

The benefits of online support to women with gynecologic cancers and pre-cancers

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ABSTRACT

The purpose of this study was to describe the benefits (personal enrichment) of online support to women diagnosed with gynecologic cancers or pre-cancers. The study consisted of a population of 472, with a total participation of 379 (80%) members of an online support group for women with gynecologic cancers and pre-cancers. The findings suggested that although these members were demographically different and were experiencing a variety of gynecologic cancers and pre-cancers, they were very cohesive in their wants and needs from online support. Conclusions and recommendations based on the findings in this study indicated that online support is a positive addition to the lives of the women dealing with cancers and pre-cancers and that more in-depth studies should be conducted and the information disseminated to cancer patients.

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

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INTRODUCTION

A woman is diagnosed with a gynecologic cancer every 7 minutes (Frosted Pink, 2007). In 2010, it was estimated that 87,010 women in the U.S. would be diagnosed with an invasive gynecologic or anal cancer and that 28,150 would die (American Cancer Society [ACS], 2010). The ACS does not include cases of cancers in situ, which are cancers detected while still in the point of origin, or cases of pre-cancerous conditions in its summation of annual estimates.

The emotional ramifications of those with cancer, and to a lesser degree, those with gynecologic cancers, have been researched and found important. This has led to an increased awareness of the need for support, including group support. However, there are few studies regarding online support and even fewer targeting gynecologic cancer patients and survivors. Face-to-face support groups are now largely promoted by medical professionals and medical centers, especially when the centers are large enough to offer in-house services (Women's Cancer Resource Center, 2006; Yaker, 2008). Yet, when online support groups are noted, it is often as an aside.

There are, approximately, 120 million females 16 years of age and older in the U.S. (U.S. Department of Labor Women's Bureau, 2008; U.S. Census Bureau, 2006). Therefore, the 55 million Pap tests a year represented less than one-half of U.S. women. If the percentages are equal, an additional 3.5 million women may have cervical abnormalities that are currently undetected and may be much more serious when detected. Cancer and pre-cancer patients and survivors face issues beyond the physical burden of treatments. Included are issues of uncertainty; possible development of second malignancies; short-term and long-term physical disabilities; providing for family needs, such as income, household responsibilities, and social relationships; cost of treatment, treatment options and side effects; loss of, and re-establishment of, life roles and relationships in the family, workplace, and community; financial and insurance problems; reestablishment of autonomy, and employment and professional development (Anderson & Lutgendorf, 1997; Gotheridge & Dresner, 2002; Woman to Woman, 2008).

With the advent of personal computers and Internet access, online support groups organized. These have been the focus of some study. Of the studies relating to illness-related online support groups, three were found (Davison, Pennebaker, & Dickerson, 2000; Meier, Lyons, Frydman, Forlenza, & Rimer, 2007; Rimer et al., 2005). Davison et al. (2000) studied why people joined support groups. They concluded that people with embarrassing conditions, conditions not readily discussed in public, and/or conditions with which friends and family could not readily empathize were the most likely to join an online support group. Gynecologic cancers were not among the groups studied. Meier et al. (2007) focused exclusively on cancer support groups. The only gynecologic cancer included was ovarian. They concluded that support groups seemed valuable for participants and seemed to offer information and support, but they did not know exactly why. Davison et al. (2000) concurred with Meier et al.'s (2007) conclusion of ambiguity. Rimer et al. (2005) studied 10 groups from the Association of Cancer Online Resources (ACOR) lists. These groups were not identified individually. The study focused only on new subscribers. They concluded that people joined online cancer support groups for information and support, and that online support groups seemed valuable. Davison et al. (2000) suggested that further research was warranted and that attention to the character and purpose of online support groups was needed. Rimer et al. (2005) concurred and concluded that online cancer support groups were under studied and may be an important resource for patients and

survivors. Therefore a study, a study of women dealing with gynecological cancers and pre-cancers in a private, listserv environment seemed timely.

THE STUDY

The purpose of this study was to examine the personal perceptions of women diagnosed with gynecological cancers or pre-cancers regarding their participation in an online support group. This study was conducted using descriptive and survey research design. A descriptive method was appropriate because answers being sought were the attitudes and perceptions of cancer patients regarding their experiences with online support. The survey methodology was appropriate because this study was non-experimental. Descriptive research involves describing and interpreting events, conditions, or situations of the present (Picciano, 2008). Descriptive survey method is also a measure of status, rather than prediction (Jefferies, 2008) and data collection may be spread over a large number of people over a large geographic area (McNabb, 2008).

The participants for this study were members of a private listserv group, which totaled 472 past and present members. Women Conquering Cancer, WCC (N=304), are women with gynecologic cancers, and its sub-group, CIN/VIN/VaIN, CVV (N=168) are women with gynecologic pre-cancers. The group requires membership and only members were allowed to read and post. Privacy was a prime concern. Posts from the women to the group went directly to each member's private email inbox, and archived messages were password protected. There was no public access. Permission to survey this group was given by the group owner contingent upon the participants' anonymity being protected. The group owner reported that the women ranged in age from 21-75, resided throughout the United States, and were of diverse backgrounds, socioeconomic status, and educational levels. The only one of these demographics included in the study was age. The ages were grouped into decades and were not recorded individually.

Age Ranges of the Respondents

There were no participants under the age of 21 in either group of women who participated in this study, as was confirmed by the category under 21. In the WCC group, the majority (54%) of the women were in the age range of 40–49. The other ages reported were: 1% in the 21–29 age range; 37% in the 30–39 age range; 2% in the 50–59 age range; 4% in the 60–69 age range; and 2% in the age range of 70 plus.

In the CVV group, the majority (47%) were in the 30–39 age range. The other ages reported were as follows: 26% in the 21–29 range; 27% in the 40–49 range; and 0 in the 50–59, 60–69, and 70 plus ranges.

Three other categories of information were collected to describe these participants. They were marital status, prevalence of accessing group, and years of association with group.

Marital Status of the Respondents

For the WCC group, 66% were married, 32% were not married, and 2% did not report their status. Of those reporting not married, 14% had a partner, while 18% reported no partner. For the CVV group, 65% were married, 30% were not married, and 5% chose not to answer. Of those reporting not married, 19% had a partner, while 11% did not have a partner (no partner).

Prevalence of Accessing Group

The majority (83%) of the WCC reported accessing their group more than once a day. The remainder of the group reported accessing their group once a day (8%) and two to three days a week (9%). The majority (72%) of the CVV reported accessing their group more than once a day. The remainder reported accessing their group once a day (14%), five to six days a week (3%), and only now and then (11%).

Years of Association with Group

The results revealed that the WCC reported that 0 had been in their group for less than one month, while 10% of the CVV had been in their group for less than one month. The WCC reported 15% and the CVV reported 7% had been in their respective groups six months to one year, while 4% of the WCC and 18% of the CVV had participated for more than one year but less than two. Participation reported for two years but less than three for the WCC was 4% and 14% for CVV, while three years but less than four was 18% for WCC and 11% for CVV. In the category of four years but less than five, WCC reported 12% and CVV 20%, while five years but less than ten was 29% for WCC and 20% for CVV. The final category, of 10 years or more, totaled 18% for WCC and 0 for CVV because the CVV had not yet been in existence for 10 years.

The total number of members for both groups was 472, with a total participation of 379 (80%). The total number of WCC members was 304, with 246 (81%) participating in the survey. The total number of CVV members was 168, with 133 (79%) participating in the survey.

INSTRUMENTATION

The survey instrument used in this study consisted of six parts, drawing content from the review of literature and was administered to the online support group WCC, and its subgroup, CVV. However, to answer the research question posed, “What are the benefits (personal enrichments) of online support to women with gynecologic cancers and pre-cancers?” the researcher tabulated the results of Part I (questions 1-22) and Part IV (questions 55-64) independently. Part I was designed to collect information regarding the benefits (personal enrichments), or lack thereof, gained from participation in the group (Adelaide Resource Centre For Women, 2004; Anderson & Lutgendorf, 1997; Kessler, 2008; Moran, 2001; Pennebaker, 2005; WholeHealthMD, 2005). Part IV was designed to collect information about the benefits (personal enrichments), or lack thereof, of interaction in an online group (Dixon, 2007; Dorazio-Schantz & Griffo, 2002; Ford-Martin, 2008; Gray, 2007; Pearman, 2003; Peeke, 2004; Pennebaker et al., 2001; Riba, 2001; Sutton & Raines, 2008; Turner, 2001).

Each response for each question was listed (i.e. Survey 1, question 1, answer: A; Survey 2, question 1, answer: B). The total of each answer (i.e. all of As, all of Bs) was tabulated and the percentage of each was calculated based on the total number of respondents. Additionally, the sum for each answer segment (i.e. all Agrees [Strongly Agree, Agree, Mildly Agree], all Disagrees [Mildly Disagree, Disagree, and Strongly Disagree], and No Answer [No opinion, Does not apply {to me}, Pass]) for all questions (i.e. 1–22) in Part I were tabulated. These tabulations were averaged and a section percentage calculated. The same was calculated for Part IV.

The instrument used in this study was designed for the specific group being studied. Questionnaires are familiar to most people because most people have had some experience completing them and generally they do not cause people to be apprehensive (StatPac, 2005; Walonick, 2004). A written questionnaire was chosen for this study because the participants who were located across a wide geographic area (Walonick, 2004) were asked some highly personal questions (Baron, 2006; Garson, 2008), and were guaranteed anonymity (Baron, 2006; Frary, 2002). Internet delivery was chosen because the participants were computer literate, had computer access, and participated in an online support group (Norman, 2006; Palmquist, 2007). Palmquist (2007) maintained that electronic survey response rates, especially on private networks, were higher than with paper surveys or interview method, and that answers were more honest with electronic surveys. The questionnaire incorporated web design and was personalized using the support group's colors and symbols (Baron, 2006; Garson, 2008; Kennedy, 2003; Norman, 2006). The owner/founder of the support group asked for anonymity. This condition was met by having an online survey, accessed by a special pin number of the group and collecting no identifying information. The special pin number was assigned to each group to further ensure security (Norman, 2006).

Careful consideration was given to the survey layout. This questionnaire was simple, straightforward, and logical (Kaden, 2006; Kennedy, 2003), as well as clear, easily understood, attractive, easy to use, and non-intimidating (Garson, 2008; O'Brien, 1997). The pages were not crowded or hard to read (Kaden, 2006). The survey was divided into sections, which fostered a sense of progress and reduced survey fatigue (Garson, 2008) and allowed the participant to complete all questions about one topic before moving on to the next topic (Garson, 2008; Kaden, 2006). Moreover, the language (jargon, abbreviations, and terminology) of the organization was used (Baron, 2006; Borgatti, 1996).

Participants in this study were voluntary members of a private organization, which helped protect against a low response rate. In 2003, Kennedy argued that web-based surveys were the future and offered the potential to provide the most sophisticated survey processes, incorporating the best features of both interviewer- administered and self-administered questionnaires, while eliminating some of the problems. The WCC/CVV questionnaire accomplished these goals.

Approval to conduct the research of both the pilot and the proposed research study was also obtained. The data were analyzed by the researcher using the descriptive univariate analysis method of frequency distribution presented in percentages. According to Trochim (2006), univariate analysis involves the examination of one variable at a time across cases, and the distribution is a summary for a variable of the frequency of individual values, or ranges of values, which can be displayed using percentages. Each of the questions on the survey instrument was evaluated independently of all others. Each response for each question was listed (i.e. Survey 1, question 1, answer: A; Survey 2, question 1, answer: B). The total for each answer (i.e. all of As, all of Bs) was tabulated by the researcher and the percentage of each was calculated based on the total number of respondents. Additionally, each section in Parts I-IV, was tabulated by the researcher in order to present a section percentage.

FINDINGS

The purpose of this study was to describe the benefits (personal enrichments of online support to women with gynecologic cancers and pre-cancers). The focus was to allow women to relate their experiences, through survey method, with online support and the benefits,

advantages, disadvantages, and/or deficiencies of participation. The results 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. A pilot study was conducted prior to conducting the actual research 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 sub-group, CVV. This return rate was achieved through an online survey using a Likert-like scale. The survey was available for two weeks.

For the research question posed, "What are the benefits (personal enrichments) of online support to women with gynecologic cancers and pre-cancers?" data reflecting the benefits (personal enrichments) for members of WCC (N=246) and its subgroup, CVV (N=133), support groups for women with gynecologic cancers and pre-cancers were collected from Part I (Questions 1–22) and Part IV (Questions 55–64) of the survey instrument.

In Part I (questions 1–22) of the survey, all 22 questions were affirmed as benefits by both groups. WCC (N=246) unanimously affirmed 14 items as benefits, while CVV (N=133) unanimously affirmed seven items. The item affirmed with the lowest percentage (75.2%) from the WCC group was question 10, "I have felt more comfortable knowing that no one is looking at me when I share my story, feelings, problems, or ask questions, etc. than I think I would have felt in a face-to-face group." The item affirmed with the lowest percentage (66.9%) from the CVV group was question 3, "I found myself being the emotional support for family (significant other, children, parents, grandparents, etc.) and/or friends [by downplaying my feelings, OR by putting on a "happy face" when I didn't feel like it, OR by not talking about my condition as much as I needed]."

In Part IV (Questions 55–64) of the survey, the 10 items were affirmed as benefits by both groups. WCC (N=246) unanimously (100%) affirmed five items as benefits, while CVV (N=133) unanimously (100%) affirmed three items. The item affirmed with the lowest percentage (85%) from the WCC group was question 62, "My support group is Peer-to-Peer (run by regular people like me who also have experienced gyne [gynecologic] cancers and disorders). I would rather be in a group that was run by trained professionals like therapists, doctors, or nurses." This was a reversed question where the affirmation was achieved by disagreeing. The item affirmed with the lowest percentage (69.9%) from the CVV group was question 57, "There have been times, because of depression, when I could not have dealt with going to a face-to-face group, but I was able to go to my online group, even if it was just to lurk." As indicated in Table 1 (Appendix) are the results from Part I (Questions 1–22) and as indicated in Table 2 (Appendix) are the results from Part IV (Questions 55–64) of the survey instrument. Reversed questions are Part I, number 8 and Part IV, number 62.

CONCLUSIONS

This study surveyed 472 current and former members of a WCC online support group as to their perceptions of benefits (personal enrichments). The total number of WCC members was 304, with 246 (80%) participating in the survey. The total number of CVV members was 168, with 133 (79%) participating in the survey.

Parts I and IV of the survey instrument were used to address the research question posed in the study. The results from these two support groups were computed separately in order to

achieve a more accurate indication of the responses because the conditions being faced by the women were different. The members of the WCC had cancer, while the members of the CVV had dysplasia, a pre-cancerous condition. The members of the WCC faced the additional concern of mortality that the members of the CVV did not. In fact, the WCC group has suffered the deaths of several of its members. Additionally, the treatments for cancer can be more brutal than for dysplasia, including radiation and chemotherapy, and recovery can be longer and more debilitating. Conversely, while some gynecologic cancers have been linked to the human papillomavirus (HPV), all the gynecologic dysplasia conditions have been linked. HPV is incurable, and permanent respite must come from the body's own immune system. HPV related conditions are subject to a high rate of recurrence. HPV can lay dormant in the body for decades and can recur when the immune system falters. Therefore, it was concluded from the results of this study that while the medical conditions are inherently different, the psychological toll from, and the emotional ramifications of the wide range of gynecologic illnesses are very much alike.

The women were varied in demographics (age, marital status, time since diagnosis, and participation in group). Yet, these differences did not divide the women's opinions along these demographic lines. The conclusion drawn was that these two groups were very cohesive in their opinions of the benefits (personal enrichments) and the advantages of support groups being online. It was further concluded that the women share many of the same psychological and emotional needs and desires, which can be met with online support.

The results revealed that the majority (WCC [N=246], 83%; CVV [N=133], 72%) of the women accessed their support group more than once a day. Therefore, it was concluded that face-to-face support groups that meet for one to two hours a week are not nearly sufficient, and that online support offers women the group time that they need.

Since online support groups offer the advantage of having many ongoing conversations at one time, the women participating in the group can choose which conversations are applicable to them. In doing so, everyone's 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. This would not be possible in a face-to-face group where only one woman at a time could speak.

The results demonstrate longevity (4 years but fewer than 5: WCC, 12%; CVV, 20%; 5 to 10 years: WCC, 29%; CVV, 20%; more than 10 years: WCC, 18%; CVV, n/a) of membership in these online support groups. This led to the conclusion that gynecologic cancers and pre-cancers and the emotional ramifications incurred are of long duration and that women need support for longer than might be expected. Coupled with the advantage of online support being available virtually 24/7 where a woman can participate at her own convenience, online support is the ideal venue for women facing conditions of long duration.

Furthermore, it was concluded that the knowledge of women being more alike than different promotes online support as the superlative medium for support. Transcending demographics and degrees of gynecologic illness and embracing large numbers of women across wide geographic areas, online support is a major tool for aiding women in finding self-help.

This study examined the benefits (personal enrichments) of online support to women with gynecologic cancers and pre-cancers. The following recommendations are based on the findings in the study.

1. The results of this study revealed that asking specific questions regarding benefits (personal enrichments) garnered more specific information than just reading emails posted to online groups. Therefore, it is recommended that further research target

specific items regarding perceived benefits and allow the participants to decide which are beneficial to them.

2. The results of this study indicated that asking precise questions regarding advantages of support being online harvested more specific information than making assumptions by reading emails posted to online groups. Therefore, it is recommended that further research target explicit items regarding perceived advantages and allow the participants to decide which are advantageous to them.

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APPENDICES

APPENDIX A

Table 1
Results of Part I (Questions 1–22)

| Part I | Group | Percentages | | | | | | | | | | | | 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 | Total No Answer | |
| Questions 1-22 | --- | | | | | | | | | | | | | |
| 1. My online support group has been (was) a positive addition to my life. | WCC | 89.4% | 10.6% | 0.0% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 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% |
| 2. I need (needed) to be with women who are experiencing the same things I am. | WCC | 81.3% | 18.7% | 0.0% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 66.2% | 28.6% | 5.3% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| 3. I found myself being the emotional support for family (significant other, children, parents, grandparents, etc) and/or friends [by downplaying my feelings, OR by putting on a “happy face” when I didn't feel like it, OR by not talking about my condition | WCC | 59.8% | 10.2% | 18.7% | 88.6% | 0.0% | 0.4% | 7.7% | 3.3% | 11.4% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 32.3% | 22.6% | 12.0% | 66.9% | 10.5% | 2.3% | 20.3% | 0.0% | 22.6% | 0.0% | 0.0% | 10.5% | 100.00% |
| 4. For whatever reasons, I would have been emotionally alone without my support group. | WCC | 56.9% | 6.5% | 26.0% | 89.4% | 0.0% | 10.2% | 0.4% | 0.0% | 10.6% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 30.1% | 35.3% | 26.3% | 91.7% | 0.0% | 4.5% | 3.8% | 0.0% | 8.3% | 0.0% | 0.0% | 0.0% | 100.00% |
| 5. My online support group helped me to deal with my emotional distress. | WCC | 64.2% | 32.9% | 2.8% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 72.9% | 21.8% | 5.3% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| 6. I believe that my online support group has made a positive difference in my quality of life. | WCC | 74.4% | 25.6% | 0.0% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 79.7% | 9.8% | 5.3% | 94.7% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 5.3% | 5.3% | 100.00% |
| 7. My online support group has made positive difference in my emotional health. | WCC | 79.7% | 14.6% | 5.7% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 80.5% | 9.0% | 5.3% | 94.7% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 5.3% | 5.3% | 100.00% |
| 8. Joining my online support group has NOT helped me. | WCC | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 8.1% | 91.9% | 100.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 40.6% | 59.4% | 100.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| 9. I bonded with the women in my online support group. | WCC | 53.3% | 22.0% | 19.5% | 94.7% | 5.3% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 5.3% | 100.00% |
| | CVV | 57.9% | 36.8% | 0.0% | 94.7% | 5.3% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 5.3% | 100.00% |

Table 1 continued

| Part I continued | 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 | | |
| Questions 1-22 | --- | | | | | | | | | | | | | |
| 10. I have felt more comfortable knowing that no one is looking at me when I share my story, feelings, problems, or ask questions, etc. than I think I would have felt in a face-to-face group. | WCC | 30.9% | 23.6% | 20.7% | 75.2% | 2.4% | 9.3% | 13.0% | 0.0% | 22.4% | 0.0% | 0.0% | 2.4% | 100.00% |
| | CVV | 12.0% | 53.4% | 29.3% | 94.7% | 5.3% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 5.3% | 100.00% |
| 11. I believe that my stress levels have been reduced because of my online support group. | WCC | 62.2% | 29.3% | 8.5% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 58.6% | 25.6% | 10.5% | 94.7% | 0.0% | 5.3% | 0.0% | 0.0% | 5.3% | 0.0% | 0.0% | 0.0% | 100.00% |
| 12. Participating in my online support group helped me find strength and/or courage to face all I have faced that I did not feel before I joined. | WCC | 66.7% | 24.8% | 8.5% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 41.4% | 23.3% | 24.8% | 89.5% | 10.5% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 10.5% | 100.00% |
| 13. Just knowing that I am (was) not alone is (was) important and makes (made) a positive difference. | WCC | 91.1% | 8.9% | 0.0% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 84.2% | 10.5% | 5.3% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| 14 Even though the gynecologic cancers and/or pre-cancers are of different types in my group, I find that the feelings, emotions, and experiences of the members are a lot like my own. | 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 | 63.9% | 36.1% | 0.0% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| 15. In my support group, I have always been encouraged to express my emotions and feelings no matter what those emotions and feelings were (are). | WCC | 88.6% | 11.4% | 0.0% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 75.2% | 24.8% | 0.0% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| 16. Just writing down my thoughts and feelings when I am getting ready to send a post to my support group makes me feel better. | WCC | 44.3% | 30.5% | 11.0% | 85.8% | 0.0% | 0.0% | 6.9% | 0.0% | 6.9% | 0.0% | 7.3% | 7.3% | 100.00% |
| | CVV | 36.8% | 34.6% | 23.3% | 94.7% | 0.0% | 0.0% | 5.3% | 0.0% | 5.3% | 0.0% | 0.0% | 0.0% | 100.00% |
| 17. I have become more confident in dealing with doctors and other medical personnel since joining my online support group. | WCC | 69.9% | 18.3% | 6.9% | 95.1% | 0.8% | 0.0% | 4.1% | 0.0% | 4.1% | 0.0% | 0.8% | 0.8% | 100.00% |
| | CVV | 53.4% | 25.6% | 10.5% | 89.5% | 10.5% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 10.5% | 10.5% | 100.00% |
| 18. My online support group has been my major source of support throughout this experience. | WCC | 89.0% | 11.0% | 0.0% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 57.9% | 16.5% | 12.0% | 86.5% | 5.3% | 4.5% | 3.8% | 0.0% | 8.3% | 0.0% | 0.0% | 5.3% | 100.00% |

Table 1 Continued

| Part I continued | Group | Percentages | | | | | | | | | | | Total No Answer | Total |
|---|-------|--------------|-------|------------|-------------|------------|----------------|-----------|------------------|-----------------|----------------|------|-----------------|---------|
| | | Strong Agree | Agree | Mild Agree | Total Agree | No Opinion | Mild Dis-Agree | Dis-Agree | Strong Dis-Agree | Total Dis-agree | Does not apply | Pass | | |
| Questions 1-22 | --- | | | | | | | | | | | | | |
| | WCC | 71.1% | 11.4% | 6.5% | 89.0% | 1.2% | 3.7% | 2.4% | 0.8% | 6.9% | 0.0% | 2.8% | 4.1% | 100.00% |
| 19. I have learned a lot about medical matters since joining my support group. | CVV | 66.9% | 22.6% | 5.3% | 94.7% | 5.3% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 5.3% | 100.00% |
| | WCC | 55.3% | 29.3% | 9.3% | 93.9% | 2.4% | 1.6% | 2.0% | 0.0% | 3.7% | 0.0% | 0.0% | 2.4% | 100.00% |
| 20. I have learned a lot about myself and what I am capable of handling since joining my support group. | CVV | 42.9% | 46.6% | 0.0% | 89.5% | 10.5% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 10.5% | 100.00% |
| | WCC | 71.5% | 19.5% | 8.9% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| 21. I have found that giving support to others in my group is helpful to me. | CVV | 49.6% | 32.3% | 12.8% | 94.7% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 5.3% | 0.0% | 5.3% | 100.00% |
| | WCC | 62.6% | 37.4% | 0.0% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| 22. My support group is helping me (or has helped me) work through the stages of the natural grieving process associated with cancers and/or pre-cancers. | CVV | 48.9% | 25.6% | 12.8% | 87.2% | 0.0% | 0.0% | 0.8% | 0.8% | 1.5% | 6.0% | 5.3% | 11.3% | 100.00% |

Due to rounding, totals may not compute to 100%

J B

S B

APPENDIX B

Table 2

Results of Part IV (Questions 55–64)

| Part IV Questions 55-64 | 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 | | | |
| 55. I like the option of being able “to lurk” (read posts, follow discussions, gain information without having to participate and without anyone knowing whether I am there or not) in my online group. | WCC | 53.3% | 29.3% | 13.8% | 96.3% | 1.2% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 2.4% | 0.0% | 3.7% | 100.00% |
| | CVV | 54.1% | 35.3% | 10.5% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| 56. I talk about things in my online support group that I would not want broadcast to the people I see on a daily basis (such as co-workers, church members, and/or casual acquaintances, etc). | WCC | 72.8% | 24.4% | 2.8% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 28.6% | 63.2% | 8.3% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| 57. There have been times, because of depression, when I could not have dealt with going to a face-to-face group, but I was able to go to my online group, even if it was just to lurk. | WCC | 70.3% | 17.5% | 2.8% | 90.7% | 0.0% | 0.0% | 9.3% | 0.0% | 9.3% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 41.4% | 28.6% | 0.0% | 69.9% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 30.1% | 0.0% | 30.1% | 100.00% | |
| 58. There have been times, (for whatever reasons - other than depression) when I could not have dealt with going to a face-to-face group, but I was able to go to my online group, even if it was just to lurk. | WCC | 52.8% | 38.2% | 8.9% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 41.4% | 32.3% | 21.1% | 94.7% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 5.3% | 0.0% | 5.3% | 100.00% | |
| 59. One of the reasons that I like my online group is because I can be somewhat detached (I do not have to actually face a woman when she is telling her emotion-filled, heart-wrenching story. I read her pain and I know her pain, but I do not have to | WCC | 51.6% | 22.0% | 19.9% | 93.5% | 3.7% | 2.8% | 0.0% | 0.0% | 2.8% | 0.0% | 0.0% | 0.0% | 3.7% | 100.00% |
| | CVV | 25.6% | 45.1% | 24.1% | 94.7% | 5.3% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 5.3% | 100.00% |
| 60. Sometimes, I just do not want to deal with a subject or topic and I can just delete it and move on. | WCC | 50.8% | 29.7% | 19.5% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 84.2% | 10.5% | 0.0% | 94.7% | 5.3% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 5.3% | 100.00% |
| 61. I am (was) able to express my full range of emotions (fears, doubts, sadness, joy, etc) by writing to the group. | WCC | 69.5% | 30.5% | 0.0% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| | CVV | 45.9% | 30.8% | 15.8% | 92.5% | 0.0% | 3.8% | 3.8% | 0.0% | 7.5% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% |
| 62. My support group is Peer-to-Peer (run by regular people like me who also have experienced gynecancers and disorders). I would rather be in a group that was run by trained professionals like therapists, doctors, or nurses. | WCC | 11.8% | 0.0% | 2.8% | 14.6% | 0.0% | 0.4% | 27.6% | 56.9% | 85.0% | 0.0% | 0.4% | 0.4% | 100.00% | |
| | CVV | 0.0% | 0.0% | 0.0% | 0.0% | 5.3% | 10.5% | 42.9% | 41.4% | 94.7% | 0.0% | 0.0% | 5.3% | 100.00% | |
| 63. When I first joined my online support group, I would have felt more cautious and/or more hesitant about speaking of private matters if I had been in a face-to-face support group in a room full of hometown local women for fear that someone might talk a | WCC | 65.0% | 8.1% | 21.5% | 94.7% | 0.0% | 5.3% | 0.0% | 0.0% | 5.3% | 0.0% | 0.0% | 0.0% | 100.00% | |
| | CVV | 40.6% | 39.8% | 8.3% | 88.7% | 5.3% | 3.0% | 3.0% | 0.0% | 6.0% | 0.0% | 0.0% | 5.3% | 100.00% | |
| 64. Since my online support group is a private group (meaning that a woman has to apply for membership and be accepted before she can post or read the posts and no outsider can read or post), I feel comfortable posting. | WCC | 80.5% | 10.6% | 8.9% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% | |
| | CVV | 66.2% | 28.6% | 5.3% | 100.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 100.00% | |