are enhancing this natural support system.

Those without strong support systems are more likely to experience distress, and when patients know ahead of time what to expect, they can prepare, which helps diminish the distress (Riba, 2001). Heilman (2003), argued that the more than 30 years of psychosocial literature in cancer shows that most interventions—including individual counseling, support groups, or educational programs—increase patients' sense of control, self-esteem, and ability to participate in their own care..

Warner (2003) conducted a study (N=200) of cancer patients regarding the importance of support and found that 75% classified support as very important/important. They divided their results by sex and found that the degree of support, as well as support preferences, differed between males and females. Of females, 82% responded that they wanted a great deal/some support, while 68% of males responded great deal/some. Consistently, females reported that they wanted more of each of the three types of support—emotional, knowledge [sic], and spiritual —mentioned in the survey. Of the support types, the category of needing emotional support elicited the greatest difference between the sexes. Of the female participants, 82% answered affirmatively to needing emotional support, compared to 53% of males.

Cancer Treatment Centers of America (as cited in Warner, 2003) conducted a study (N=1,071) surveying members of the general public about the effectiveness of support cancer patients receive. More than 50% of the participants reported that they were not sure how to provide appropriate support to family and friends who were diagnosed with cancer.

Warner (2003) compared the results of the report from Cancer Treatment Centers of America with their own study (N=200) and concluded that these results emphasize the chasm between the kind of support cancer patients feel is most important and the help that loved ones feel qualified to give.

Some support groups have professional facilitators or moderators but many do not. While participants may not be opposed to professional input, they may prefer to speak and be heard about issues not addressed within the health care setting (Partenheimer, 2000). He suggested that there is tremendous therapeutic potential in the

self-help movement especially because institutional health care is still far from including psychological support as a routine part of the health care delivery system.

Confronting deeply personal issues through talking has been found to promote physical health, subjective well-being, and selected adaptive behaviors (Pennebaker et al., 2001). They suggested that people who experience an emotion feel compelled to talk about it and to share it, preferably with their intimates. Additionally, they talk quite willingly, despite the fact that the sharing process reactivates the negative aspects of the emotional experience.

Cancer is an isolating situation and people living with the discomfort and uncertainties of cancer gain reassurance and a better QOL when they reach out for support (Haran, 2004). If isolation is the problem, then support groups, counseling, and/or workshops, which are all aimed at discovering and completing the unfinished emotional business that fuels the isolation, are helpful (Healthy Place, 2004). Webster (2002) suggested talking with people who understand you, and if no one in your circle of family and friends seems to understand, find a support group.

Turner (2001) suggested that, generally, while families are the first line of defense and our staunchest supporters in times of crisis, families are often feeling many of the same emotions that the patient is feeling. She argued that it is very difficult for love ones to stand by and see someone undergo treatment for cancer, especially when they feel helpless. According to Turner (2001), family members are often extremely stressed, anxious, or clinically depressed and are struggling to come to terms with their own feelings, doubts, and fears, including the possibility that the patient might die.

Additionally, families often find it hard to talk about issues and often avoid any emotionally difficult subjects. Moreover, Turner (2001) suggested that partners often feel particularly helpless if the woman is upset. Partners may urge her to think positively, which is not always best or most helpful for women. Turner (2001) also argued that many women need to share thoughts and feelings even if they are painful.

Sometimes friends and family are not enough when it comes to support. There are deficits when relying on them because they are dealing with their own emotions regarding the situation, the impact on their own lives, the possibility of losing a loved one, and the awkwardness of what to say (Canadian Women's Health Network, 2004; Haran, 2004; Sharma, 2005). Patients may feel pressured by loved ones to stay upbeat (Haran, 2004). Sharma (2005) concluded that in a support group one does not have the same concerns that one has dealing with relatives and friends. He suggested that in a support group one can share bad feelings without having to worry if those feelings will be an emotional burden to the listeners.

Webster (2002) suggested that the people at home often do not understand what the person with cancer is experiencing, and that often the patient does not feel comfortable talking about the experience of cancer with family or friends. Additionally, she suggested that the support group is the only place where everyone understands each other. She concluded that this common understanding is particularly comforting and that the group experience is extremely powerful.

Hebert and Roumeliotis (2005) suggested that support groups can provide a voice of experience because of members who have traveled the same path. Moreover, support groups are a good place to find women with a like diagnosis, some of whom are going through treatment and can give advice. Heilman (2003) also concluded that there is

something special about talking to someone who has been through treatment and recovery because those who have experienced cancer can offer different perspectives and coping strategies.

Schimmel (2003) suggested that what we can do for each other in a support group is inspire hope, and support each other to cope. She concluded that a common discovery is that it may not be so much that you are receiving advice as it is an exchange of information and common feelings. She also suggested that deep bonds of friendship can form between support group members brought together by cancer. Sharma (2005) argued that members of a support group will feel good about giving support to other members of the group.

One study found that face-to-face support groups are of little value (Veronesi, vanKleeist, Redmond, Delvaux, Freilich & Serin, 1999) and one found that some face-to-face groups even have a negative effect on patients (Galinsky & Schopler, 1994). Another study found that a reluctance to share feelings with strangers may cause some not to attend, and in some cases, may even have a negative effect on the patients (Galinsky & Schopler, 1994).

Partie (2000) focused on the negative experiences some women have as a result of joining a face-to-face support group. One participant was described as an enthusiastic, capable woman who met her cancer diagnosis head-on, but she reported that her face-to-face group experience left her deflated and depressed.

Helgeson, Cohen, Schulz, and Yasko (2000) conducted a study (N=203) and found that some women may find the face-to-face, self-help group experience disturbing, even to the point of some detriment to their physical well being. They concluded that hearing another woman's story is not always helpful. If the listener shares the same condition as the speaker and the speaker is not doing well, this can make the listener feel threatened and more worried. Helgeson et al. (2000) suggested that women who had perceived their outside support as adequate may have reconsidered after hearing the stories or opinions of others, thus causing distress.

Partenheimer (2000) suggested that online support groups may offer some solutions to problems common in face-to-face support groups and credits the increasing availability of the Internet for the rapid growth of online self-help groups. He concluded that there is a certain amount of anonymity in online support groups; consequently, confiding can occur without immediate social repercussions. Furthermore, he concluded that online support is attractive to those with rare or debilitating conditions where getting together physically would present a number of practical barriers. If discussing sexual matters face-to-face with strangers is embarrassing, the online environment provides anonymity (Mayo Clinic, 2005).

Rochman (2007) found that online groups work well for those who live in rural areas or cannot easily leave home, and may offer a better fit than those attended in person. Davison et al. (2000) concluded that the individuals most motivated to join support groups are those with diseases that are the most difficult to talk about in polite company, most embarrassing, and/or most socially stigmatizing.

Emotional Support

“Oh, God, I don’t want to die.” These were the first words uttered by Baginski (as cited in Moran, 2001) after hearing her cancer diagnosis. She went on to report, “My first emotions were terror laced with fear” (p. 1). She described her feelings as an urgent need for expert medical advice and treatment, and support from friends, family, acquaintances, and others who had already passed through the furnace of diagnosis and treatment. She concluded that the latter element is particularly important. “You could have the most loving, supportive family imaginable, but no one knows what it feels like to have cancer except one who has it,” said Baginski (as cited in Moran, 2001, p. 1).

Farrell and Farrell (2008) argued that women like to talk and talk and talk some more, and that talking is the way in which women get in touch with their feelings, work through their problems and come to terms with the situations in their lives. Pennebaker, Zech, and Rime (2001) found that, in a sample (N=1024) of laypersons, 89% endorsed the view that talking about an emotional experience is relieving.

A woman is likely to experience shock when she first receives a gynecologic cancer diagnosis (Hebert & Roumeliotis, 2005). The authors argued that there is no time to recover from this shock before moving into cancer treatment. They concluded that it will be necessary for each woman to collect a great deal of information in a brief amount of time and make decisions that will affect her life. Moreover, they concluded that support persons can be most helpful by being her eyes, ears, and informational back up during this period. Furthermore, they suggested that it is common for a woman to experience a wide variety of emotions and that support people should be there to allow her to rant, cry, or just talk out her fears and feelings, allowing her go through each one at a pace that fits her needs. Ultimately, Carlson (as cited in Haran, 2004) has argued that major ramifications can occur from individuals not getting help. She concluded that distress just snowballs over time if people do not feel like they can talk to anyone, and that untreated depression and anxiety can prompt more doctor visits.

Online Support

Ford-Martin (2008) defined support groups as “groups that support communities of peers with a similar interest or illness” (p. 1) and provides support for individuals who have health issues. She asserted that the growing trend is the formation of online support communities, including chat-rooms, bulletin boards, and electronic mailing lists, which provide convenient, around-the-clock access to peer support. Moreover, she concluded that self-help groups are becoming as accessible to those in rural areas as they are to those in large cities because of the rapid increase of new online support communities and easier access to the Internet.

Ford-Martin (2008) suggested that an essential sense of community and belonging is provided by participation in self-help groups. Furthermore, she asserted that there are those who may be lacking emotional support and empathy from their friends and family and that these, as well as the sense of community and belonging, are a critical part of recovery.

A new technologic alternative to the traditional practice of bringing people together to share information, experiences, and support has been provided by the

widespread use of the Internet, which is without boundaries so information is readily available (Sutton & Raines, 2008). They suggested that health providers need to acknowledge the numbers of people who are turning to interactive communities on the Internet to find information, support, and to connect with others, and that health providers need to incorporate this into patient care strategies. Furthermore, they assert that online forums allow people from diverse locations and backgrounds to come together and easily share information, problems, and solutions at the time information or support is needed, and that online support groups eliminate traditional barriers of time and place.

Dixon (2007) reported that online groups have become so highly specialized that users can connect with others who are experiencing the same situations, conditions, and emotions, and that groups are immediate, anonymous, and abundant. Gould (as cited in Dixon, 2007) suggested that online groups are a good way to network, seek support, and get practical information. Suler (as cited in Dixon, 2007) concluded that people often tend to be more honest and open about themselves in online groups because of what psychologists call the online disinhibition effect, which he defined as the state of anonymity that people can feel when they communicate with text. Moreover, Suler (as cited in Dixon, 2007) suggested that accessibility from home and the ease and convenience of online groups are other advantages. Byrd (as cited in Dixon, 2007) suggested that an important advantage of Internet groups is not having to wait for a face-to-face group to meet in order to vent because the online support group is accessible 24/7.

The Study

The purpose of this study was to examine the perceptions of women diagnosed with gynecologic cancers or pre-cancers regarding online support, illness, information and awareness. A descriptive and survey research design was used to conduct this study. The participants for this study were members of a private listserv group with no public access, which totaled 472 past and present members. Women Conquering Cancer WCC (N=304), are women with gynecologic cancers, and its subgroup, CIN/VIN/VaIN CVV (N=168), are women with gynecologic pre-cancers. Both groups required membership.

Data were collected from 246 (81%) participants from the population (N=304) of the Women Conquering Cancer (WCC) online support group, and 133 (79%) participants from the population (N=168) of the subgroup, Cin/Vin/Vain (CVV).

Descriptive statistics were utilized to analyze the data and answer the research questions posed in the study. Descriptive research involves describing and interpreting events, conditions, or situations of the present (Picciano, 2008). The results presented affirm that descriptive survey method is also a measure of status, rather than prediction (Jefferies, 2008) and that data collection may be spread over a large number of people over a large geographic area (McNabb, 2008). A survey instrument consisting of 6 parts was used in this study. However, Part V of the instrument collected data regarding online support, illness, information, awareness, and sense of self, which was the focus of this study.

Instrumentation

The survey instrument used in this study consisted of six parts and was administered to the online support group WCC, and its subgroup, CVV. In order to answer the research question posed in the study, “What are members’ perceptions about support, illness, information, awareness, and sense of self?” the researcher tabulated the results of Part V (questions 65-89). Part V of the survey instrument was designed to collect information about members’ perceptions about support, illness, information, awareness, and sense of self (Anderson & Lutgendorf 1997; Gotheridge & Dresner, 2002; Kate, 1998; National Cancer Institute, 2007; Woman to Woman, 2008).

FINDINGS

The purpose of this study was to examine the perceptions of women diagnosed with gynecologic cancers or pre-cancers regarding online support, illness, information and awareness. The results of Part V of the survey instrument, "Survey of Members of Online Support Groups for Women with Gynecologic Cancers and Pre-Cancers Regarding Online Support," were utilized to answer the research question posed in this study. Data were collected from 246 (81%) participants from the population (N=304) of the WCC group, and 133 (79%) participants from the population (N=168) of the subgroup, CVV. The return rate was achieved through an online survey using a Likert-type scale.

For the research question posed, “What are members’ perceptions about support, illness, information, and sense of self?” data were collected from Part V of the survey instrument. Part V (Questions 65-89) of the survey instrument used in this study was comprised of a variety of topics and offered to the participating members of WCC and its subgroup, CVV support groups for women with gynecologic cancers and pre-cancers in order to collect data regarding members’ perceptions about support, illness, information, awareness and sense of self. The items in this section were not, necessarily, grouped together, nor were they labeled as to their category (i.e. support, illness, information, etc.). The items were phrased to elicit a response formed from the participant's personal experience and frame of reference. Tables 1-5 in the Appendices show the results for each category. Reversed questions are 67, 76, and 86.

Perceptions about Support

Three items regarding perceptions about support were addressed in Part V of the survey instrument. Two (questions 65 and 66) asked about knowledge of the existence of online support groups. The participants of both groups overwhelmingly affirmed that they accidentally found their online support group (question 65), and that they did not know support groups were online (question 66). The third question (question 89) asked if participants would recommend online support. Each group affirmed with 100%. See Table 1 in Appendix A for the results.

Perceptions about Illness

Five items regarding perceptions about illness were included in Part V of the survey instrument. One item (question 70) inquired about depression. From both groups, the majority (WCC, 98.8%; CVV, 63.9%) affirmed they had suffered from depression, with the prevalence much higher in the women with cancer (WCC). Two items (questions 73 and 74) addressed embarrassment or shame. An overwhelming majority of the participants of both groups (WCC, 93.1%; CVV, 97.0%) reported feelings of embarrassment or shame because of the nature of their diseases (question 73). A majority of both groups (WCC, 83.3%; CVV, 63.2%) reported that embarrassment or shame was a motivating factor in seeking support (question 74).

Three items inquired about diagnosis(es) and misdiagnosis(es). A majority of the members of WCC (79.7%) agreed that their doctors did not seem well informed about their conditions, while only 43.6% of the CVV concurred (question 81). Additionally, the majority of WCC (63.8%) confirmed that they were misdiagnosed (question 82), and that their (WCC, 63.0%) conditions worsened because of the misdiagnosis (question 83). The majority of CVV respondents (51.1%) disagreed that their doctors did not seem knowledgeable about their conditions (question 81). While the majority of CVV (69.2%) reported that they were misdiagnosed (question 82), most (41.4%) reported that their conditions did not worsen because of it and 27.0% reported *does not apply* (question 83). The results are displayed in Table 2 of Appendix B.

Perceptions about Information

Five items regarding information that were not addressed in any other section were included in Part V of the survey instrument. Three items (questions 67, 76, and 86) inquired about information received from doctors and other medical personnel. The vast majority of the participants (WCC, 85.0%; CVV, 89.5%) affirmed that none of their medical attendants suggested group support (question 67), and none of their (WCC, 91.5%; CVV 94.7%) medical teams offered sufficient information about the medical diagnosis (question 76). Questions 67 and 76 required disagreement in order to affirm. The participants (WCC, 79.3%; CVV, 82.1%) confirmed that they had not received information from doctors throughout the years regarding self-exams and symptoms of which to be aware (question 86).

Two items (questions 79 and 80) asked participants about the information they wanted and where they turned to acquire it. The participants of both groups unanimously (100%) affirmed that they wanted information regarding their illnesses (question 79). The WCC group, of which 8% of participants were over 50 years of age, reported that they had turned to the Internet for information (97.6%), while 100% of the participants of the CVV group, having no members over the age of 50, had turned to the Internet for information. Table 3 in Appendix C shows the results.

Perceptions about Awareness

Five items regarding awareness that were not addressed in any other section were included in Part V of the survey instrument. One item (question 71) inquired about

doctors treating depression. The majority in both groups (WCC, 78.5%; CVV 66.9%) reported that their doctors had treated them for depression, but had not recommended support.

Four items (questions 77, 78, 84, and 85) addressed prior knowledge of the diagnosed illness and closely related conditions. The participants (WCC, 92.7%; CVV, 94.7%) of both groups affirmed that they were very, or totally, unaware of the conditions for which they had been diagnosed (question 77). Question 78 inquired about those participants who were familiar with their condition, but knew very little about it, and was a question for those who had not affirmed question 77.

A majority in both groups (WCC, 98.0%; CVV, 73.7%) affirmed that they did not know the signs or symptoms of their respective illnesses (question 84). Question 85 inquired as to previous knowledge of HPV, regardless of any association with the participant's own condition. The majority in both groups (WCC, 81.3%; CVV, 71.4%) affirmed that they had not heard of HPV, the virus that causes many gynecologic cancers and pre-cancers. The results are displayed in Table 4 in Appendix D.

Perceptions about Sense of Self

Six items regarding sense of self that were not addressed in any other section were included in Part V of the survey instrument. Two items (questions 68 and 69) broached the subject of the personal mores of the biology of gynecologic matters. The majority of both groups for both questions responded affirmatively that at the time they joined their respective groups, the elements of their (WCC, 71.5%; CVV, 88.0%) reproductive systems were private topics not openly discussed even with other women (question 68), and they (WCC, 70.0%; CVV, 77.4%) felt embarrassed about speaking of these subjects in group in the beginning of their association with the online group (question 69).

Two items (questions 74 and 75) inquired as to the consequences to sense of self. A majority (WCC, 82.1%; CVV, 86.5%) responded that their sense of self decreased with the diagnosis (question 74), and that participation in their respective groups (WCC, 93.1%; CVV, 75.2%) helped them to recover some of the loss (question 75).

The final two items (questions 87 and 88) asked about the experience of discussing the illness with others. Both groups affirmed (WCC, 90.2%; CVV, 100%) that it was difficult to discuss their illnesses with family and friends because it was gynecologic (question 87). The majority (WCC, 97.2%; CVV, 84.2%) responded that many outside of the support group environment were embarrassed or uncomfortable when the participant spoke of her illness (question 88). Table 5 in Appendix E displays the responses.

CONCLUSION

Prior to the Internet, the only self-help support groups available were peer support groups (led by one who has had the experience as opposed to traditional support groups led by a medical professional), which were usually grassroots organizations that commonly met once a week in a community building of some kind (Gray, 2007). Moreover, Gray (2007) argued that there are barriers that keep some people from participating in face-to-face groups, such as physical issues like geographic distance for

those who live in rural areas, being homebound, having to worry about bad weather when traveling, or not having access to transportation. Additionally, working parents, single mothers, or caregivers might find it difficult, or even impossible, to fit the meetings of face-to-face groups into their schedules and in-person groups with a set meeting time can be inconvenient and inflexible for many others. Thus, Sutton and Raines (2008) found that participating from the privacy of one's secure environment could aid individuals, who may be uncomfortable, unable, or unwilling to attend a traditional face-to-face support group, in finding an acceptable alternative in Internet support groups. They also concluded that since three out of four U.S. households have a computer technology is not a barrier, and instead, may result in making health resources available to those who are unable to access more traditional resources. Finally, they concluded that the potential benefits for online support has not been adequately studied.

This study dealt with the perceptions of members of only one online gynecologic cancer support group and one online pre-cancer group. Prior research identified and confirmed the need for attention to both the physical and emotional health for women with gynecologic cancers and pre-cancers (Anderson & Lutgendorf, 1997; Barnett, 2007; Beesley, Eakin, Steginga, Aitken, Dunn, & Battistutta, 2005; Chan, Molassiotis, Yam, Chan, & Lam, 2001; Corney, Everett, Howells, & Crowther, 1992; Gotheridge & Dresner, 2002; IOM Committee, 2007; Pearman, 2003; Puccio, 2007; Yaker, 2008). Therefore, data were collected regarding selected facets of online support in order to answer the research question posed in this study.

This study examined the perceptions of women diagnosed with gynecologic cancers or pre-cancers regarding online support, illness, information and awareness. The following recommendations are based on the findings in the study.

The findings in this study revealed strong affirmation of some topics, such as QOL, Writing Therapy, Sense of Self for online support groups with gynecologic cancer and pre-cancer. Each of the major topics of this study deserves more thorough attention in studies focusing on expanded data collection of these items. Therefore, it is recommended that more studies be conducted on these topics using qualitative investigation. It is also recommended that studies with other online gynecologic cancer support groups should be conducted in order to determine if the findings in this study are supported by other groups.

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APPENDICES

APPENDIX A

Table 1
Results of Part V: Support

Part V	Group	Percentages												
Regarding: Support	---	Strong Agree	Agree	Mild Agree	Total Agree	No Opinion	Mild Dis-Agree	Dis-Agree	Strong Dis-Agree	Total Dis-agree	Does not apply	Pass	Total No Answer	Total of Shaded Areas
65. I accidentally found my online support group.	WCC	63.4%	21.1%	7.3%	91.9%	0.0%	0.0%	0.0%	8.1%	8.1%	0.0%	0.0%	0.0%	100.00%
	CVV	48.1%	30.8%	5.3%	84.2%	5.3%	0.0%	10.5%	0.0%	10.5%	0.0%	0.0%	5.3%	100.00%
66. I did not know that there were online support groups until I found mine.	WCC	70.7%	9.3%	11.4%	91.5%	0.0%	0.0%	6.5%	2.0%	8.5%	0.0%	0.0%	0.0%	100.00%
	CVV	10.5%	48.1%	25.6%	84.2%	5.3%	0.0%	10.5%	0.0%	10.5%	0.0%	0.0%	5.3%	100.00%
89. I would recommend online support to family or friends who were in need of support.	WCC	100.0%	0.0%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
	CVV	86.5%	13.5%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%

APPENDIX B

Table 2
Results of Part V: Perceptions about Illness

Part V Regarding: Illness	Group	Percentages											Total No Answer	Total of Shaded Areas
		Strong Agree	Agree	Mild Agree	Total Agree	No Opinion	Mild Dis-Agree	Dis-Agree	Strong Dis-Agree	Total Dis-agree	Does not apply	Pass		
70. I have suffered some bouts of depression because of my illness.	WCC	71.5%	10.6%	16.7%	98.8%	0.0%	0.0%	0.0%	0.0%	0.0%	1.2%	0.0%	1.2%	100.00%
	CVV	42.1%	0.0%	21.8%	63.9%	0.0%	0.0%	0.0%	4.5%	4.5%	31.6%	0.0%	31.6%	100.00%
72. Since I was diagnosed, I have had times when I was embarrassed or ashamed to talk about my condition (outside of group) because it was gynecologic.	WCC	79.7%	6.9%	6.5%	93.1%	0.0%	0.0%	2.8%	2.8%	5.7%	1.2%	0.0%	1.2%	100.00%
	CVV	36.1%	45.9%	15.0%	97.0%	0.0%	0.0%	3.0%	0.0%	3.0%	0.0%	0.0%	0.0%	100.00%
73. I was motivated to join a support group because of embarrassment or shame about my condition.	WCC	76.8%	6.5%	0.0%	83.3%	0.0%	6.9%	0.0%	6.1%	13.0%	3.7%	0.0%	3.7%	100.00%
	CVV	19.5%	24.8%	18.8%	63.2%	10.5%	26.3%	0.0%	0.0%	26.3%	0.0%	0.0%	10.5%	100.00%
81. In looking back to when I was diagnosed, I believe that my original doctor(s) was (were) not very informed about my condition.	WCC	52.4%	9.3%	17.9%	79.7%	0.0%	0.0%	17.5%	2.8%	20.3%	0.0%	0.0%	0.0%	100.00%
	CVV	24.1%	19.5%	0.0%	43.6%	5.3%	6.8%	17.3%	27.1%	51.1%	0.0%	0.0%	5.3%	100.00%
82. Before I was correctly diagnosed with my cancer or pre-cancer, my condition was mis-diagnosed.	WCC	45.1%	9.8%	8.9%	63.8%	0.0%	0.0%	24.4%	7.7%	32.1%	4.1%	0.0%	4.1%	100.00%
	CVV	48.9%	20.3%	0.0%	69.2%	0.0%	5.3%	15.0%	5.3%	25.6%	5.3%	0.0%	5.3%	100.00%
83. My condition got worse because of the time lost on mis-diagnosis(es).	WCC	43.5%	10.6%	8.9%	63.0%	2.4%	0.0%	2.4%	2.4%	4.9%	29.7%	0.0%	32.1%	100.00%
	CVV	17.3%	9.0%	5.3%	31.6%	0.0%	9.8%	21.1%	10.5%	41.4%	27.0%	0.0%	27.0%	100.00%

APPENDIX C

Table 3
Results of Part V: Perceptions about Information

Part V Regarding Information	Group	Percentages											Total No Answer	Total of Shaded Areas
		Strong Agree	Agree	Mid Agree	Total Agree	No Opinion	Mild Dis-Agree	Dis-Agree	Strong Dis-Agree	Total Dis-agree	Does not apply	Pass		
67. My doctor, nurse, medical person suggested I join a support group.	WCC	9.8%	0.0%	0.0%	9.8%	0.0%	2.8%	26.4%	55.7%	85.0%	5.3%	0.0%	5.3%	100.00%
	CVW	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	12.8%	76.7%	89.5%	10.5%	0.0%	10.5%	100.00%
76. My doctor/nurse/medical professional gave me a sufficient amount of information about my condition and explained it to me so that I did not need to search for answers elsewhere.	WCC	8.5%	0.0%	0.0%	8.5%	0.0%	17.9%	35.8%	37.8%	91.5%	0.0%	0.0%	0.0%	100.00%
	CVW	0.0%	5.3%	0.0%	5.3%	0.0%	18.8%	50.4%	25.6%	94.7%	0.0%	0.0%	0.0%	100.00%
79. When I was diagnosed, I wanted information about my condition.	WCC	90.2%	9.8%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
	CVW	68.4%	31.6%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
80. When I was diagnosed, I turned to the Internet for information.	WCC	78.9%	15.9%	2.8%	97.6%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	2.4%	2.4%	100.00%
	CVW	66.9%	33.1%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
86. Through the years, as I was getting gynecologic check-ups, my doctor(s) gave me information on doing self-exams and/or signs, symptoms, and changes to watch for before I ever had a	WCC	6.1%	0.0%	8.5%	14.6%	6.1%	0.0%	17.9%	61.4%	79.3%	0.0%	0.0%	6.1%	100.00%
	CVW	6.0%	0.8%	5.3%	12.0%	0.0%	7.5%	12.8%	60.9%	81.2%	6.8%	0.0%	6.8%	100.00%

APPENDIX D

Table 4
Results of part V: Awareness

Part V	Group	Percentages											Total No Answer	Total of Shaded Areas
		Strong Agree	Agree	Mild Agree	Total Agree	No Opinion	Mild Dis-Agree	Dis-Agree	Strong Dis-Agree	Total Dis-agree	Does not apply	Pass		
71. My doctor treated me for depression with medications, but never suggested I join a support group.	WCC	64.6%	7.3%	6.5%	78.5%	0.0%	0.0%	10.6%	6.1%	16.7%	4.9%	0.0%	4.9%	100.00%
	CVV	48.9%	0.0%	18.0%	66.9%	0.0%	0.0%	0.0%	0.0%	0.0%	33.1%	0.0%	33.1%	100.00%
77. When I was diagnosed, I was very (or totally) unfamiliar with my condition.	WCC	63.0%	12.2%	17.5%	92.7%	0.0%	0.0%	7.3%	0.0%	7.3%	0.0%	0.0%	0.0%	100.00%
	CVV	59.4%	30.1%	5.3%	94.7%	5.3%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	5.3%	100.00%
78. When I was diagnosed, I was familiar with my condition but I knew very little about it.	WCC	20.7%	9.8%	17.1%	47.6%	0.0%	11.4%	11.4%	26.8%	49.6%	0.0%	2.8%	2.8%	100.00%
	CVV	5.3%	0.0%	5.3%	10.5%	0.0%	0.0%	5.3%	10.5%	15.8%	73.7%	0.0%	73.7%	100.00%
84. I did not know the signs/symptoms of my illness.	WCC	66.7%	27.2%	4.1%	98.0%	0.0%	0.8%	0.4%	0.8%	2.0%	0.0%	0.0%	0.0%	100.00%
	CVV	71.4%	2.3%	0.0%	73.7%	0.0%	0.0%	10.5%	9.0%	19.5%	6.8%	0.0%	6.8%	100.00%
85. I had never heard of HPV prior to my illness (regardless of an HPV connection).	WCC	54.1%	27.2%	0.0%	81.3%	0.0%	0.0%	0.0%	9.8%	9.8%	8.9%	0.0%	8.9%	100.00%
	CVV	54.1%	17.3%	0.0%	71.4%	0.0%	0.0%	23.3%	0.0%	23.3%	5.3%	0.0%	5.3%	100.00%

APPENDIX E

Table 5
Results of Part V: Sense of Self

Part V	Group	Percentages											Total No Answer	Total of Shaded Areas
		Strong Agree	Agree	Mild Agree	Total Agree	No Opinion	Mild Dis-Agree	Dis-Agree	Strong Dis-Agree	Total Dis-agree	Does not apply	Pass		
68. When I joined my online support group, I considered my female reproductive system (vulva, vagina, cervix, uterus, ovaries, etc) to be a PRIVATE matter to be discussed only with a few close friends or family members or not at all.	WCC	50.4%	10.2%	11.0%	71.5%	8.9%	10.2%	9.3%	0.0%	19.5%	0.0%	0.0%	8.9%	100.00%
	CVV	36.8%	33.1%	18.0%	88.0%	5.3%	3.0%	3.8%	0.0%	6.8%	0.0%	0.0%	5.3%	100.00%
69. I felt uncomfortable in the beginning talking about these gynecologic issues even with my online support group.	WCC	47.6%	13.4%	9.3%	70.3%	0.0%	0.0%	29.7%	0.0%	29.7%	0.0%	0.0%	0.0%	100.00%
	CVV	21.1%	38.3%	18.0%	77.4%	0.0%	8.3%	9.0%	5.3%	22.6%	0.0%	0.0%	0.0%	100.00%
74. My "sense of self" decreased after my diagnosis. [this includes any degree of decrease, whether temporary or permanent during any phase of the illness]	WCC	63.4%	9.8%	8.9%	82.1%	0.0%	6.5%	7.7%	0.0%	14.2%	3.7%	0.0%	3.7%	100.00%
	CVV	39.8%	15.8%	30.8%	86.5%	0.0%	0.0%	0.0%	13.5%	13.5%	0.0%	0.0%	0.0%	100.00%
75. My group participation has helped me recover my sense of self (in any degree).	WCC	42.7%	29.7%	20.7%	93.1%	0.0%	0.0%	0.8%	0.0%	0.8%	6.1%	0.0%	6.1%	100.00%
	CVV	7.5%	67.7%	0.0%	75.2%	15.0%	0.0%	9.8%	0.0%	9.8%	0.0%	0.0%	15.0%	100.00%
87. When I was diagnosed, I found it difficult to discuss my condition with some family, friends, co-workers, etc. because it was gynecologic.	WCC	54.5%	35.8%	0.0%	90.2%	0.0%	2.8%	6.9%	0.0%	9.8%	0.0%	0.0%	0.0%	100.00%
	CVV	33.1%	45.1%	21.8%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
88. Some people (not including my support group) were (are) embarrassed or uncomfortable when I talk about my gynecologic condition.	WCC	63.0%	26.8%	7.3%	97.2%	0.0%	2.8%	0.0%	0.0%	2.8%	0.0%	0.0%	0.0%	100.00%
	CVV	24.8%	55.6%	3.8%	84.2%	10.5%	0.0%	0.0%	0.0%	0.0%	5.3%	0.0%	15.8%	100.00%