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PERCEPTIONS OF THE MEMBERS OF AN ONLINE SUPPORT GROUP FOR WOMEN WITH GYNECOLOGIC CANCERS AND PRE-CANCERS REGARDING ONLINE SUPPORT, ILLNESS, INFORMATION, AND AWARENESS

By

Elaine Parrish

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PERCEPTIONS OF THE MEMBERS OF AN ONLINE SUPPORT GROUP FOR WOMEN WITH GYNECOLOGIC CANCERS AND PRE-CANCERS REGARDING ONLINE SUPPORT, ILLNESS, INFORMATION, AND AWARENESS

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The purpose of this study was to describe the perceptions of women diagnosed with gynecologic cancers or pre-cancers regarding participation in an online support group. 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.

A survey instrument consisting of 6 parts was used in this study. Part I and Part IV of the instrument were designed to collect data regarding the benefits (personal enrichments) of participating in an online support group. Part II and Part III were designed to collect data regarding the advantages of a support group being online, while Part V collected data regarding online support, illness, information, awareness, and sense of self. Part VI collected demographic information and personal information. The research questions posed in the study were developed to examine benefits, advantages, and information about participating in an online support group.

The results from this study indicated that there are many benefits (personal enrichments) of online support for the women with gynecologic cancers and pre-cancers who joined these groups, as well as many advantages for them of a support group being online. The results also 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. 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 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.

DEDICATION

This doctoral dissertation is dedicated, first and foremost, to the members of my family for their support, encouragement, and tolerance throughout this journey. Additionally, it is dedicated to Marie and the ladies of Women Conquering Cancer (WCC) and CIN/VIN/VaIN (CVV) for their friendship, commitment, counsel, and assistance, and without whom this pursuit would not have been possible. A special note of gratitude to Marie for her years of devotion to the WCC and CVV, and for her unwavering friendship. Finally, it is dedicated to the memory of the WCC ladies who departed from us too soon, but touched our hearts and made us stronger–Terrie, Frankie, Antoinette, and JoAnn.

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A heartfelt thank you to all the friends who stood by me during this process. I am so grateful to you all for your support. Respecting the limited space, I'd like to mention a few who contributed so much. Melissa, thank you for always being there. To Cindy and Paul, thank you for answering my desperate call for technical help and giving so freely of your time and resources. Thank you Carol and Cheryl, for giving me encouragement and confidence. To the Wrens, thank you for so much for so long. I always knew you were there when I needed a place to turn.

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CHAPTER I

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.

Of the gynecologic cancers, only cervical cancer has a standard screening test, which is called the Pap test (National Cancer Institute, 2007). It is estimated that cases of In Situ cervical cancer, also known as non-invasive cervical cancer or stage 0, is 4 times more prevalent than the number of invasive cervical cancer cases (Frosted Pink, 2007; Oregon Health & Science University [OHSU], 2003; Robert Wood Johnson University Hospital, 2004; St. John's Mercy Health Care, 2008). This would bring the total cases of cervical cancer to 48,800 for 2010. If the four-times-more estimate were indicative of all gynecologic and female anal cancers, the total cases of cancer would be 348,040 for 2010.

The Pap test screens for and detects pre-cancerous conditions called cervical intraepithelial dysplasia (CIN), which is categorized in three stages. Of the, approximately, 55 million Pap tests a year, approximately, 3.5 million will show abnormalities (National Cancer Institute, 2007). Approximately 1.2 million of these 3.5 million women have a cervical squamous cell intraepithelial lesion (SIL), categorized as low-grade dysplasia known as cervical intraepithelial neoplasia stage one (CIN 1).

An additional 300,000 women have high-grade dysplasia known as CIN 2 or CIN 3, depending on the severity (Mahdavi & Monk, 2005; Tigris Pharmaceuticals, 2005). CIN 3 is the stage before In Situ (stage 0) cancer. The treatments for the three stages of CIN, In Situ, and the earlier stages of cervical cancer are basically the same (Mayo Clinic, 2007; Trust, 2008). There are no screening tests for the other four gynecologic intraepithelial (I) neoplasia (N) conditions (vulvar [VIN], vaginal [VaIN], perianal [PaIN], and anal [AIN]) and, consequently, no uniform tracking systems.

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).

Additionally, 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).

These physical, social, and life maintenance issues prompted researchers 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 (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). 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 concluded, as did Anderson and Lutgendorf (1997), that the reasons for the conflicting results included 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. These authors concluded that attention to these physical and emotional conditions was important for the overall health and well-being of patients and survivors.

The importance of attention to the emotional ramifications of gynecologic cancer emerged as a major element for the overall health and well-being of cancer patients (Barnett, 2007; Beesley et al., 2005; Chan, Molassiotis, Yam, Chan, & Lam, 2001; Corney, Everett, Howells, & Crowther, 1992; Institute of Medicine [IOM] Committee, 2007; Puccio, 2007). The evolution of this research led to a focus on group support (Boscaglia & Clarke, 2007; Butow et al., 2007; Hodgkinson et al., 2007; Steginga & Dunn, 1997). The groups studied were face-to-face groups where women gathered together at a physical location. These researchers have concluded that support and support groups are important, even vital, to a woman's coping with all stages of disease and recovery.

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) also 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.

Statement of the Problem

The emotional ramifications of those with cancer, and to a lesser degree, those with gynecologic cancers, have been researched and found imporant. 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.

As the literature confirmed (Davison et al., 2000; Meier et al., 2007) not a lot of attention has been given to online support groups. 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 et al. (2005), also using 10 groups from ACOR, did invite new members to participate in a survey, which focused on why they joined. The study has not been found that has directly addressed the women dealing with gynecologic cancers and pre-cancers in a private, listserv environment.

Purpose

The purpose of this study was to describe the personal perceptions of women diagnosed with gynecological cancers or pre-cancers regarding participation in an online support group. 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 women are members of a private listserv group, Women Conquering Cancer (WCC), who are women with gynecologic cancers, and its subgroup, CIN/VIN/VaIN (CVV), who are women with gynecologic pre-cancers, that requires membership. Only members were allowed to read or 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.

Research Questions

This study focused on women diagnosed with a gynecologic cancer or pre-cancer who joined the online support group, WCC, and its subgroup, CVV, and their perceptions of online support and the benefits, advantages, disadvantages, and/or deficiencies of participation. The study answered the following research questions:

1. What are the benefits (personal enrichments) of online support to women with gynecologic cancers and pre-cancers?
2. What are the advantages of a support group being online?
3. What are the members' perceptions about support, illness, information, awareness, and sense of self?

Definition of Terms

The following definitions were used in this study:

Members [of an Online support group]: Females over the age of 21 years who joined the online support group, WCC, and its subgroup, CVV.

Online support group: Refers to two private listserv groups offering a self-help environment where women gain access by applying for membership and being accepted.

Perceptions regarding online support, illness, information, and awareness: For the purposes of this 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.

Limitations

This study was limited to the 472 members, past and present, of the online support group, WCC, and its subgroup, CVV. While this group represented less than .01% of the women expected to be diagnosed in 2010 with a gynecologic cancer (83,750), prior research, such as that listed in this section of this report, has shown that women experience many of the same reactions, treatments, problems, and concerns, and have many factors in common. Generalizations from the study should be limited to only the population described and cannot be applied to any other group.

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 is 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 increase the base of information and knowledge.

A comparable study of an online support group of 10 years with a membership of 472 may exist, but this researcher has not found one. The areas of inquiry of this study included some of the areas of inquiry, findings, assumptions, and conclusions of other researchers as are reported in Chapter II, the Review of Related Literature.

The findings of this study supported or refuted some of those assumptions and conclusions. Where supporting results were found, it provided credence to the former assumptions and conclusions as well as to this study. Where the results were in opposition, it may prompt other researchers to question. Either way, the results of this study offer other researchers a basis for further inquiry.

CHAPTER II

REVIEW OF RELATED LITERATURE

The purpose of this study was to focus on a group of women diagnosed with a gynecologic cancer or pre-cancer and their perceptions of online support and the benefits, advantages, disadvantages, and/or deficiencies of participation. Each joined the online support group, WCC, or its subgroup, CVV.

This chapter is divided into eight sections. The first section is Overview of Gynecologic Cancer and Pre-cancer, which defines and explains the cancers and pre-cancers. The second section is Physical Aspects of Gynecologic Cancer and Pre-cancer, which describes and explains the physical ramifications of these cancers. The third section is Emotional Aspects of Gynecologic Cancer and Pre-Cancer, which defines, describes and explains the emotional consequences of these cancers. The fourth section, Emotional Support, describes and explains the importance and benefits of emotional support.

The fifth section, Support Groups, defines, describes and explains the effects, both positive and negative, of face-to-face support groups, and the advantages of face-to-face groups, much of which is applicable to online groups. The sixth section, Writing Therapy, describes and explains the importance and benefits of writing therapy, which is an ancillary therapy gained by participation in an online support group. The seventh section is Online Support, which defines, describes and explains online support. The chapter concludes with an eighth section, Summary of the Review of Related Literature.

Overview of Gynecologic Cancer and Pre-cancer

For the purposes of this study, gynecologic cancer was separated into invasive cancer (those reported by the ACS (2010) in its annual report, *Cancer Facts & Figures 2010*) and non-invasive cancer (called carcinoma in situ (CIS) as well as cancer, stage 0), which is not counted in the ACS annual report of totals of cancer cases (p. 1). All pre-cancers fall into the non-invasive category and, therefore, are not included in the annual report from the ACS.

Non-invasive cancer (CIS; cancer, stage 0) is cancer detected at its earliest stage while it is still confined to the point of origin (i.e. it has not begun to spread deeper, which constitutes invasive cancer); (Cherath, Alic, & Odle, 2004; Ninger & Odle, 2004; Medterms, 2005).

Gynecologic cancer–invasive, non-invasive, and pre-cancer–originates in the female reproductive organs, which include the cervix, ovaries, uterus, endometrium, vagina, vulva, and fallopian tubes (Canadian Women’s Health Network, 2004). The vulva is the area of the female genitalia that is exterior on the body and this exterior area includes the vulva, perineum, and anus (American College of Obstetricians and Gynecologists [ACOG], 2007). Female anal and perianal cancers were included in the category of gynecologic cancers for the purposes of this study because the support group studied here includes them.

ACS (2010) annual report, *Cancer Facts & Figures 2010*, estimated that 83,750 women would be diagnosed with an invasive gynecologic cancer in 2010 and 27,710 (33%) would die. It divided these invasive cancers into five sub-groups. The five sub-groups with the number of women projected to be diagnosed in 2010 and the number of expected deaths were as follows: cervical cancer diagnoses were expected to be 12,200 with 4,210 (35%) deaths; uterine corpus diagnoses, which includes endometrial (42,270 cases) and uterine sarcoma (1,200 cases), were expected to be 43,470 with 7,950 (18%) deaths; ovarian cancer diagnoses were expected to be 21,880 with 13,850 (63%) deaths; vaginal and other genital cancers diagnoses were expected to be 2,300 with 780 (33%) deaths (other genital was not defined); and vulvar cancer diagnoses were expected to be 3,900 with 920 (24%) deaths. Additionally, there is female invasive anal cancer and 3,260 diagnoses were expected with 440 (14%) deaths. This brought the total number of women estimated by the ACS to be diagnosed with invasive gynecologic cancer in the U.S. in 2010 to 87,010 and the total deaths estimated to 28,150 (32%).

The ACS (2010) annual report, *Cancer Facts & Figures 2010*, did not include CIS, which is non-invasive cancer, or pre-cancer statistics. Some researchers believe that non-invasive cervical cancer is about 4 times as common as invasive types (ACS, 2008; OHSU, 2003; Robert Wood Johnson University Hospital, 2004; St. John's Mercy Health Care, 2008).

If the invasive cervical cancer cases number 12,200, then 4 times as many cases of non-invasive cervical cancer would equal 48,800. Consequently, this omission in the *Cancer Facts & Figures 2010* report from the ACS (2010) includes women with vulvar, vaginal, and anal cancer (external gynecologic cancers) staged carcinoma in situ (CIS;

cancer, stage 0). If there are 4 times as many CIS cases for each of these cancers also, the CIS cases would total 86,640. The figures would be 48,800 cervical, 9,200 vaginal, 15,600 vulvar, and 13,040 anal. It would almost double the ACS 2010 projection of 87,010 cases for a subtotal of 173,650 women with both invasive and non-invasive gynecologic cancer in 2010. If the internal gynecologic cancers (endometrial [42,270], uterine corpus [1,200], and ovarian [21,880]) are also 4 times as prevalent, the numbers become endometrial 169,080, uterine corpus 4,800, and ovarian 87,520 for an additional sum of 261,400. That would bring the total of all active gynecologic cancers to 435,050.

There are five gynecologic pre-cancers (Cherath, Alic, & Odle, 2004; Indman, 2000). They are CIN, VIN, and VaIN, PaIN and AIN. *Intraepithelial Neoplasia* simply translated means *new* (neo) *growth of cells that are not normal* (plasia) in the *outer layer* (named epithelial) of the *skin cells* (named squamous) and *contained to this area* (intra).

These pre-cancerous cells form a lesion also called dysplasia. Dysplasia is also known as *squamous intraepithelial lesions*, so-named because it occurs within the epithelial layer (outer layer) of skin cells (named squamous). These abnormal cell conditions are commonly described as *Intraepithelial Neoplasia*, hence CIN, VIN, VaIN, PaIN, and AIN.

These pre-cancerous situations, if not treated, can progress to cancer if the abnormal cells start to grow uncontrollably into the deeper layers of the skin. This growth into the deeper layers constitutes invasive cancer (Cherath et al., 2004). Severe dysplasia (stage 3 of 3 stages) may be categorized as, or may progress to, *carcinoma in situ* [cancer contained to the site of origin], which is non-invasive cancer (also known as cancer, stage

0) and is cancer detected at its earliest point before it invades surrounding tissue (Cherath et al., 2004; Medterms, 2005).

One known fact regarding causes of gynecologic cancers and pre-cancers is the human papillomavirus [sic] (HPV) (ACS, 2007b; Friedlander, 2005a, 2005b, 2005c; Palkhivala, 2001). HPV is a group of viruses with over 100 identified strains which range from the innocuous to the pernicious (CDC Fact Sheet, 2006). A papilloma is a wart-like growth and some of the strains cause the innocuous common warts occurring on the hands, feet, and extremities. HPV is a virus that lives on the skin and is transferred by skin-to-skin contact (Friedlander, 2005a, 2005b, 2005c; Palkhivala, 2001).

More than 30 of these 100 virus strains are sexually transmitted and can infect the genital area of men and women (CDC, 2008). The CDC reported that approximately 20 million people are currently infected with genital HPV and about 6.2 million people acquire genital HPV each year. At least 50% of sexually active men and women acquire a genital HPV infection at some point in their lives, and by age 50, at least 80% of women will have acquired a genital HPV infection (Brodsky, 2004; CDC Fact Sheet, 2006).

These 30 strains come in low-risk and high-risk categories with about half of them being high-risk [cancer causing] (CDC, 2008). The most common evidence of infection of the high-risk strains is the abnormal Pap test results indicating CIN, cervical CIS, or invasive cervical cancer. This group of the high-risk strains of the genital HPV viruses causes approximately 90% of all cervical cancers and pre-cancers (CDC Fact Sheet, 2006). Additionally, some vulvar, vaginal, perianal, and anal cancers and pre-cancers, as well as some cancers of the mouth, throat, and neck have been associated with HPV infections (Brodsky, 2004).

Most people with HPV do not ever develop symptoms. Even so, the virus is still highly contagious. Some researchers believe that HPV infections may self-resolve and may not be life-long like the herpes virus (American Social Health Association [ASHA], 2005). Others believe that the virus lives, but lays dormant because a healthy immune system keeps it in check (ASHA, 2005; CDC Fact Sheet, 2006). Recurrence is common because there is no cure once identified. Those infected with HPV can be infected simultaneously with multiple HPV types, including both low-risk and high risk strains, as well as multiples of either (CDC Fact Sheet, 2006).

Because of the Pap test, the only uniform statistics for a pre-cancer are for cervical dysplasia, and one million (1,000,000) cases of CIN are detected each year in the U.S. (Cherath, Alic, & Odle, 2004; Lynch, 2003). Through extrapolation (1,000,000/12,200 = 81.97), CIN (1,000,000) is 81.97 times more prevalent than invasive cervical cancer (12,200). If VIN, VaIN, and AIN are 81.97 times as prevalent also, the numbers are 1,000,000 cervical; 188,525 vaginal; 319,672 vulvar; and 267,213 anal for a total of 1,775,410 women afflicted with a pre-cancer condition in 2010. This would bring the total number of women with an invasive gynecologic cancer (87,010) or external CIS (86,640) or internal CIS (261,400) or a pre-cancer (1,775,410) to 2,210,460.

Cooper Surgical, Inc. (2001) reported that 50 million Pap tests are done each year. The U.S. Census Bureau (2006) reported that there were 108,369,877 adult women in the U.S. as of 2000. That equates into less than half of the adult female population getting a Pap test each year. According to the rules of mathematical probability, that indicates that the numbers for invasive cervical cancer (12,200), non-invasive cervical CIS (48,800), and CIN (1,000,000) could double if every woman had a gynecologic exam each year.

The Pap test for cervical cancers and pre-cancers is unique to gynecologic cancers and is credited with the early detection of cervical disorders (ACS, 2008b). Yet, vaginal, vulvar, and anal CIS and pre-cancers do have signs that allow for early detection, though many are easily overlooked by women and the doctors who treat them (ACS, 2006a, 2006b, 2007a). Additionally, a simple acetic acid (3-5%) solution (basically, white vinegar) can be applied to the vulva, vagina, and anus and abnormal cell growth will turn white (Friedlander, 2005a; Larsen & Davis, 2005).

Physical Aspects of Gynecologic Cancer and Pre-cancer

Because of embarrassment or fear, diagnoses are often delayed (Berkow & Beers, 2005). Gale (2006) cites embarrassment or denial as the cause of delay in seeking medical attention. A Harris Poll of physicians (N=230) found that 68% of physicans responded that it was difficult to treat hesitant or embarrassed patients and 93% responded that more serious problems could be avoided if patients were more candid (Kate, 1998).

Kate (1998) also reported the findings of the same Harris poll which focused on patients (N=1008) regarding the barriers to patient-physician communication. One goal was to determine why people did not talk about conditions with their doctors. The results showed that 25% of respondents stated *embarrassment/sensitive topic,* making it the number one reason. The response, *symptoms did not seem important,* came in a distant second with 11%. Another goal was to determine which conditions were considered most embarrassing by patients. Both men and women were surveyed, though no gender breakdown was given. Gynecologic conditions ranked fifth behind incontinence (#1)

(85% of sufferers are women), prostate problems, Sexual dysfunction (most common was erectile dysfunction), and sexually transmitted diseases (STDs), in that order.

Public education efforts and media coverage regarding breast cancer screening have made women acutely aware of the importance of mammograms and self-breast examination, but the same cannot be said for gynecologic cancer (Silver, 2003). Gostout (as cited in Silver, 2003) stated, “Far too many patients my fellow gynecologic oncologists and I encounter say they did not know the warning signs or symptoms of various gynecologic cancers until after they were diagnosed with one of these cancers” (p. 1). Many women do not learn that they possess one or more known risk factors until they are diagnosed, while others think all is well if their most recent Pap test results were normal because they incorrectly assume the Pap test screens for all gynecologic cancers, when, in fact, it only reliably screens for cervical cancer (Silver, 2003).

Treatments for gynecologic cancers, including CIS (cancer, stage 0) and all pre-cancers, include doing nothing (called watch and wait); simple surgeries to radical surgeries, both external and internal; pelvic exenteration (removing all female organs, bladder, and rectum); radiation of the female genitalia and pelvic area, both internal and external; chemotherapy; and combinations of these treatments, based on what is seen as most productive for each particular case (Davis, 2004; Ezzell, 2001; Juretzka, Teng, & Husain, 2006; Mayo Clinic, 2007; National Cancer Institute Editorial Board, 2008; Stanford Cancer Center, 2008).

A study (Greimel, Thiel, Peintinger, Cegnar, & Pongratz, 2002) of patients with gynecologic and breast cancer (N=248) found that women with breast cancer had significantly higher mean scores in physical functioning during active treatment compared to women with gynecologic cancers.

Emotional Aspects of Gynecologic Cancer and Pre-Cancer

According to Palkhivala (2001), *You have cancer* are the three scariest words in the English language. The question, *now what?* easily describes the feelings of almost every newly diagnosed cancer patient.

The scope, depth, breadth, and duration of emotions are as unique as each woman, and each phase of the cancer journey–diagnosis, treatment(s), recovery(ies) from treatment(s), adjusting to the aftermath of treatment(s), and moving forward with life–can bring a new cycle of emotions that must be sorted out and worked through (Dorazio-Schantz & Griffo, 2002; Pearman, 2003; Peeke, 2004; Riba, 2001; Turner, 2001).

Riba (2001) reported that many of her patients believe that the emotional issues are often more difficult to deal with than the physical ones, and that about 50% of patients have some form of diagnosable psychiatric disorder sometime during their course of care. She lists psychological distress as including adjustment problems, depression, anxiety, delirium, and substance abuse as major categories with difficulties such as pain management, faith/spirituality, difficulties with family, work-related problems, financial issues, and worries about children causing distress. In a study (N=74), approximately 40% of the sample were found to have sleep disturbance (Pearman, 2003). Factors affecting women are the ramifications of the illness and treatments, the bearing on sexuality, reproduction, and relationships, the effect of forever being changed, and the knowledge that recurrence is always a possibility (Dorazio-Schantz & Griffo, 2002; Pearman, 2003; Peeke, 2004; Riba, 2001; Turner, 2001).

Heilman (2003) suggested that entering into the circumstances that the cancer diagnosis brings does not happen in a vacuum and that people have full lives, problems, and situations with which they are dealing before the diagnosis. She argued that in the midst of the extreme emotions of helplessness, hopelessness, and despair, patients and their families are suddenly faced with the task of learning about a complex disease and managing the intricacies of cancer and its treatment. According to Heilman (2003), it is hard to receive a diagnosis of cancer without thinking about dying—even when the prognosis is good—and some respond to the diagnosis as though it is potentially fatal.

The cancers associated with the female reproductive system presented some unique problems for women that other cancers do not, according to Canavan and Cohen (2002) and DiSaia and Creasman (1997). The reproductive system has an emotional significance beyond that of other body parts and gynecologic cancers are directly tied to a woman's sense of self and sexuality (Canavan & Cohen, 2002; DiSaia & Creasman, 1997). Frequently, women must adjust to physical changes after treatment including loss of ovarian function, hot flashes, vaginal dryness, hair and skin changes, mood changes, surgical scarring, the need for urostomy or colostomy, impaired sexual and reproductive function, infertility, and changes in bowel, bladder, and hormones (Pearman, 2003).

A survey (Basen-Engquist, 2004) of survivors of ovarian cancer (N=200) found that more than half of the women reported that their sex lives had been negatively affected by cancer or its treatment, and 75% described their sex lives as poor to adequate. Basen-Engquist (2004) also reported that in studies of women treated for cervical or endometrial cancer, from 31% to 88% reported problems with sexuality, particularly those who underwent radiotherapy (radiation).

Sexuality does not only refer to sexual intercourse, but includes other methods and means of sexual expression, such as touching and kissing, and intimacy is defined as physical or emotional closeness with another (Women's Cancer Network, 2003). Moreover, women may define how they feel about themselves based on self-esteem and body image, and the many changes that can occur with cancer treatments can affect both. Additionally, changes may be temporary, long lasting, or even permanent. Some of the changes that women can face are hair loss, weight changes, menopause, fatigue, pain, and anxiety. All these changes can have an impact on sexuality and interest (Women's Cancer Network, 2003).

Much of womanhood is defined through the reproductive organs, physiologically because ovaries produce estrogen, and emotionally because of the significance of the womb (Peeke, 2004). Turner (2001) concluded that many women are concerned about their femininity and how their sex lives will be affected. She suggested that, even if they consider their family complete, having a hysterectomy is a concern for many women because they see their uterus as defining their status as a woman. Turner (2001) argued that distress about aging and concerns about sex drive may occur following treatment associated with the onset of menopause.

It is estimated that between 22% and 50% of the women with cancer are depressed, 33% have acute stress disorder, and 3% to 19% have post-traumatic stress disorder (PTSD); (Haran, 2004). She defined PTSD as a condition seen in people who have experienced traumatic events such as natural disasters or military combat.

There is the element of loss in the cancer diagnosis and the grief that accompanies that loss (Kessler, 2008). The grieving process has long been a topic of psychology and has been defined in various stages and assigned assorted names (Babcock, 1997; Bear, 2004; Bissler, 2008; Cancer Survivors Organization, 2004; Memorial Hospital, 2003).

The standard today is the list first formulated by Kubler-Ross (as cited in Kessler, 2008) while working with terminally ill patients when she defined the process her patients went through while coming to terms with their diagnoses. Kubler-Ross named the list the five stages of receiving catastrophic news, which she also called, the five stages of dying (as cited in Bissler, 2008). Kubler-Ross's five stages are denial, anger/blaming, bargaining, depression, and acceptance. Through the years, the list has been, commonly, but erroneously, called the five stages of grief (Bissler, 2008). The true value of the five stages of grief is in the stages being used as originally intended by Kubler-Ross, which is as the five stages of receiving catastrophic news (Bissler, 2008). Additionally, the author maintained that we can extrapolate these stages to the five stages of coping with trauma and death need not be an element. Bissler offered the equation "Change = Loss = Grief" (para. 4).

Bissler (2008) explained Kubler-Ross's five stages by using a traumatic event most have experienced when already late for work: the lost car keys. The first stage is denial (They were right here! This cannot be happening!). The second is anger (*&%#% keys! You are always right here! Somebody moved them!). The third is bargaining (If you will just show up, I will be more careful). The fourth is depression (What's the point? I'm late for work. I give up). The fifth is acceptance (Ok, what's done is done. Let's just move on). Bissler (2008) argued that this is not a trivial example, and that we all go through this process numerous times a day. Each person’s perception of the significance of the loss is produced by the intensity and duration of the change.

Additionally, Bissler (2008) argued that loss covers many events, such as lost keys, a dead battery, the loss of a parking space, a wrong number, the loss of a pet, a job, a move to another city, an overdrawn bank account, etc. The lost keys could take maybe 5 to 10 minutes, the loss of a parking space 5 to 10 seconds, and a traumatic event that involves the criminal justice system can take years (Bissler, 2008).

In death, divorce, or any other significant emotional loss, it is important for a person to grieve and complete the relationship to the pain and unfinished business (Healthy Place, 2004). The way to get over the grief is to go through it because there are no short cuts to it and no bypasses (Sharma, 2005). Failing to work through the five stages of grief is harder on the body and mind than going through the emotions (Healthy Place, 2004).

Being diagnosed with a gynecologic cancer or pre-cancer represents a major loss in a woman’s life (Hebert & Roumeliotis, 2005; Heilman, 2003; Morris, 2008). A woman is forever changed, and there is an adjustment to this new life situation. A woman must allow herself to grieve her loss.

Maizler (2005) concurred that the normal human emotional reaction to a significant loss is grief and that all types of loss carry a certain amount of grief. It is common during grief to have many conflicting feelings, such as sorrow, anger, loneliness, sadness, shame, anxiety, guilt, and that having so many strong feelings can be very stressful (Memorial Hospital, 2003).

For some, the end of cancer treatment is the most difficult time of all because patients feel that they are no longer fighting, and the support of the medical teams is gone (Rich, 2005). He suggested that emotions see-saw and the stages tend to fluctuate as well as flow together.

Grayson (2005) suggested that most workers wonder if they will be able to return to work and whether having a cancer history will make a difference in their employment prospects. She concluded that some do not return to work, and others cannot, but most survivors do return and that returning to work can symbolize a return to normalcy and routine. However, Grayson (2005) argued that one in four cancer survivor employees face some form of employment discrimination. Among the reasons she offered were wrong ideas, false fears about cancer, and uniformed or misinformed management and coworkers.

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 diagnosis of cancer can affect all relationships, and a woman may become closer to some of the people in her life, while others, who are important to the patient, may back away (Adelaide Resource Centre for Women [ARCW], 2004). The researchers did a qualitative study (N=10) and reported that all of the women interviewed had experiences where people who were meaningful to them could not cope with their cancer.

They suggested that a woman surround herself with people who are good for her, that different people give different things, and that positive thoughts and actions are needed. They concluded that a woman needs people who will be sad and angry with her, and people with whom she can be just herself. They argued that good support is invaluable to getting through the time around and after diagnosis.

A woman is likely to experience shock when she first receives a gynecologic cancer diagnosis (Hebert & Roumeliotis, 2005). They 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.

Haran (2004) reported on a Canadian study (N=3,095) that tested participants with breast, prostate, colorectal, and lung cancer with a criteria for measuring distress levels. The study found almost 38% [38% of 3,095 is 1176] of the participants had stress levels that should be treated. Yet, almost half [588] had not sought psychosocial support because they were not aware that they needed it or did not know that support services existed. In a study (N=49) more than half of the women surveyed indicated that they would have attended a support group if one were available to them at the time of diagnosis and treatment (Pearman, 2003).

Carlson (as cited in Haran, 2004) argued that major ramifications can occur from 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.

When cancer treatment is finished, it may still take time for life to get back to normal and one may still feel the need for support from a mental health professional or a support group (National Cancer Institute, 2006). Pollin and Golant (2003) argued that research has shown that cancer patients involved in support groups lived longer than those who were not in a support group.

Hebert and Roumeliotis (2005) suggested that some of the losses experienced from a diagnosis of gynecologic cancer might not be fully realized until several months after treatment has ended. They concluded that it is vital that a woman has a strong support system who will understand the situation and allow her to go through multiple grieving processes over the course of her diagnosis and recovery. Savard (as cited in Haran, 2004) argued this same point and added that some patients find it most difficult when treatments end because they do not have the support of their medical team and they do not feel they are fighting anymore.

Schimmel and Fox (2003) promoted the many benefits of reaching out for support. They concluded, “Anyone whose life has been touched by cancer will find new support from the intimate and empowering voices of the only real experts out there–the people who live with cancer” (p. 1).

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) 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) 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) 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 et al., 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.

Writing Therapy

Since the 1960s, writing one’s feelings has been a legitimate therapeutic tool (Pennebaker, 2005; WholeHealthMD, 2005). WholeHealthMD (2005) reported that while writing therapy has several approaches and is an organized therapy with trained professionals, it is about writing down one’s most private thoughts, fears, and problems, focusing on expressing innermost emotions, and delving into one's internal self. Additionally, WholeHealthMD (2005) argued that there are health benefits from writing therapy, which have been effective in helping people with a variety of physical and emotional problems, including trauma, low self-esteem, depression, grief and loss, and life-threatening illnesses such as cancer.

Sharma (2005) suggested that writing can clarify what you are really thinking and feeling about yourself, about the events related to the loss, and about what you are feeling in relation to others. Pennebaker (2005) concluded that writing about emotional difficulties in our lives can improve physical and mental health.

Weihs (as cited in Mann, 2001) reported about a study regarding women with breast cancer, which found that the women who participated in online support groups were less distressed than women who did not participate. Weihs concluded that there is a beneficial side effect of participating in online groups because of the physical act of writing about strong emotions and feelings.

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.

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.

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.

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) 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) 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.

The Sutton and Raines (2008) study (N=81) found a number of sought after results, such as demographics (the majority were married, white, employed full-time, and had attended some college), Internet use frequency (regular users (72.8% [n=59] daily; 6% [n=4] monthly; and one respondent answered less than monthly), longevity of Internet use (77% [n=63] seven or more years; 17.3% [n=14] four to six years; and 5%

[n=4] two to three years [all had at least two years experience]); and frequency of accessing their online support groups (65% [n=49] daily, 30.9% [n=25] weekly, and 8.6% [n=7] monthly). Additionally, they studied QOL and found 80% (N=64) rated their QOL as excellent or very good, and none rated QOL as poor (M=1.7 [SD 0.8] where 1=excellent and 5=poor).

Furthermore, they found that demographics did not impact self-perceived QOL in any of the participants. They also found that obtaining information was the most frequently given reason for accessing their online support group. Convenience of time and location were the next most frequent reasons. When asked about attending a face-to-face support group, 59 (72.8%) reported that they never attended; 15 (18.6%) reported occasional attendance, and 7 (8.6%) reported monthly attendance in addition to attending the online support group. Participants identified benefits of online support not found in traditional face-to-face support group forum, including the ability to access information 24/7, the freedom of seeking advice by posting questions and reading responses at any time, the elimination of conforming to a set schedule, and the avoidance of waiting until the next scheduled face-to-face group meeting, which could be as many as three to four weeks away.

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.

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.

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.

Gray (2007) also suggested that for some people shyness is the most insurmountable barrier to attending an in-person support group because some find just the prospect of meeting a new group of people daunting, and speaking in a group even more so, while others find talking to other people about very personal issues difficult, if not impossible. Additionally, Gray (2007) argued that there are legitimate issues of the fear of being seen or associated with face-to-face group meetings. She concluded that, for some members, the group needs to be constantly available, not just once a week or so. Gray (2007) contended that these barriers do not exist when one joins online peer support groups because of the flexibility of the groups and because one can attend in one's pajamas without leaving home. She maintained that finding someone online in groups or chat is always possible, especially if you need to talk to someone right away. She concluded that the types of interactions one will find in online peer support groups are much the same as in face-to-face support groups, but without the barriers.

Summary of the Review of Literature

Gynecologic cancer conditions include invasive cancer, non-invasive cancer, and pre-cancer, and originate in the female reproductive organs (Canadian Women's Health Network, 2004). Anal and perianal are also included because they are included in the support group being studied. ACS (2010) annual report, *Cancer Facts & Figures 2010*, estimates that 83,750 women will be diagnosed with an invasive gynecologic cancer in

2010 and 27,710 (33%) will die. Anal cancer adds another 3,260 to the diagnosed and 440 (13%) to the death toll, for an ACS total of 87,010 diagnosed and 28,150 (32%) dying.

Some researchers believed that non-invasive cervical cancer is about 4 times as common as invasive types (ACS, 2008c; OHSU, 2003; Robert Wood Johnson University Hospital, 2004; St. John's Mercy Health Care, 2008). If the invasive cervical cancer cases number 12,200, then 4 times as many cases of non-invasive cancer (CIS; cancer, stage 0) would equal 48,800. As well, this omission in the ACS annual report includes women with vulvar, vaginal, and anal cancer staged carcinoma in situ (CIS; cancer, stage 0). If there are 4 times as many CIS cases for each of these cancers also, the CIS cases would total 86,640 for a total of 173,650 women with both invasive and non-invasive gynecologic cancer in 2010.

There are five gynecologic pre-cancers (Cherath et al., 2004; Indman, 2000). They are CIN, VIN, VaIN, PaIN and AIN. Because of the Pap test, the only uniform statistics for a pre-cancer are for cervical dysplasia, and one million (1,000,000) cases of CIN are detected each year in the U.S. (Cherath et al., 2004; Lynch, 2003). Through extrapolation, that makes CIN 81.97 times more prevalent than invasive cervical cancer (12,200). If VIN, VaIN, and AIN are 81.97 times as prevalent also, then a total of 1,775,410 women are afflicted with a pre-cancer condition in 2010. This could bring the total number of women afflicted in 2010 with an invasive gynecologic cancer (87,010), or external CIS (86,640), or internal CIS (261,400) or a pre-cancer (1,775,410) to 2,210,460.

Cooper Surgical, Inc. (2001) reported that 50 million Pap tests are done each year. The U.S. Census Bureau (2006) reports that there are 108,369,877 adult women in the U.S. (as of 2000). That equates into less than half of the adult female population getting a Pap test each year. Therefore, the numbers, both actual and extrapolated, of those afflicted could be double.

Embarrassment, fear, denial or lack of knowledge can keep women from seeking medical care, which can allow the diseases to progress before diagnosis (Berkow & Beers, 2005; Gale, 2006; Kate, 1998; Silver, 2003). Treatments for gynecologic cancers, CIS (cancer, stage 0) and all pre-cancers, include doing nothing (called watch and wait); simple surgeries to radical surgeries, both external and internal; pelvic exenteration (removing all female organs, bladder, and rectum); radiation of the female genitalia and pelvic area, both internal and external; chemotherapy; and combinations of these treatments, based on what is seen as most productive for each particular case (Davis, 2004; Ezzell, 2001; Juretzka, Teng & Husain, 2006; Mayo Clinic, 2007; National Cancer Institute Editorial Board, 2008; Stanford Cancer Center, 2008).

The scope, depth, breadth, and duration of emotions are as unique as each woman, and each phase of the cancer journey can bring a new cycle of emotions that must be sorted out and worked through (Dorazio-Schantz & Griffo, 2002; Pearman, 2003; Peeke, 2004; Riba, 2001; Turner, 2001). Riba (2001) reported that about 50% of patients have some form of diagnosable psychiatric disorder, such as adjustment problems, depression, anxiety, delirium, or substance abuse, sometime during their course of care. Distress can result from difficulties such as pain management, faith/spirituality, difficulties with family, work-related problems, financial issues, and worries about children (Riba, 2001).

Heilman (2003) suggested that people have full lives, problems, and situations with which they are dealing before the diagnosis, and that in the midst of the extreme emotions of helplessness, hopelessness, and despair, patients and their families are suddenly faced with the task of learning about a complex disease and managing the intricacies of cancer and its treatment. Pearman (2003) concluded that frequently women must adjust to physical changes after treatment including loss of ovarian function, hot flashes, vaginal dryness, hair and skin changes, mood changes, surgical scarring, the need for urostomy or colostomy, impaired sexual and reproductive function, infertility, and changes in bowel, bladder, and hormones. Women’s Cancer Network (2003) asserted that changes (i.e. hair loss, weight changes, menopause, fatigue, pain, and anxiety) may be temporary, long lasting, or even permanent. It is estimated that between 22% and 50% of the women with cancer are depressed, 33% have acute stress disorder, and 3% to 19% have post-traumatic stress disorder (PTSD); (Haran, 2004). Being diagnosed with a gynecologic cancer or pre-cancer represents a major loss in a woman’s life and a woman must allow herself to grieve her loss (Bissler, 2008; Hebert & Roumeliotis, 2005; Heilman, 2003; Morris, 2008).

Adelaide Resource Centre for Women (ARCW); (2004) argued that good support is invaluable to getting through the time around and after diagnosis. Hebert and Roumeliotis (2005) asserted that there is no time to recover from the shock before moving into cancer treatment and that it will be necessary for each woman to collect a lot of information in a brief amount of time in order to 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. Carlson (as cited in Haran, 2004) argued that major ramifications can occur from 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.

When cancer treatment is finished, it may still take time for life to get back to normal and one may still feel the need for support (National Cancer Institute, 2006). Hebert and Roumeliotis (2005) suggested that it is vital that a woman has a strong support system that will understand the situation and allow her to go through multiple grieving processes over the course of her diagnosis and recovery. Schimmel and Fox (2003) concluded, "Anyone whose life has been touched by cancer will find new support from the intimate and empowering voices of the only real experts out there—the people who live with cancer" (p. 1).

Support groups for cancer patients can enhance self-esteem, reduce depression, decrease anxiety and improve relationships with family and friends (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 concluded that cancer patients who attend support groups lead good lives and survive longer than those just receiving medical treatment alone. Confronting deeply personal issues through talking has been found to promote physical health, subjective well-being, and selected adaptive behaviors (Pennebaker et al., 2001).

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. Sharma (2005) concluded 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) concluded that the common understanding within a group is particularly comforting and that the group experience is extremely powerful. Schimmel (2003) suggested that what we can do for each other in a support group is inspire hope and support each other to cope.

One study showed that face-to-face support groups are of little value (Veronesi et al., 1999) and one showed that some face-to-face groups even have a negative effect on patients (Galinsky & Schopler, 1994). Another study showed 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).

Partenheimer (2000) suggested that online support groups may offer some solutions to problems common in face-to-face support groups. He concluded that there is a certain amount of anonymity in online support groups and, 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) suggested 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.

WholeHealthMD (2005) argued that there are health benefits from writing therapy, which have been effective in helping people with a variety of physical and emotional problems, including trauma, low self-esteem, depression, grief and loss, and life-threatening illnesses such as cancer. Pennebaker (2005) concluded that writing about emotional difficulties in our lives can improve physical and mental health. Weihs (as cited in Mann, 2001) concluded that there is a beneficial side effect of participating in online groups because of the physical act of writing about strong emotions and feelings.

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, not having access to transportation, or having to worry about bad weather when traveling. Moreover, 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. Gray (2007) suggested that for some people shyness is the most insurmountable barrier to attending an in-person support group because some find just the prospect of meeting a new group of people daunting, and speaking in a group, even more so, while others find that talking to other people about very personal issues difficult, if not impossible. Gray (2007) concluded that, for some members, the group needs to be constantly available, not just once a week or so. Gray (2007) contended that these barriers do not exist when one joins online peer support groups. She maintained that finding someone online in groups or chat is always possible, especially if you need to talk to someone right away.

In conclusion, 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.

CHAPTER III

METHODOLOGY

The purpose of this study was to describe the personal perceptions of women diagnosed with gynecological cancers or pre-cancers regarding participation in an online support group. The focus was to allow women to relate their experiences with online support and the benefits, advantages, disadvantages, and/or deficiencies of participation. Survey method was used to gather the data.

This chapter describes the methodology and procedures that were used to conduct this study. This chapter includes the following sections: research design, population, instrumentation, data collection, and data analysis.

Research Design

The research design for this study was descriptive method and employed survey methodology. Quantitative research was appropriate for this study since the data collected was presented numerically in percentages. Descriptive method was appropriate because answers being sought were the attitudes and perceptions of cancer patients regarding their experiences with online support. 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).

Participants

The participants for this study were members of an online support group, which totaled 472 past and present members. WCC (N=344), and its sub-group, CVV (N=168), are private groups with 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, 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 consisted of six parts (see APPENDIX A) and was administered to the online support group, WCC, and its subgroup, CVV. The instrument 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). A special pin number was assigned to each group to further ensure security (Norman, 2006).

Careful consideration was given to 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 are 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). The language (jargon, abbreviations, and terminology) of the organization was used (Baron, 2006; Borgatti, 1996).

This questionnaire was extremely long with 102 questions. According to Kaden (2006) the study objectives determine questionnaire length. Sheth (1975) found, through analysis of variance, that there was no difference in the response rates of a mailed survey with 23 questions and a mailed survey with 49 questions. Garson (2008) advocated that there is no set length for a survey, and it should be as long as needed, keeping the attention span and interest level of respondents in mind. Interest level in the subject matter of the participants emerged as a main factor for success of longer questionnaires (i.e. 100 questions, 45 minutes to 1 hour to complete, 40-page survey), especially when the participants were members of a group, organization, or company, and the survey focused on them (Henning & McGraw, 2009; Kaden, 2006; Walonick, 1993, 2004).

Additionally, the fact that these participants were voluntary members of an organization 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.

A concerted effort was made to avoid question phrasing problems such as bias, hypothetical situations, hearsay, ambiguity, confusion, vagueness, double topics, leading, double negatives, and questions that respondents cannot answer (Baron, 2006; Borgatti, 1996; Britton, 1996; Kaden, 2006; O'Brien, 1997). For example, to avoid hypothetical situations, actual situations were included, such as "I can save posts for future reference" (Part III, question 50). To avoid confusion, ambiguity, and vagueness, and in order to avoid any semblance of a trick question, the negative descriptor was emphasized in the questions requiring a negative answer in order to give a positive response, such as "Joining my online support group has NOT helped me" (Part I question 8). Additionally, a rigorous endeavor was made to avoid double topics, which require a participant to like or dislike both topics equally. For example, instead of one question stating, "My online support group has made a positive difference in *my quality of life* and in *my emotional health,*" two questions were offered inquiring about each separately (Part I questions 6 and 7).

Demographic questions and questions of a private, sensitive, or embarrassing nature should be left for last (Baron, 2006; Borgatti, 1996; Britton, 1996; O'Brien, 1997; Walonick, 2004). This study questionnaire collected demographic information and extremely private information in Part VI, the final section. A researcher should only ask for the demographic/personal information that is absolutely needed (Borgatti, 1996;

Britton, 1996; Garson, 2008; O'Brien, 1997; Walonick, 2004). Part VI had two demographic questions (age and marital status) because those were the only ones of relevance. There was one question asking how many times a week the participant accessed the support group and one asking how long the participant had been associated with the group. The remainder of Part VI was very personal information about the physical effects of cancer/pre-cancer and about diagnosis and treatment.

The decision assuring anonymity was in great part decided by Part VI. Additionally, the owner/founder of the support group asked for anonymity. This condition was met by having an online survey, accessed by the pin number of the group and collecting no identifying information. This researcher does not know which survey answers belong to which respondent. All communication, except for the pilot study participants, went to the group email addresses.

According to Walonick (2004), the possibility of low response rates is a major disadvantage of written questionnaires. Additionally, Walonick (1993) maintained that the single most important indicator of confidence in the results of a mail survey was response rate. Baron (2006) contended that greater internal and external validity are accomplished with high response rates and high quality data. In addition to the factors listed, the opportunity to maximize a high response rate and increase validity was optimized. Self-administered questionnaires elicit more honesty in answers, especially in areas of personal information (Baron, 2006; Garson, 2008). Incentives to participate were offered (Baron, 2006). These were non-monetary incentives and included involving the participants in the decision to participate, customizing the instrument, sending follow-up letters, and offering of the results. An additional incentive was contact prior to survey. This contact included an invitation to participate letter, cover letter, and letters explaining anonymity and answer options.

The instrument was divided into six parts, drawing content from the review of literature. 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 II was designed to collect information regarding the advantages, or lack thereof, of being online (Rochman, 2007; Schimmel, 2003; Silver, 2003).

Part III was designed to collect information about the advantages, or lack thereof, of the specific workings of this online group. 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).

Part V 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). Part VI was designed to collect personal information (i.e. age, effects of disease) from the members (Canavan & Cohen, 2002; DiSaia & Creasman, 1997; Pearman, 2003; Peeke, 2004; Turner, 2001).

The response segment of this survey instrument was devised specifically for this study, utilizing the advice and methods of those in the field of instrument design (Ary, Jacobs, & Razavieh, 1990; Borgatti, 1996; Frary, 2002; MacGregor, 2000; McNamara, 2004; Walonick, 2004). The first 89 statements (Parts I–V) on the instrument asked the participant to agree or disagree, and to what extent, using a Likert-like scale incorporating common vernacular. Each answer segment was exactly alike; therefore, familiarity with the answer scale minimized confusion and aided in allowing the participants to move more quickly through the lengthy questionnaire. According to Borgatti (1996), statistical reliability of the data increases sharply with the number of scale step-ups to about seven steps. At that point, it increases more slowly, reaching the leveling off point around eleven. The answer choices for Parts I–V (Questions 1–89) were as follows: A. Strongly agree, B. Agree, C. Mildly agree, D. No opinion, E. Mildly disagree, F. Disagree, G. Strongly disagree, H. This doesn't apply to me, Z. Pass. Parts I and IV each had one reverse answer question, while Part II had three, Part III had two, and Part V had three. Part VI did not have a reverse answer question. The reverse answer questions were presented positively in the Data Analysis.

Part VI consisted of 13 questions that were designed to collect personal and demographic data on the participants in the study. These 13 questions followed the overall format of a statement and then choices for an answer. Included herein were questions about (Q. 90) frequency of accessing the online support group (more than once a day, once each day, five to six days a week, three to four days a week… not even once a week), (Q. 91) age (21 through 29, 30 through 39 … 70 years or older, Pass), and (Q. 92) marital status (Never been married, Married, Divorced, Separated, Widowed, Pass).

Questions 94 and 95 inquired as to the relationship of current marital status with status before illness (Did your relationship survive your illness?). Questions 96 and 97 inquired about children (Did your illness affect childbearing desires?). Question 98 inquired about sexual morbidity and mortality, while Question 99 inquired about the degree of morbidity or mortality the illness had on QOL as compared to the days of pre-illness. Question 100 sought a time frame since diagnosis (less than three months …five years or more). Question 101 asked for the diagnosis (cancer or pre-cancer, which cancer or pre-cancer, and what stage of cancer or pre-cancer) and Question 102 asked for the treatments received.

Pilot Study

Once approval was received from the Institutional Review Board (IRB) at Mississippi State University, a pilot study (see APPENDIX B) was conducted. A pilot study is a model of the full research study administered on a smaller scale using fewer participants. The purpose of the pilot study was to test the research instrument and allow for adjustments before the main study (Simon, 1999; van Teijlingen & Hundley, 2001). The pilot study instrument, identical to the study instrument, was altered by adding an area for critique after each question ([checkbox] This question is OK, or Problem/Suggestion [space to answer]); (see APPENDIX B). From the population of 472 members of the online support group, WCC, and its subgroup, CVV, 10 participants were randomly chosen and, by email, invited to participate in the online survey (see APPENDIX C).

The full, six-part survey was administered to the pilot group in the same manner as was administered to the actual study group. Participants were asked to critique the instrument for clarity and to make any recommendations and suggestions about form and content that they deemed necessary. The results of the critique area were used to accept the question as it was designed. No changes were required. The results of participants' responses to the instrument were used to answer the research questions and to test the statistical procedures. The participants needed approximately 30 minutes to complete the study instrument.

Data Collection

Once approval from the Institutional Review Board (IRB) at Mississippi State University was received, a letter of invitation (see APPENDIX D) was sent to the group, explaining the study, inviting them to participate, and giving them the contact information of the researcher and of the IRB. A separate email was sent to the group explaining the information regarding consent (see APPENDIX E). An email detailing the answer options was sent so that the participants would be familiar with them in order that they could move through this long survey more quickly and so that there was no confusion about the answer options (see APPENDIX F).

One week was given for the participants to read these answer options and contact the researcher with any questions or confusion, which no one did. The URL letter for the study was sent to the group (see APPENDIX G). This letter contained the web address (URL), the password for accessing the survey, and the opening and closing dates of the survey. In accordance with IRB policy, consent to participate in the study was given by the participant when she submitted the completed survey. This protected the participant's anonymity, as was a condition of the group owner's permission to survey (see APPENDIX H). Seven days after the URL letter was sent, a reminder letter (see APPENDIX I) was sent to the groups encouraging anyone who had not participated to do so. The private, unpublished URL for the survey was listed along with the password in the reminder letter.

Data Analysis

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 102 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.

Research Question 1 was "What are the benefits (personal enrichments) of online support to women with gynecologic cancers and pre-cancers?" To answer research question 1, the researcher tabulated the results of Part I (questions 1–22) and Part IV (questions 55–64) independently. 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.

Research Question 2 was "What are the advantages of a support group being online?" To answer research question 2, the researcher tabulated the results of Part II (questions 23–47) and Part III (questions 48–54) were tabulated independently. Each response for each question was listed (i.e. Survey 1, question 23, answer: A; Survey 2, question 23, answer: B). The total of 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, 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. 23–47) in Part II was tabulated. These tabulations were averaged and a section percentage calculated. The same was calculated for Part III.

Research Question 3 was "What are the members' perceptions about support, illness, information, awareness, and sense of self?" To answer research question 3, the researcher tabulated the results of Part V (questions 650-89). Each response for each question was listed (i.e. Survey 1, question 65, answer: A; Survey 2, question 65, answer:

B). The total of each letter (i.e. all of As, all of Bs) was tabulated and the percentage of each was calculated based on the total number of respondents.

Part V differed from the previous four parts (Part I–Part IV) in that a variety of topics was presented for evaluation by the participants, and consequently, this section did not lend itself to a section total. As was outlined in the body of research question 3, the topics are support, illness, information, awareness, and sense of self. Therefore, the items related to each topic were grouped together and a sub-section total for each item was calculated by the researcher. The sum for each sub-section 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 was tabulated and a sub-section percentage was calculated by the researcher.

Part VI (questions 90–102) was personal information and demographic data and was not directly related to the research questions in that this information does not, directly, nor necessarily, impact the answers given in the previous sections. However, this information could, possibly, further qualify the answers given in the previous parts of this instrument. The results of Part VI (questions 90–102) were tabulated by the researcher. Each response for each question was listed (i.e. Survey 1, question 90, answer: A; Survey 2, question 90, answer: B). The researcher tabulated the total of each answer (i.e. all of As, all of Bs) and the percentage of each was calculated based on the total number of respondents. The sum for each answer choice (i.e. all As, all Bs) for all questions (i.e. 90-102) in Part VI was not tabulated for a section percentage because the information regarded a variety of personal topics (i.e. age, marital status, diagnosis, treatment).

CHAPTER IV

RESULTS

The emotional ramifications of those with cancer, and to a lesser degree, those with gynecologic cancers, have been researched and found to be important (Barnett, 2007; Beesley et al., 2005; Chan et al., 2001; Corney et al., 1992; IOM Committee, 2007; Puccio, 2007). This led to an increased awareness of the need for support, including face-to-face group support (Boscaglia & Clarke, 2007; Butow et al., 2007; Hodgkinson et al., 2007; Steginga & Dunn, 1997). There were 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.

As the literature confirmed (Davison et al., 2000; Meier et al., 2007) little attention has been given to online support groups. Neither set of researchers directly involved participants in their studies. They did not use a survey, other instrument, or personal interviews in order to get direct answers from the group members. Both sets of researchers monitored posts to the group and drew conclusions from what they read in emails posted to the groups.

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 et al. (2005) also used 10 groups from ACOR. They did use a survey, but they only invited members that were new to the groups to participate. Their survey focused on why the new members had joined.

This researcher did not find a study that invited the participation of all of the members of a gynecologic cancers and pre-cancers online support group. Additionally, no study was found that focused on gathering information directly from the women involved in online support in either public or private online groups.

Therefore, the purpose of this study was to describe the personal perceptions of women diagnosed with gynecologic cancers or pre-cancers regarding participation in an online support group. 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 following research questions guided this investigation:

1. What are the benefits (personal enrichments) of online support to women with gynecologic cancers and pre-cancers?
2. What are the advantages of a support group being online?
3. What are the members' perceptions about support, illness, information, awareness, and sense of self?

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 questions 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. This chapter includes a description of the survey results and the analysis of data in this study.

Since this study instrument was long and was divided into sections, and for the purpose of reporting overall results, the results are grouped by *agree*, which includes strongly agree, agree, and mildly agree; *disagree*, which includes strongly disagree, disagree, and mildly disagree; and *no answer*, which includes no opinion, does not apply, and pass. The included tables show the levels of agreement and disagreement. In describing the results, synonyms for *agree,* such as affirmed, were used.

Table 1

Response Percentages

Group Name	Total Members	Returned Surveys	Response Percentage
WCC	304	246	81.0%
CVV	168	133	79.0%
Totals	472	379	80.0%

Due to rounding, totals may not compute to 100%

Demographic Data

A description of the demographic characteristics of the members of WCC, and members of the subgroup, CVV relating to sex, age, marital status, accessing group, and years associated with group is presented in this section. Demographic data were obtained from Part VI of the survey instrument. These data are offered in order to add a frame of reference for the results.

The demographic data revealed that the two groups are more alike than different and demographics did not seem to constitute a major division in opinion, either within the groups or between them. The data showed that most differences in opinion between the groups were motivated more by illness and the consequences of illness than by demographics. For example, in Part II, question 38 stated, "During my treatments and/or recovery from surgery, etc., my ability to do some routine things like driving, socializing, or shopping, etc. was limited (or eliminated)." The women diagnosed with a gynecologic cancer—the members of the support group, WCC (N=246)—affirmed this statement by 96.3%, while the women diagnosed with a dysplastic condition (pre-cancerous)—the members of CVV (N=133)—affirmed by 63.9%. In Part V question 70 stated, "I have suffered some bouts of depression because of my illness." The members of the support group, WCC (N=246)—those diagnosed with cancer—affirmed this statement by 98.8%, while the women diagnosed with a pre-cancerous condition—the members of CVV (N=133)–affirmed by 63.9%.

The data revealed that many topics transcended demographic lines and specific illness. Question 74 in Part V, "My *sense of self* decreased after my diagnosis [this includes any degree of decrease, whether temporary or permanent during any phase of the illness]", was affirmed by the WCC (women with cancer) group by 82.1% and by the CVV (women with dysplasia [pre-cancerous conditions]) group by 86.5%. In Part I, question 2, "I need (needed) to be with women who are experiencing the same things I am," was affirmed by 100% in both groups.

Tables 2-5 show the summarized results of the demographic data included here. Table 2 demonstrates the age ranges. Table 3 shows marital status. Table 4 explains how often participants accessed their respective group, and Table 5 illustrates the years each had been associated with their group. The sex of the participants was 100% female as males are not allowed to join either group. Race, creed, color, national origin, sexual preference, or religious affiliation were never asked or required in order to join or participate so that no woman would ever feel there might be a basis for discrimination against her. Therefore, these items were not asked of these participants on this survey.

Age Ranges of the Respondents

Table 2 shows the classification of the respondents from WCC and its subgroup, CVV according to age. The age distributions, 246 from the WCC and 133 from the CVV, revealed that respondents from WCC had a much wider age range than those from CVV. The greatest difference in the groups was in the age category of 21–29, where 1% of WCC respondents reported being in this range as opposed to 26% of CVV. WCC reported 54% were 40–49, while only 27% of CVV were in this range. The WCC reported that 8% were over the age of 50, while no participant from CVV was age 50 or older.

Table 2

Age Ranges of the Respondents

	Percentages	
Age Range	WCC	CVV
Under 21	0.0%	0.0%
21 - 29	1.0%	26.0%
30 - 39	37.0%	47.0%
40 - 49	54.0%	27.0%
50 - 59	2.0%	0.0%
60 - 69	4.0%	0.0%
70 plus	2.0%	0.0%
Totals	100.0%	100.0%

Due to rounding, totals may not compute to 100%

Marital Status of the Respondents

Table 3 shows the marital status of the respondents from WCC (N=246) and its subgroup, CVV (N=133). The data revealed that respondents from both groups were well matched regarding marital status. The majority were married (WCC, 66%; CVV, 65%), while *not married* was reported by 32% of WCC and 30% of CVV. Of those reporting *not married,* there was not an extreme difference within or between groups in either those reporting *not married, but with a partner* (WCC, 14%; CVV, 19%) or *no partner* (WCC, 18%; CVV, 11%). There were 2% of WCC members and 5% of CVV members not reporting any marital status.

Table 3

Marital Status of the Respondents

Percentages							
Marital Status	Married	Not Married	Not Reported	Total	Not Married; with Partner	No Partner	Total Not Married
WCC	66.0%	32.0%	2.0%	100.0%	14.0%	18.0%	32.0%
CVV	65.0%	30.0%	5.0%	100.0%	19.0%	11.0%	30.0%

Due to rounding, totals may not compute to 100%

Prevalence of Accessing Group

Table 4 shows how often participants accessed their respective group from WCC (N=246) and its subgroup, CVV (N=133). The data revealed that the members of the WCC access their group slightly more often than the members of the CVV. The overwhelming majority (WCC, 83%; CVV, 72%) reported accessing their respective groups *more than once a day*.

Table 4

Prevalence of Accessing Group

Percentages										
Group	More than once a day	Once a day	5 to 6 days a week	3 to 4 days a week	2 to 3 days a week	Not even once a week	Only now and then	I don't know	Pass	Totals
WCC	83.0%	8.0%	0.0%	0.0%	9.0%	0.0%	0.0%	0.0%	0.0%	100.0%
CVV	72.0%	14.0%	3.0%	0.0%	0.0%	0.0%	11.0%	0.0%	0.0%	100.0%

Due to rounding, totals may not compute to 100%

Years of Association with Group

Table 5 indicates the years each respondent was associated with her group. WCC (N=246) has been in existence since the summer of 2000 while its subgroup, CVV (N=133) began three years later. Women move in and out of the group as need dictates. The respondents represent present and past members, so they were asked how long they had participated. The results data show that the majority of both groups were long-term members of three years or more (WCC, 77%; CVV, 51%).

Table 5

Years of Association with Group

Percentages										
Time in Group	< 1 month	1 mo to 6 mos	6 mos to 1 year	>1 yr but < 2 yrs	2 yrs but < 3	3 yrs but < 4	4 yrs but <5	5 yrs but <10	10 yrs or more	Totals
WCC	0.0%	0.0%	15.0%	4.0%	4.0%	18.0%	12.0%	29.0%	18.0%	100.0%
CVV	0.0%	10.0%	7.0%	18.0%	14.0%	11.0%	20.0%	20.0%	0.0%	100.0%

Due to rounding, totals may not compute to 100%

Analysis of Research Questions

There were three research questions. Data were analyzed to answer the research questions as follows.

Research question one was “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), 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), 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." Table 6 shows the results from Part I (Questions 1–22) and Table 7 shows the results from Part IV (Questions 55–64) of the survey instrument. Reversed questions are Part I, number 8 and Part IV, number 62 .

Table 6

Results of Part I (Questions 1–22)

Part I	Group	Percentages												
Questions 1-22	---	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
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%

Due to rounding, totals may not compute to 100%

Table 6 continued

Part I continued	Group	Percentages												
Questions 1-22	---	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
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%	0.0%	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%	0.0%	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%

Due to rounding, totals may not compute to 100%

Table 6 continued

Part I continued	Group	Percentages												
Questions 1-22	---	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
19. I have learned a lot about medical matters since joining my support group.	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%
	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%
20. I have learned a lot about myself and what I am capable of handling since joining my support group.	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%
	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%
21. I have found that giving support to others in my group is helpful to me.	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%
	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%
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.	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%
	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%

Table 7

Results of Part IV (Questions 55–64)

Part IV	Group	Percentages												
Questions 55-64	---	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
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%	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%	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%	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%	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%	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%	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%	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%	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%	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%	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%	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%	100.00%
62. My support group is Peer-to-Peer (run by regular people like me who also have experienced gyne cancers 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%

Due to rounding, totals may not compute to 100%

Research question two was “What are the advantages of a support group being online?” Part II and Part III of the survey instrument were used to collect data regarding the advantages of a support group being online from members of WCC (N=246) and its subgroup, CVV (N=133), support groups for women with gynecologic cancers and pre-cancers. Part II (Questions 23–47) was composed of situations afforded by online delivery of support, such as not having to leave home to participate and support being available 24/7 as opposed to a scheduled meeting time. Part III (Questions 48–54) was composed of options offered by technology, such as having access to links to information and having emails delivered to one's email inbox. Part III was designed as a statement of fact regarding these options and the participant was asked whether this option was an advantage to her.

All items in Part II and Part III were affirmed as advantages of online support by both groups. In Part II (Questions 23–47), members of WCC (N=246) unanimously (100%) endorsed 10 items, while CVV (N=133), unanimously (100%) endorsed 12 items, two of which were 100% "A. Strongly Agree," (Questions 35 and 36). The item with the greatest difference of opinion was question 39, "During my treatments and/or recovery from surgery, etc., I took pain medications, which hindered my ability to do some routine things like driving, socializing, or shopping, etc." The members of WCC (N=246) affirmed this item by 98.9%, while only 50.4% of the members of CVV (N=133) agreed.

In Part III (questions 48–54), each item was listed as “Statement of fact:” with a factual statement regarding technological options offered to both groups. The participant was then asked to agree or disagree to the statement, "This is an advantage for me" or

"This is not an advantage for me" added after the statement of fact. Both groups endorsed each item as an advantage, with WCC affirming three items 100% and CVV affirming four items 100%. The most variation of scores was for question 54, "Statement of fact: We talk about many topics other than just the illness-related ones. This is an advantage for me," where WCC affirmed with 94.3% and CVV affirmed with 81.2%, which was also the lowest percentage offered for the section. The lowest percentage submitted by the WCC for this section was 88.6% for question 50, "Statement of fact: I can save posts for future reference. This is not an advantage for me." Question 50 was a reversed question where disagreeing was an endorsement of the item.

Table 8 shows the results from Part II (Questions 23–47) and Table 9 shows the results from Part III (Questions 48–54) of the survey instrument. Reversed questions are Part II, questions 34, 43, and 45, and Part III, questions 50 and 52.

Table 8

Results of Part II (Questions 23–47)

Part II	Group	Percentages												
Questions 23-47	---	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
23. My online support group is large and includes women from all over the US and from different countries. I see this as a good thing.	WCC	55.7%	30.5%	12.2%	98.4%	0.4%	0.0%	0.8%	0.0%	0.8%	0.4%	0.0%	0.8%	100.00%
	CVV	50.4%	36.1%	4.5%	91.0%	3.8%	0.0%	0.0%	0.0%	0.0%	0.0%	5.3%	9.1%	100.04%
24. I like the fact that my group has archived files, links to information, and personal stories so I can revisit topics or explore topics discussed before I joined, if I choose.	WCC	87.0%	9.8%	2.8%	99.6%	0.4%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.4%	100.00%
	CVV	25.6%	51.9%	17.3%	94.7%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	5.3%	5.3%	100.00%
25. I like not having to leave home to participate in my support group.	WCC	87.0%	9.8%	2.8%	99.6%	0.4%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.4%	100.00%
	CVV	33.8%	66.2%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
26. I like having as much time as I need to compose my thoughts before I "speak" in my online support group.	WCC	68.3%	19.1%	3.7%	91.1%	8.9%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	8.9%	100.00%
	CVV	48.1%	30.8%	21.1%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
27. I like having access to my support group, virtually, 24 hours a day 7 days a week (24/7).	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	66.2%	33.8%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
28. Usually, someone is available to me virtually 24 hours a day, 7 days a week in my online support group.	WCC	58.1%	28.0%	13.8%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
	CVV	40.6%	33.1%	26.3%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
29. Since my online support group is large, there is at least one woman who knows firsthand what I am going through, no matter what I am facing or feeling.	WCC	75.6%	15.0%	9.3%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
	CVV	33.8%	48.1%	18.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
30. In the beginning, I felt more comfortable talking about my personal issues in an online group than I think I would have in a face-to-face support group.	WCC	44.3%	28.5%	9.8%	82.5%	0.0%	8.9%	8.5%	0.0%	17.5%	0.0%	0.0%	0.0%	100.00%
	CVV	41.4%	27.8%	20.3%	89.5%	10.5%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	10.5%	100.00%
31. I like being able to pick and choose which conversations (topics) I participate in on my online group.	WCC	66.3%	33.7%	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%	42.1%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
32. I like being able to ignore conversations (topics) that I don't want to participate in.	WCC	63.8%	36.2%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
	CVV	51.1%	48.9%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
33. In my online group, I get to "talk" (express myself and my feelings) as much as I want to.	WCC	65.9%	34.1%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
	CVV	33.1%	66.9%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%

Due to rounding, totals may not compute to 100%

Table 8 continued

Part II	Group	Percentages												
Questions 23-47	---	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
34. I believe that, if I were in a face-to-face group that met once a week for two hours, I <u>WOULD</u> be able to say as much and exchange as much information and share as much as I do in my online group.	WCC	2.4%	4.9%	2.8%	10.2%	0.0%	2.4%	37.0%	50.4%	89.8%	0.0%	0.0%	0.0%	100.00%
	CVV	0.0%	14.3%	11.3%	25.6%	0.0%	0.0%	34.6%	39.8%	74.4%	0.0%	0.0%	0.0%	100.00%
35. I like being able to visit the group when I want to instead of having a specific time to meet.	WCC	79.7%	11.0%	6.5%	97.2%	2.8%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	2.8%	100.00%
	CVV	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%
36. During my recovery from treatment and/or radiation and/or chemotherapy and/or recovery from surgery, I participated in my online support group.	WCC	72.8%	23.6%	0.0%	96.3%	0.0%	0.0%	0.0%	0.0%	0.0%	3.7%	0.0%	3.7%	100.00%
	CVV	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%
37. During my radiation and/or chemotherapy and/or recovery from surgery and/or recovery from treatment, I would <u>NOT</u> have been able to participate in a face-to-face group because I was too ill and/or too physically uncomfortable to have attended meetings.	WCC	58.9%	20.7%	8.9%	88.6%	0.0%	0.0%	2.4%	5.3%	7.7%	3.7%	0.0%	3.7%	100.00%
	CVV	43.6%	33.1%	0.0%	76.7%	0.0%	0.0%	23.3%	0.0%	23.3%	0.0%	0.0%	0.0%	100.00%
38. During my treatments and/or recovery from surgery, etc., my ability to do some routine things like driving, socializing, or shopping, etc. was limited (or eliminated).	WCC	65.9%	22.4%	8.1%	96.3%	0.0%	0.0%	0.0%	0.0%	0.0%	1.2%	2.4%	3.7%	100.00%
	CVV	31.6%	21.8%	10.5%	63.9%	0.0%	0.0%	25.6%	0.0%	25.6%	10.5%	0.0%	10.5%	100.00%
39. During my treatments and/or recovery from surgery, etc., I took pain medications, which hindered my ability to do some routine things like driving, socializing, or shopping, etc.	WCC	60.6%	29.3%	8.9%	98.8%	0.0%	0.0%	0.0%	0.0%	0.0%	1.2%	0.0%	1.2%	100.00%
	CVV	33.8%	0.0%	16.5%	50.4%	0.0%	0.0%	0.0%	0.0%	0.0%	49.6%	0.0%	49.6%	100.00%
40. I like knowing that, because no one can see me in my online support group, I am not being judged by the way I look, or by what I have or don't have, or by my race, creed, color, or national origin.	WCC	61.0%	20.3%	14.6%	95.9%	1.2%	1.2%	0.8%	0.8%	2.8%	0.0%	0.0%	1.2%	100.00%
	CVV	42.1%	16.5%	11.3%	69.9%	21.1%	6.0%	3.0%	0.0%	9.0%	0.0%	0.0%	21.1%	100.00%
41. When I first joined my online support group, I discussed topics OR asked (or answered) questions in the group that I could not have talked about comfortably in a face-to-face group.	WCC	50.0%	15.9%	19.9%	85.8%	4.5%	2.0%	7.7%	0.0%	9.8%	0.0%	0.0%	4.5%	100.00%
	CVV	51.1%	16.5%	18.0%	85.7%	5.3%	6.0%	3.0%	0.0%	9.0%	0.0%	0.0%	5.3%	100.00%

Due to rounding, totals may not compute to 100%

Table 8 continued

Part II Continued	Group	Percentages												
Questions 23-47	---	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
42. Face-to-face support groups are (were) NOT available in the area where I live.	WCC	51.6%	16.7%	11.4%	79.7%	0.0%	0.0%	8.1%	12.2%	20.3%	0.0%	0.0%	0.0%	100.00%
	CVV	35.3%	52.6%	0.0%	88.0%	0.0%	0.0%	5.3%	6.8%	12.0%	0.0%	0.0%	0.0%	100.00%
43. Face-to-face support groups are (were) available in the area where I live, but they are (were; would be; would have been) inconvenient for me (because of driving distance, scheduled meeting times, lack of transportation, or other reasons).	WCC	18.7%	10.2%	12.2%	41.1%	7.3%	0.0%	6.5%	21.5%	28.0%	23.6%	0.0%	30.9%	100.00%
	CVV	6.8%	5.3%	5.3%	17.3%	0.0%	0.0%	5.3%	35.3%	40.6%	36.8%	5.3%	42.1%	100.00%
44. Online support is (was) my only option for a support group that is only about gynecologic cancers or pre-cancers.	WCC	62.2%	17.5%	0.0%	79.7%	0.0%	0.0%	20.3%	0.0%	20.3%	0.0%	0.0%	0.0%	100.00%
	CVV	63.9%	30.8%	0.0%	94.7%	5.3%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	5.3%	100.00%
45. If I had a choice today between face-to-face support and online support, I would choose FACE-TO-FACE support.	WCC	0.0%	0.0%	5.3%	5.3%	0.0%	7.7%	33.7%	53.3%	94.7%	0.0%	0.0%	0.0%	100.00%
	CVV	0.0%	0.0%	0.0%	0.0%	5.3%	0.0%	30.8%	63.9%	94.7%	0.0%	0.0%	5.3%	100.00%
46. I have participated in my online support group after 10 p.m. and/OR before 8 a.m. and/OR on weekends and/OR on holidays (either by posting, reading posts, chat, etc).	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%
	CVV	31.6%	68.4%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
47. I like the fact that we can have many conversations (topics) going on at the same time in my online group.	WCC	72.8%	27.2%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
	CVV	33.1%	66.9%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%

Due to rounding, totals may not compute to 100%

Table 9

Results of Part III (Questions 48–54)

Part III	Group	Percentages												
Questions 48-54	---	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
Statement of fact: In my online support group, the posts come to my email address.	WCC	76.8%	22.4%	0.0%	99.2%	0.8%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.8%	100.00%
48. This is an advantage for me.	CVV	81.2%	18.8%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
Statement of fact: Since I can read posts from my email, I have access to my group from any location where I have access to a computer with internet.	WCC	77.2%	22.8%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
49. This is an advantage for me.	CVV	67.7%	32.3%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
Statement of fact: I can save posts for future reference.	WCC	5.7%	3.3%	0.0%	8.9%	2.4%	0.0%	35.8%	52.8%	88.6%	0.0%	0.0%	2.4%	99.96%
50. This is NOT an advantage for me.	CVV	0.0%	5.3%	0.0%	5.3%	0.0%	0.0%	23.3%	71.4%	94.7%	0.0%	0.0%	0.0%	100.00%
Statement of fact: If I am going to be away, I do not miss any posts because of email and I can catch-up anytime.	WCC	74.4%	23.2%	2.4%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
51. This is an advantage for me.	CVV	69.9%	30.1%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
Statement of fact: My support group keeps a list of links to medical information, nutrition, and general health sites that I can access whenever I want to.	WCC	2.4%	1.2%	2.4%	6.1%	0.0%	0.0%	26.4%	67.5%	93.9%	0.0%	0.0%	0.0%	100.00%
52. This is NOT an advantage for me.	CVV	0.8%	0.0%	0.8%	1.5%	14.3%	0.0%	35.3%	48.9%	84.2%	0.0%	0.0%	14.3%	100.00%
Statement of fact: There are never any required costs or fees associated with membership in my group.	WCC	70.3%	29.7%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
53. This is an advantage for me.	CVV	89.5%	5.3%	5.3%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.00%
Statement of fact: We talk about many topics other than just the illness-related ones.	WCC	59.8%	25.2%	9.3%	94.3%	0.0%	5.7%	0.0%	0.0%	5.7%	0.0%	0.0%	0.0%	100.00%
54. This is an advantage for me.	CVV	39.8%	36.1%	5.3%	81.2%	3.8%	9.8%	3.0%	2.3%	15.0%	0.0%	0.0%	3.8%	100.00%

Due to rounding, totals may not compute to 100%

Research question three was “What are the members’ perceptions about support, illness, information, awareness, and sense of self?” Part V (Questions 65-89) of the survey instrument was comprised of a variety of topics and offered to the participating members of WCC (N=246) and its subgroup, CVV (N=133) 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 10-14 show the results for each category. Reversed questions are 67, 76, and 86.

Perceptions about Support

Three items regarding support that were not addressed in any other section were added to Part V. 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%. Table 10 shows the results.

Table 10

Results of Part V Re: 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%

Due to rounding, totals may not compute to 100%

Perceptions about Illness

Five items regarding illness that were not addressed in any other section were included in Part V. 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 11.

Table 11

Results of Part V Re: Perceptions about Illness

Part V	Group	Percentages												
Regarding: Illness	---	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
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%

Due to rounding, totals may not compute to 100%

Perceptions about Information

Five items regarding information that were not addressed in any other section were included in Part V. 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 12 shows the results.

Table 12

Results of Part V Re: Perceptions about Information

Part V	Group	Percentages												
Regarding: Information	---	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
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%
	CVV	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%
	CVV	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%
	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%
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%
	CVV	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%
	CVV	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%

Due to rounding, totals may not compute to 100%

Perceptions about Awareness

Five items regarding awareness that were not addressed in any other section were included in Part V. 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 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 13.

Table 13

Results of Part V Re: Awareness

Part V	Group	Percentages												
Regarding: Awareness	---	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
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%

Due to rounding, totals may not compute to 100%

Perceptions about Sense of Self

Six items regarding sense of self that were not addressed in any other section were included in Part V. 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 14 displays the responses.

Table 14

Results of Part V Re: Sense of Self

Part V	Group	Percentages												
Regarding: Sense of Self	---	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
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%

Due to rounding, totals may not compute to 100%

Summary of Results

Data were collected from 246 (81%) participants from the actual population (N=304) of the WCC group, and 133 (79%) participants from the actual population (N=168) of the subgroup, CVV, which were used to present the results in this chapter that were obtained from this study.

The results from this study indicated that there are many benefits (personal enrichments) of online support for the women with gynecologic cancers and pre-cancers who joined these groups, as well as many advantages for them of a support group being online.

The results also suggested that although these members are demographically different and are experiencing a variety of gynecologic cancers and pre-cancers, they are very cohesive in their wants and needs from online support. The results indicate that the experiences, both physical and emotional, of the women in these groups are more similar than different.

The data that were collected in this study have helped the researcher draw conclusions and formulate recommendations for conducting future research studies relating to the benefits (personal enrichments) of online support to women with gynecologic cancers and pre-cancers and the advantages of a support group being online. These conclusions and recommendations are described in Chapter V.

CHAPTER V

SUMMARY, DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

Summary

A woman is diagnosed with a gynecologic cancer every seven minutes (Frosted Pink, 2007). In 2008, it is estimated that 81,540 women in the U.S. will be diagnosed with an invasive gynecologic or anal cancer and that 28,920 will die (ACS, 2008a). 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.

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 et al., 2005; Chan et al., 2001; Corney et al., 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 three research questions posed in this study. This study surveyed the current and former members of WCC online support group (N=246 [81%]), and its subgroup, CVV (N=133 [79%]) as to their perceptions of benefits (personal enrichments), Parts I and IV of the survey instrument (Research Question 1); advantages of support being online, Parts II and III of the survey instrument (Research Question 2); and support, illness, information, awareness and sense of self, Part V of the survey instrument (Research Question 3). Part VI of the survey instrument collected demographic information, such as age and marital status.

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).

Discussion

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

Descriptive statistics were utilized to analyze the data and answer the three research questions posed in the study. Descriptive research involves describing and interpreting events, conditions, or situations of the present (Picciano, 2008), which was the goal of this research. 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).

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 online support groups; however, gynecologic cancers were not among the groups studied. 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. Two questions from the current study were added specifically because of the Davison et al. (2000) study. From Part V, Question 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" and Question 73 "I was motivated to join a support group because of embarrassment or shame about my condition." The results showed that both of these items were validated. Members of the WCC online support group (N=246) affirmed Question 72 by 93.1%, and its subgroup, CVV (N=133) affirmed by 97.0%. WCC affirmed Question 73 by 83.3%, while CVV affirmed by 63.9%.

Other items in the survey also addressed this topic, such as Question 87, "When I was diagnosed, I found it difficult to discuss my condition with some family, friends, co-workers, etc. because it was gynecologic," which was affirmed by 90.2% of the WCC members and 100% of the CVV members, and Question 88, "Some people (not including my support group) were (are) embarrassed or uncomfortable when I talk about my gynecologic condition," which was affirmed by 97.2% of WCC and 84.2% of CVV.

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. Meier et al. (2007) focused exclusively on cancer support groups, but 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. concurred with the Meier et al.'s conclusion of ambiguity. There was no ambiguity in the results of the study being presented here. Specific items were offered for assessment by the participants and the participants evaluated each as to personal relevance. The results from this study indicate that there are many benefits (personal enrichments) of online support for the women with gynecologic cancers and pre-cancers who joined these groups, as well as many advantages for them of a support group being online.

Conclusions of 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 lead 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.

Recommendations for Further Research

Based on the results from this study, several areas are suggested for future research. These recommendations are listed below:

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.
3. This study dealt with the members of only one online gynecologic cancer support group and one online pre-cancer group. Studies with other groups should be conducted in order to determine if the findings here are supported by other groups.
4. The perceptions gathered in this study indicate that the participants are dealing with many physical, emotional, and social aspects of gynecologic illness. These topics would lend themselves well to qualitative investigation.
5. Pearman (2003) concluded, as did Anderson and Lutgendorf (1997), that the reasons for the conflicting results in QOL studies included too many possible variables for which to account in any given study. These authors concluded that attention to these physical and emotional conditions was important for the overall health and well-being of patients and survivors. This study was extremely long and included a wide variety of topics. Yet, only two or three questions per topic could be added due to space. Each of the major topics of this study deserves more thorough attention in studies focusing on expanded data collection of these items.

6. The results of this study revealed strong affirmation of some topics, such as QOL, Writing Therapy, Sense of Self, used to answer the three research questions, however, none was the topic of its own investigation. Further research of more depth, both quantitative and qualitative, is recommended.

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APPENDIX A

SURVEY INSTRUMENT

Survey of Members of Online Support Groups for Women with Gynecologic
Cancers and Pre-Cancers Regarding Online Support

Enter Code Number

(My group's code number)

Ladies, please answer the questions based on the time frame that you were a member of your group.

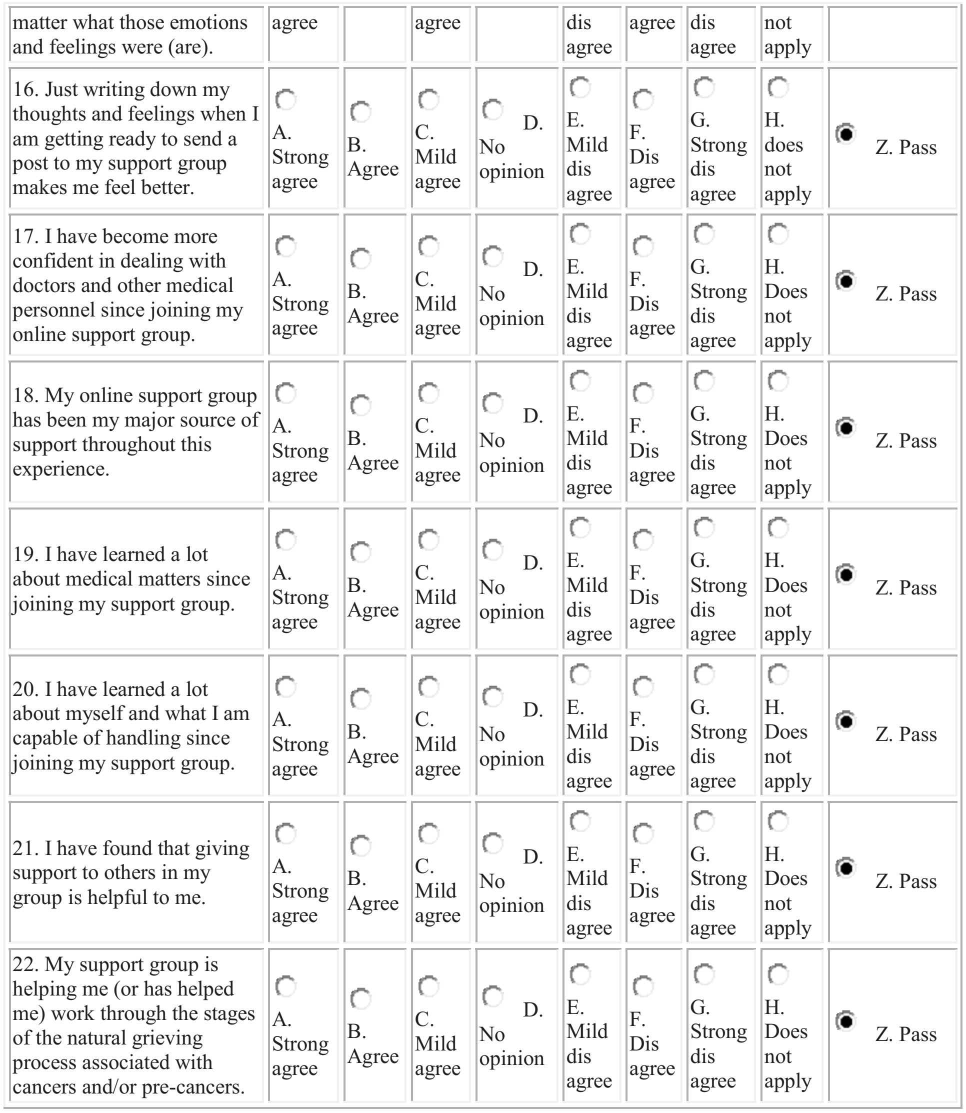
To answer questions: click the circle (radio button) beside the letter of the answer you prefer. A black dot will appear in the circle. This indicates that the answer is "chosen". If you want to change your answer, just click another circle (radio button) and the black dot will appear in your new choice.

Part I

○ I am (was) the one with a medical condition.
○ I am (was) the caregiver.
○ I am (was) the caregiver answering for both of us.

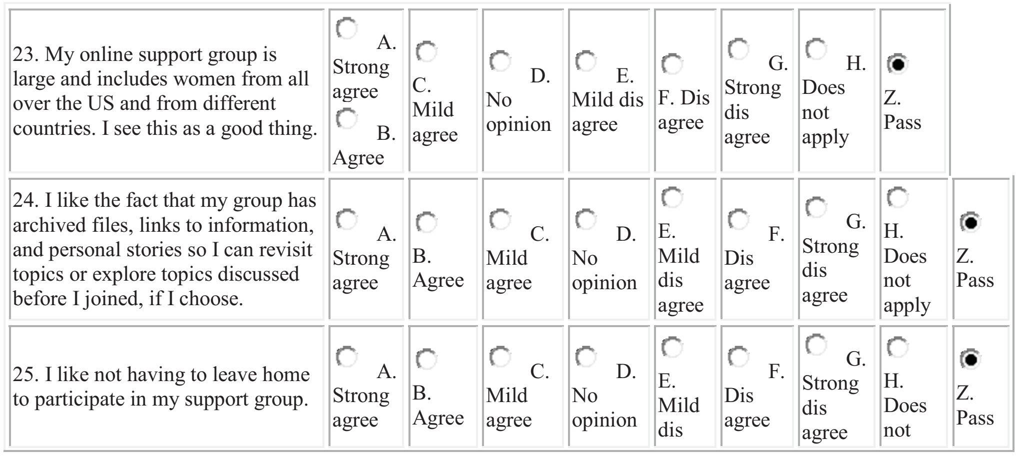
1. My online support group has been (was) a positive addition to my life.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
2. I need (needed) to be with women who are experiencing the same things I am.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No Opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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 and feelings as much as I needed to, OR other reasons].	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
4. For whatever reasons, I would have been emotionally alone without my support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
5. My online support group helped me to deal with my emotional distress.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No Opinion	○ E. Mild dis	○ F. Dis agree	○ G. Strong dis	○ H. Does not	● Z. Pass

					agree		agree	apply	
6. I believe that my online support group has made a positive difference in my quality of life.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
7. My online support group has made positive difference in my emotional health.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
8. Joining my online support group has NOT helped me.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
9. I bonded with the women in my online support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
11. I believe that my stress levels have been reduced because of my online support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. does not apply	● Z. Pass
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.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. does not apply	● Z. Pass
13. Just knowing that I am (was) not alone is (was) important and makes (made) a positive difference.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. does not apply	● Z. Pass
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.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. does not apply	● Z. Pass
15. In my support group, I have always been encouraged to express my emotions and feelings no	○ A. Strong	○ B. Agree	○ C. Mild	○ D. No opinion	○ E. Mild	○ F. Dis	○ G. Strong	○ H. does	● Z. Pass

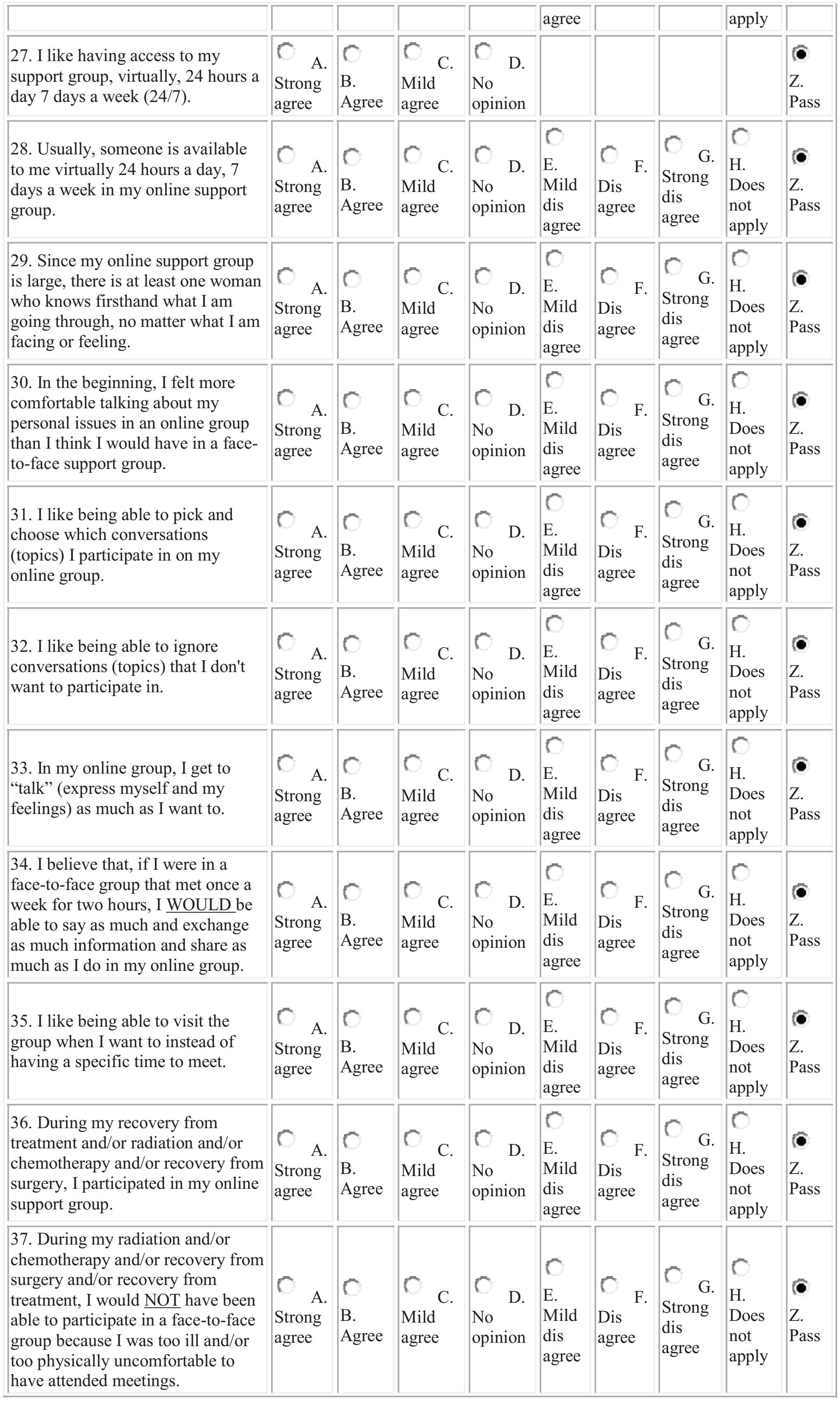


matter what those emotions and feelings were (are).	agree		agree		dis agree	agree	dis agree	not apply	
16. Just writing down my thoughts and feelings when I am getting ready to send a post to my support group makes me feel better.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. does not apply	● Z. Pass
17. I have become more confident in dealing with doctors and other medical personnel since joining my online support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
18. My online support group has been my major source of support throughout this experience.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
19. I have learned a lot about medical matters since joining my support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
20. I have learned a lot about myself and what I am capable of handling since joining my support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
21. I have found that giving support to others in my group is helpful to me.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass

Part II



23. My online support group is large and includes women from all over the US and from different countries. I see this as a good thing.	○ A. Strong agree ○ B. Agree		○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
24. I like the fact that my group has archived files, links to information, and personal stories so I can revisit topics or explore topics discussed before I joined, if I choose.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
25. I like not having to leave home to participate in my support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not	● Z. Pass



					agree			apply	
27. I like having access to my support group, virtually, 24 hours a day 7 days a week (24/7).	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion					● Z. Pass
28. Usually, someone is available to me virtually 24 hours a day, 7 days a week in my online support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
29. Since my online support group is large, there is at least one woman who knows firsthand what I am going through, no matter what I am facing or feeling.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
30. In the beginning, I felt more comfortable talking about my personal issues in an online group than I think I would have in a face-to-face support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
31. I like being able to pick and choose which conversations (topics) I participate in on my online group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
32. I like being able to ignore conversations (topics) that I don't want to participate in.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
33. In my online group, I get to "talk" (express myself and my feelings) as much as I want to.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
34. I believe that, if I were in a face-to-face group that met once a week for two hours, I <u>WOULD</u> be able to say as much and exchange as much information and share as much as I do in my online group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
35. I like being able to visit the group when I want to instead of having a specific time to meet.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
36. During my recovery from treatment and/or radiation and/or chemotherapy and/or recovery from surgery, I participated in my online support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
37. During my radiation and/or chemotherapy and/or recovery from surgery and/or recovery from treatment, I would <u>NOT</u> have been able to participate in a face-to-face group because I was too ill and/or too physically uncomfortable to have attended meetings.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass

38. During my treatments and/or recovery from surgery, etc., my ability to do some routine things like driving, socializing, or shopping, etc. was limited (or eliminated).	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
39. During my treatments and/or recovery from surgery, etc., I took pain medications, which hindered my ability to do some routine things like driving, socializing, or shopping, etc.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
40. I like knowing that, because no one can see me in my online support group, I am not being judged by the way I look, or by what I have or don't have, or by my race, creed, color, or national origin.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
41. When I first joined my online support group, I discussed topics OR asked (or answered) questions in the group that I could not have talked about comfortably in a face-to-face group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
42. Face-to-face support groups are (were) NOT available in the area where I live.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
43. Face-to-face support groups are (were) available in the area where I live, but they are (were; would be; would have been) inconvenient for me (because of driving distance, scheduled meeting times, lack of transportation, or other reasons).	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
44. Online support is (was) my only option for a support group that is only about gynecologic cancers or pre-cancers.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
45. If I had a choice today between face-to-face support and online support, I would choose FACE-TO-FACE support.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
47. I like the fact that we can have many conversations (topics) going on at the same time in my online group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass

Part III

In this section, there is a statement of fact listed. Then there is the statement for you to address (answer). The statement of fact is a fact and is true. You are not being asked to agree or disagree with the statement of fact. You are being asked to agree or disagree (and how strongly) to the statement that follows the statement of fact.

The word "advantage", as in "this is an advantage for me", means this is good for me or helpful to me, or positive for me, or a plus for me, etc.If it says, 'this is NOT an advantage for me," this means this is NOT good for me or NOT helpful to me or is NOT positive (which equals "IS Negative") for me, or is NOT a plus (which equals "IS A MINUS") for me.

Statement of fact: In my online support group, the posts come to my email address. 48. This is an advantage for me.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
Statement of fact: Since I can read posts from my email, I have access to my group from any location where I have access to a computer with Internet. 49. This is an advantage for me.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
Statement of fact: I can save posts for future reference. 50. This is NOT an advantage for me.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
Statement of fact: If I am going to be away, I do not miss any posts because of email and I can catch-up anytime. 51. This is an advantage for me.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
Statement of fact: My support group keeps a list of links to medical information, nutrition, and general health sites that I can access whenever I want to. 52. This is NOT an advantage for me.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
Statement of fact: There are never any required costs or fees associated with membership in my group. 53. This is an advantage for me.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
Statement of fact: We talk about many topics other than just the illness-related ones. 54. This is an advantage for me.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass

Part IV

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.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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).	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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 actually see it and experience it. If I am not in the mood to deal with her pain, I can ignore her post.)	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
60. Sometimes, I just do not want to deal with a subject or topic and I can just delete it and move on.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
61. I am (was) able to express my full range of emotions (fears, doubts, sadness, joy, etc) by writing to the group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass

62. My support group is Peer-to-Peer (run by regular people like me who also have experienced gyne cancers and disorders). I would rather be in a group that was run by trained professionals like therapists, doctors, or nurses.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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 about my private issues to outsiders, and/or gossip about me, and/or use the information against me sometime in the future, etc.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass

Part V

65. I accidentally found my online support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
66. I did not know that there were online support groups until I found mine.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
67. My doctor, nurse, medical person suggested I join a support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. 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.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
69. I felt uncomfortable in the beginning talking about these gynecologic issues even with my online support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass

					agree				
70. I have suffered some bouts of depression because of my illness.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
71. My doctor treated me for depression with medications, but never suggested I join a support group.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass

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.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
73. I was motivated to join a support group because of embarrassment or shame about my condition.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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]	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
75. My group participation has helped me recover my sense of self (in any degree).	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
77. When I was diagnosed, I was very (or totally) unfamiliar with my condition.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
78. When I was diagnosed, I was familiar with my condition but I knew very little about it.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
79. When I was diagnosed, I wanted information about my condition.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
80. When I was diagnosed, I turned to the Internet for information.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass

					agree				
81. In looking back to when I was diagnosed, I believe that my original doctor(s) was (were) not very informed about my condition.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
82. Before I was correctly diagnosed with my cancer or pre-cancer, my condition was mis-diagnosed.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
83. My condition got worse because of the time lost on mis-diagnosis(es).	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
84. I did not know the signs/symptoms of my illness.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass

85. I had never heard of HPV prior to my illness (regardless of an HPV connection).	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
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 problem.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
87. When I was diagnosed, I found it difficult to discuss my condition with some family, friends, co-workers, etc. because it was gynecologic.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
88. Some people (not including my support group) were (are) embarrassed or uncomfortable when I talk about my gynecologic condition.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass
89. I would recommend online support to family or friends who were in need of support.	○ A. Strong agree	○ B. Agree	○ C. Mild agree	○ D. No opinion	○ E. Mild dis agree	○ F. Dis agree	○ G. Strong dis agree	○ H. Does not apply	● Z. Pass

Part VI

This section is personal information. These questions are optional, as are all the questions in this survey. You do not have to answer, but if you choose to answer, it will help to put the answers to the above questions into better perspective and show the scope of what women are facing and enduring.

90. In an average week, I access (accessed) my online group (either to participate or to lurk)

○ A. More than once a day

○ B. Once every day

○ C. 5 to 6 days a week

○ D. 3 to 4 days a week

○ E. 2 to 3 days a week

○ F. not even once a week

○ G. only now and then

○ H. I don't know

● Z. Pass (I choose not to answer this question)

91. My age group is/was (during the time I participated in my support group)

○ A. under 21

○ B. 21 through 29

○ C. 30 through 39

○ D. 40 through 49

○ E. 50 through 59

○ F. 60 through 69

○ G. 70 and over

● Z. Pass (I choose not to answer this question)

CAREGIVERS, please note that questions 92 through 99 regard changes due to the effects of illness. If you are not answering "for both of us", please skip to question 100.

92. I am/was (during the time I participated in my support group)

○ A. Never been married

○ B. Married

○ C. Widowed

○ D. Divorced

○ E. Separated

● Z. Pass (I choose not to answer this question)

93. If Single, Widowed, Divorced or Separated (during the time I participated in my support group)

○ A. I have a Significant Other

○ B. I do not have a Significant Other at this time

○ C. This does not apply to my situation

● Z. Pass (I choose not to answer this question)

94. If Married or with a Significant Other (SO) now

○ A. I was with this person before my diagnosis

○ B. I met this person after my diagnosis

○ C. This does not apply to my situation

● Z. Pass (I choose not to answer this question)

95. At the time of my diagnosis, I had a husband or Significant Other, but the relationship did not last because of my illness.

○ A. Yes, this is true

○ B. No, this is not true. My relationship survived

○ C. I was not in a relationship

○ D. This does not apply to my situation

● Z. Pass (I choose not to answer this question)

96. At the time of my diagnosis

○ A. I had already had all of the children I wanted to have and/or I had passed the realistic age (for me) of childbearing, and/or I could not have and/or did not choose to have, children, and/or I was post-menopausal.

○ B. I was of childbearing age and had (at least) 1 child, but I had not yet had all of the children I wanted to have.

○ C. I was of childbearing age and had not yet had any children, but I wanted children.

○ D. This does not apply to my situation

● Z. Pass (I choose not to answer this question)

97. My illness (and/or the treatments for it) stopped me from having the children I wanted to have

○ A. Yes, this is true.

○ B. No, this is not true. I had already had all of the children I wanted to have and/or I had passed the realistic age (for me) of childbearing, and/or I could not have and/or did not choose to have, children, and/or I was post-menopausal.

○ C. No, this is not true. I had a child (or children) after my diagnosis.

○ D. No, this is not true. I can still have a child if I choose.

○ E. I do not know yet. It is too soon for me to know whether or not I will be able to have children (or more children).

○ F. None of these describe my situation

● Z. Pass (I choose not to answer this question)

98. My illness made my long-term ability to have satisfying sex

○ A. more difficult or more uncomfortable

○ B. totally uncomfortable or totally unbearable

○ C. non-existent; I can't have sex now

○ D. impossible; I can't achieve orgasm now

○ E. improbable; I no longer have any desire

○ F. It is too soon for me to know.

○ G. none of the above; My sex life is fine.

○ H. none of these describe my situation.

● Z. Pass (I choose not to answer this question).

99. The effects of my illness altered my life and my ability to resume the life I had before

○ A. Totally and drastically; I will never be the same; I will never be able to do the things I once did; There is no "full recovery" for me.

○ B. Greatly; There are many physical limitations for me now.

○ C. Somewhat; I can still do (or will be able to, when I am recovered and healed) most of the things I did before.

○ D. A little; I have been able (or will be able when I recover) to return to doing almost 100 percent of the things I did before my illness.

○ E. Not at all; I am (or will be when I am fully recovered) 100 percent.

○ F. It is too soon for me to know.

○ G. none of these describe my situation.

● Z. Pass (I choose not to answer this question)

100. I (or the person for which I am/was a caregiver) was diagnosed with the condition for which I joined my support group [calculate from this survey date]

○ A. Less than 3 months ago

○ B. 3 to 6 months ago

○ C. 7 months to 1 year ago

○ D. More than 1 year but less than 2 years ago

○ E. 2 years but less than 3 years ago

○ F. 3 years but less than 4 years ago

○ G. 4 years but less than 5 years ago

○ H. 5 years but less than 10

○ I. 10 years or more

● Z. Pass (I choose not to answer this question)

100a. I participated in my support group for (approximately)

○ A. Less than 1 month

○ B. 1 month but less than 6 months

○ C. 6 months to 1 year

○ D. More than 1 year but less than 2 years

○ E. 2 years but less than 3 years

○ F. 3 years but less than 4 years

○ G. 4 years but less than 5 years

○ H. 5 years but less than 10

○ I. 10 years or more

● Z. Pass (I choose not to answer this question)

CAREGIVERS, please note that questions 101 and 102 regard illnesses and treatments. You may answer for the person for whom you are (were) the caregiver or skip to the SUBMIT button.

Please note:

The last two questions are about your medical conditions and treatments. Under each condition and treatment statement there are two choices, "yes" and "no". The "no" choice is automatically pre-set and a small black dot is in the circle. If the "no" choice applies to you (NO, this is not my condition or treatment), then just skip over that entry and look for the one(s) that applies (apply) to you and click the "yes" option.

The first entry is a little confusing. It asks about HPV. "HPV was not related". If HPV was NOT related to your condition, the correct answer is: YES. YES, It is true that HPV was not related. If HPV WAS related to your condition, then NO is the correct choice. NO, it is not true that HPV was not related.

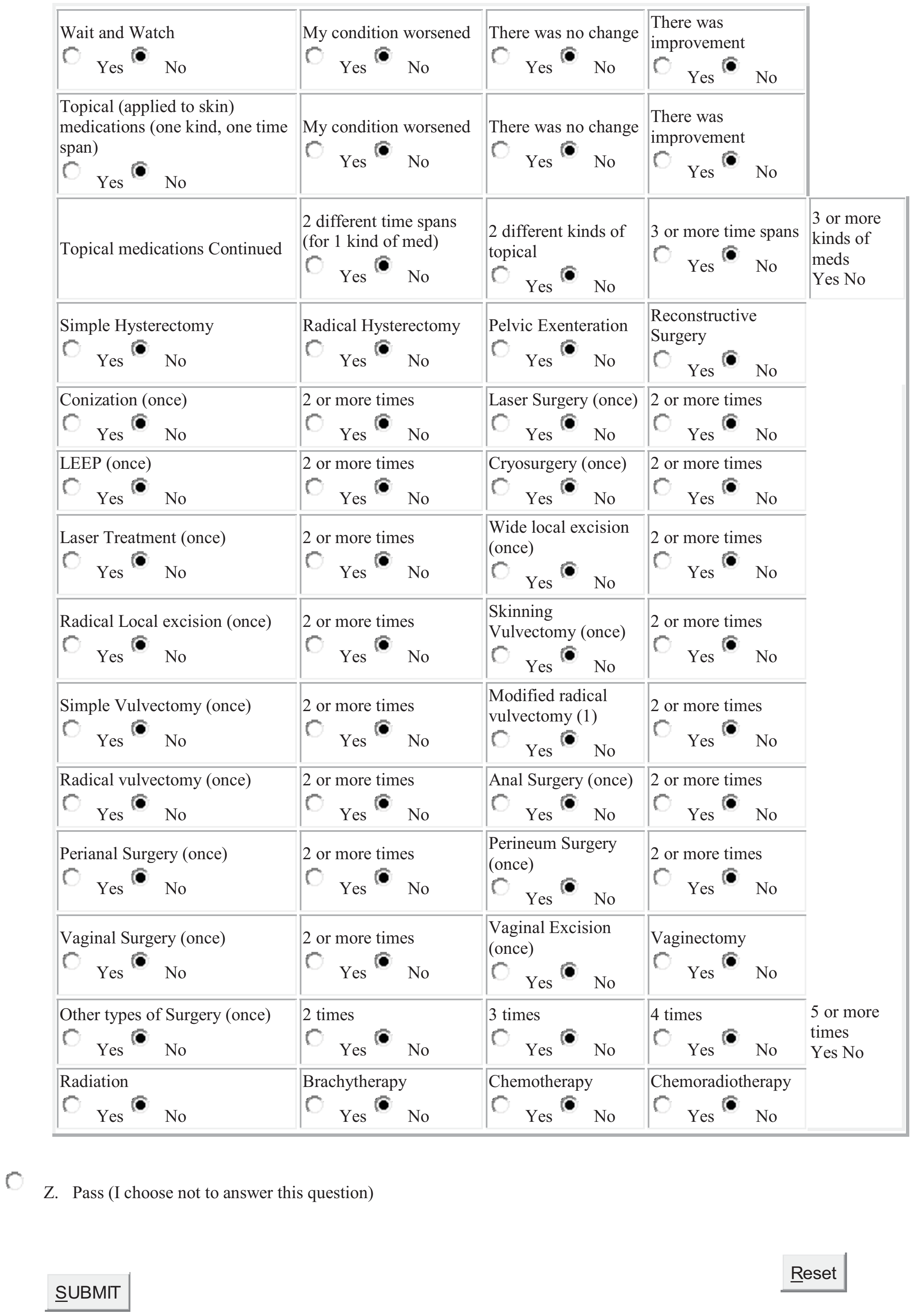
101. My condition(s) is/was (are/were) (Mark all that apply.)

HPV is not related ○ Yes ● No	HPV was suspected by Dr.(s) ○ Yes ● No	HPV was confirmed by Dr.(s) ○ Yes ● No	HPV was never mentioned by Dr.(s) ○ Yes ● No	
CIN (not staged) ○ Yes ● No	CIN 1 ○ Yes ● No	CIN 2 ○ Yes ● No	CIN 3 ○ Yes ● No	
VIN (not staged) ○ Yes ● No	VIN 1 ○ Yes ● No	VIN 2 ○ Yes ● No	VIN 3 ○ Yes ● No	
VaIN (not staged) ○ Yes ● No	VaIN 1 ○ Yes ● No	VaIN 2 ○ Yes ● No	VaIN 3 ○ Yes ● No	
PaIN (not staged) ○ Yes ● No	PaIN 1 ○ Yes ● No	PaIN 2 ○ Yes ● No	PaIN 3 ○ Yes ● No	
AIN (not staged) ○ Yes ● No	AIN 1 ○ Yes ● No	AIN 2 ○ Yes ● No	AIN 3 ○ Yes ● No	
Cervical unstaged ○ Yes ● No	Endometrial unstaged ○ Yes ● No	Ovarian unstaged ○ Yes ● No	Vaginal unstaged ○ Yes ● No	
Uterine Corpus unstaged ○ Yes ● No	Vulvar unstaged ○ Yes ● No	Anal unstaged ○ Yes ● No	Perianal unstaged ○ Yes ● No	
Cervical CIS ○ Yes ● No	Cervical stage 1 ○ Yes ● No	Cervical stage 2 ○ Yes ● No	Cervical stage 3 ○ Yes ● No	Cervical stage 4 ○ Yes ● No
Endometrial CIS ○ Yes ● No	Endometrial stage 1 ○ Yes ● No	Endometrial stage 2 ○ Yes ● No	Endometrial stage 3 ○ Yes ● No	Endometrial stage 4 ○ Yes ● No
Ovarian CIS ○ Yes ● No	Ovarian stage 1 ○ Yes ● No	Ovarian stage 2 ○ Yes ● No	Ovarian stage 3 ○ Yes ● No	Ovarian stage 4 ○ Yes ● No
Vaginal CIS ○ Yes ● No	Vaginal stage 1 ○ Yes ● No	Vaginal stage 2 ○ Yes ● No	Vaginal stage 3 ○ Yes ● No	Vaginal stage 4 ○ Yes ● No
Uterine Corpus CIS ○ Yes ● No	Uterine Corpus stage 1 ○ Yes ● No	Uterine Corpus stage 2 ○ Yes ● No	Uterine Corpus stage 3 ○ Yes ● No	Uterine Corpus stage 4 ○ Yes ● No
Vulvar CIS ○ Yes ● No	Vulvar stage 1 ○ Yes ● No	Vulvar stage 2 ○ Yes ● No	Vulvar stage 3 ○ Yes ● No	Vulvar stage 4 ○ Yes ● No
Anal CIS ○ Yes ● No	Anal stage 1 ○ Yes ● No	Anal stage 2 ○ Yes ● No	Anal stage 3 ○ Yes ● No	Anal stage 4 ○ Yes ● No
Perianal CIS ○ Yes ● No	Perianal stage 1 ○ Yes ● No	Perianal stage 2 ○ Yes ● No	Perianal stage 3 ○ Yes ● No	Perianal stage 4 ○ Yes ● No

○ Z. Pass (I choose not to answer this question)

102. I have had the following treatments:

Choose all that apply, including outpatient treatments and cervical treatments.
Please read across the table from left to right on each row.



Wait and Watch ○ Yes ● No	My condition worsened ○ Yes ● No	There was no change ○ Yes ● No	There was improvement ○ Yes ● No	
Topical (applied to skin) medications (one kind, one time span) ○ Yes ● No	My condition worsened ○ Yes ● No	There was no change ○ Yes ● No	There was improvement ○ Yes ● No	
Topical medications Continued	2 different time spans (for 1 kind of med) ○ Yes ● No	2 different kinds of topical ○ Yes ● No	3 or more time spans ○ Yes ● No	3 or more kinds of meds Yes No
Simple Hysterectomy ○ Yes ● No	Radical Hysterectomy ○ Yes ● No	Pelvic Exenteration ○ Yes ● No	Reconstructive Surgery ○ Yes ● No	
Conization (once) ○ Yes ● No	2 or more times ○ Yes ● No	Laser Surgery (once) ○ Yes ● No	2 or more times ○ Yes ● No	
LEEP (once) ○ Yes ● No	2 or more times ○ Yes ● No	Cryosurgery (once) ○ Yes ● No	2 or more times ○ Yes ● No	
Laser Treatment (once) ○ Yes ● No	2 or more times ○ Yes ● No	Wide local excision (once) ○ Yes ● No	2 or more times ○ Yes ● No	
Radical Local excision (once) ○ Yes ● No	2 or more times ○ Yes ● No	Skinning Vulvectomy (once) ○ Yes ● No	2 or more times ○ Yes ● No	
Simple Vulvectomy (once) ○ Yes ● No	2 or more times ○ Yes ● No	Modified radical vulvectomy (1) ○ Yes ● No	2 or more times ○ Yes ● No	
Radical vulvectomy (once) ○ Yes ● No	2 or more times ○ Yes ● No	Anal Surgery (once) ○ Yes ● No	2 or more times ○ Yes ● No	
Perianal Surgery (once) ○ Yes ● No	2 or more times ○ Yes ● No	Perineum Surgery (once) ○ Yes ● No	2 or more times ○ Yes ● No	
Vaginal Surgery (once) ○ Yes ● No	2 or more times ○ Yes ● No	Vaginal Excision (once) ○ Yes ● No	Vaginectomy ○ Yes ● No	
Other types of Surgery (once) ○ Yes ● No	2 times ○ Yes ● No	3 times ○ Yes ● No	4 times ○ Yes ● No	5 or more times Yes No
Radiation ○ Yes ● No	Brachytherapy ○ Yes ● No	Chemotherapy ○ Yes ● No	Chemoradiotherapy ○ Yes ● No	

○ Z. Pass (I choose not to answer this question)

APPENDIX B

PILOT STUDY

The pilot study questionnaire is exactly the same as the questionnaire included in Appendix A. The differences are the boxes shown below. These are for commenting on each question and each section. Each question has a yellow box and each section has an orange box. In order not to add another 50 pages to this presentation, only the additions are shown here. These two exhibits are representative of the entire questionnaire.

Evaluation of the above survey question:

○ This question is OK (click the small, round [radio button] button)

State a problem or Make a suggestion:

This is the end of Part X. Please evaluate the section.

Evaluation of the above section:

○ This section is OK (click the small, round [radio button] button)

State a problem or Make a suggestion

APPENDIX C

PILOT STUDY INVITATION LETTER

Pilot Study Invitation Email to Research Study Participants
Women Conquering Cancer Support Group
CIN/VIN/VaIN Cancer Support Group

Elaine Parrish
P.O. Box 2821
Columbus, MS 39704

August 30, 2010

Dear Ladies:

NOTE: This email, regarding the pilot study for Elaine's doctoral research, is being sent to you from Marie on behalf of Elaine Parrish. The reason this email is being sent by Marie is to assure your anonymity in the research process.

I am a doctoral candidate in the department of Instructional Systems and Workforce Development at Mississippi State University. I am conducting a research study that is designed to describe the personal perceptions of women diagnosed with gynecological cancers or pre-cancers regarding participation in an online support group.

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. The results of this study will increase the base of information and knowledge and should also benefit caregivers and loved ones.

The Institutional Review Board (IRB) at Mississippi State University has approved this study. For questions regarding your rights as a research participant, or to express concerns or complaints, please feel free to contact the MSU Regulatory Compliance Office by phone at 662-325-3994, by e-mail at irb@research.msstate.edu, or on the web at http://orc.msstate.edu (http://www.google.com/url?q=http%3A%2F%2Forc.msstate.edu%2Fparticipant%2F&sa=D&sntz=1&usg=AFQjCNEABnSiN4krMXs1PrZ87ljmKs_0zg)/participant/ (http://www.google.com/url?q=http%3A%2F%2Forc.msstate.edu%2Fparticipant%2F&sa=D&sntz=1&usg=AFQjCNEABnSiN4krMXs1PrZ87ljmKs_0zg).

The population for this study will be all of the members, past and present, of Women Conquering Cancer and its sister site, CIN/VIN/VaIN. The responses will be summarized along with others who respond. One code number for each group (WCC and CVV) will be issued to access the website, but individual forms will not be marked with any other identifying information. Only select members have been chosen to participate in the pilot study.

You have been chosen to participate in the pilot study. A pilot study is a pre-study where the chosen participants will take the exact same survey that the whole group will take (at a later date), but in the pilot study, you will be asked to judge the questions, the format, the layout, etc. in addition to answering the questions. The things that you will be judging include, for example, "Is this question easy to understand?" "Is this question confusing to you", "Are the answer options easy to understand and do they include the options that you would like to see in order to answer this question?", "Is the survey easy to read?" etc.

To make this judging process easier to accomplish, there is a box in bright yellow after each question. It has two options for you to choose. The first option is "This question is OK" and a radio button (like a checkbox, but round). The second option is "Suggestions/comments" and is a text box where you can elaborate on any problems. At the end of each section (labeled Part I through Part VI) there is an orange box with the same options, but this is for you to judge the section as a whole unit. The purpose of this judging option is to find any problems or confusion or difficulties so they can be corrected before the survey is taken by the whole group.

I realize that your professional and personal duties, as well as other responsibilities demand a great deal of your time and that your participation in this study will require additional time. However, your responses to the survey form, which will take approximately 30 minutes of your time, will be very important to this research study.

Your participation is strictly voluntary and you may withdraw at any time. Please know that your name and other identifying information will not be included in the questionnaire and even I will not know which questionnaire is yours.

I hope you will accept this invitation to participate in the pilot study, but if, for any reason, you cannot participate, that will be ok. Please contact Marie if you accept or if you decline.

Thank you so much for your consideration of this matter. I look forward to hearing from you soon. I will be sending the URL and the date and times of the pilot study to you if you choose to participate.

Sincerely,

Elaine Parrish
Doctoral Candidate

APPENDIX D

INVITATION LETTER

Invitation to Participate Email to Research Study Participants
Women Conquering Cancer Support Group
CIN/VIN/VaIN Cancer Support Group

Elaine Parrish
P.O. Box 2821
Columbus, MS 39704

October 4, 2010

Dear Ladies:

I am a doctoral candidate in the department of Instructional Systems and Workforce Development at Mississippi State University. I am conducting a research study that is designed to describe the personal perceptions of women diagnosed with gynecological cancers or pre-cancers regarding participation in an online support group.

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. The results of this study will increase the base of information and knowledge and should also benefit caregivers and loved ones.

The Institutional Review Board (IRB) at Mississippi State University has approved this study. For questions regarding your rights as a research participant, or to express concerns or complaints, please feel free to contact the MSU Regulatory Compliance Office by phone at 662-325-3994, by e-mail at irb@research.msstate.edu, or on the web at http://orc.msstate.edu (http://www.google.com/url?q=http%3A%2F%2Forc.msstate.edu%2Fparticipant%2F&sa=D&sntz=1&usg=AFQjCNEABnSiN4krMXs1PrZ87ljmKs_0zg)/participant/ (http://www.google.com/url?q=http%3A%2F%2Forc.msstate.edu%2Fparticipant%2F&sa=D&sntz=1&usg=AFQjCNEABnSiN4krMXs1PrZ87ljmKs_0zg).

The population for this study will be all of the members, past and present, of Women Conquering Cancer and its sister site, CIN/VIN/VaIN. So, you are invited to participate. I realize that your professional and personal duties, as well as other responsibilities, demand a great deal of your time and that your participation in this study will require additional time. However, your responses to the survey form, which will take approximately 30 minutes of your time, will be very important to this research study. Your participation is strictly voluntary and you may withdraw at any time. Please know that your name and other identifying information will not be included in the questionnaire and even I will not know which questionnaire is yours. The responses will be summarized along with others who respond. One code number for each group (WCC and CVV) will be issued to access to the website, but individual forms will not be marked with any other identifying information.

I know that your time is valuable, but without your assistance, this research study cannot be completed. If you have questions about this study, please contact me at (662) 327-4009 or at esp@ebicom.net

Your assistance is greatly appreciated. More details about the survey will follow.

Sincerely,

Elaine Parrish
Doctoral Candidate

APPENDIX E

CONSENT INFORMATION

Consent Email to Research Study Participants
Women Conquering Cancer Support Group
CIN/VIN/VaIN Cancer Support Group

Elaine Parrish
P.O. Box 2821
Columbus, MS 39704

October 11, 2010

Dear Ladies:

I am a doctoral candidate in the department of Instructional Systems and Workforce Development at Mississippi State University. I am conducting a research study that is designed to describe the personal perceptions of women diagnosed with gynecological cancers or pre-cancers regarding participation in an online support group.

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. The results of this study will increase the base of information and knowledge and should also benefit caregivers and loved ones.

The population for this study will be all of the members, past and present, of Women Conquering Cancer and its sister site, CIN/VIN/VaIN. So, you are invited to participate. I realize that your professional and personal duties, as well as other responsibilities, demand a great deal of your time and that your participation in this study will require additional time. However, your responses to the survey form, which will take approximately 30 minutes of your time, will be very important to this research study. Please know that your name and other identifying information will not be included in the questionnaire and even I will not know which questionnaire is yours. The responses will be summarized along with others who respond. One code number for each group (WCC and CVV) will be issued to access to the website, but individual forms will not be marked with any other identifying information.

There are federal regulations governing research involving human participants. Typically, a participant is asked to read and sign a consent form agreeing to participate in a research study. This survey is designed to protect your identity. Therefore, you will not be asked to sign a consent form. However, by completing and submitting the survey, you will be stating that you understand your rights, and agree to participate in the research study.

Your participation in this study is strictly voluntary. You may withdraw at any time. You may refuse to answer any specific question that may be asked of you. If you choose not to answer any given question, there is no penalty. You may decline to answer as many questions as you choose. The rest of your answers will be summarized with those of other individuals who respond.

The Institutional Review Board (IRB) at Mississippi State University has approved this study. If you have any questions about this study, you may contact me at esp@ebicom.net or 1-662-327-4009 or you may contact the Director of my dissertation, Dr. Linda Cornelious at 1-662-325-2281. For questions regarding your rights as a research participant, or to express concerns or complaints, please feel free to contact the MSU Regulatory Compliance Office by phone at 662-325-3994, by e-mail at irb@research.msstate.edu, or on the web at http://orc.msstate.edu (http://www.google.com/url?q=http%3A%2F%2Forc.msstate.edu%2Fparticipant%2F&sa=D&sntz=1&usg=AFQjCNEABnSiN4krMXs1PrZ87ljmKs_0zg)/participant/ (http://www.google.com/url?q=http%3A%2F%2Forc.msstate.edu%2Fparticipant%2F&sa=D&sntz=1&usg=AFQjCNEABnSiN4krMXs1PrZ87ljmKs_0zg).

Thank you in advance for your time and consideration. This research study will not be possible without your participation.

Sincerely,

Elaine Parrish
Doctoral Candidate

APPENDIX F

ANSWER OPTIONS DETAILS LETTER

Explanation of Answer Options Email to Research Study Participants
Women Conquering Cancer Support Group
CIN/VIN/VaIN Cancer Support Group

Elaine Parrish
P.O. Box 2821
Columbus, MS 39704

October 18, 2010

Dear Ladies:

I am a doctoral candidate in the department of Instructional Systems and Workforce Development at Mississippi State University. I am conducting a research study that is designed to describe the personal perceptions of women diagnosed with gynecological cancers or pre-cancers regarding participation in an online support group.

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. The results of this study will increase the base of information and knowledge and should also benefit caregivers and loved ones.

The Institutional Review Board (IRB) at Mississippi State University has approved this study. If you have any questions about your rights as a research subject in this study, you may contact the Office for Regulatory Compliance at Mississippi State University at 662-325-5220.

The population for this study will be all of the members, past and present, of Women Conquering Cancer and its sister site, CIN/VIN/VaIN. So, you are invited to participate. I realize that your professional and personal duties, as well as other responsibilities, demand a great deal of your time and that your participation in this study will require additional time. However, your responses to the survey form, which will take approximately 30 minutes of your time, will be very important to this research study. Your participation is strictly voluntary and you may withdraw at any time. Please know that your name and other identifying information will not be included in the questionnaire and even I will not know which questionnaire is yours. The responses will be summarized along with others who respond. One code number for each group (WCC and CVV) will be issued to access to the website, but individual forms will not be marked with any other identifying information.

The following information is an explanation of answer options as they will appear on the survey.

Explanation of Answer Options

The answer options as they will appear on the first part of the questionnaire are listed below. Please take a moment and read through them.

The first 89 questions have the same answer options.

A. Strong agree	B. Agree	C. Mild agree	D. No opinion	E. Mild dis agree	F. Dis agree	G. Strong dis agree	H. Does not apply	Z. Pass

Each question on the survey is a statement. You are being asked to agree (yes) or disagree (no) and to what degree (strong, medium, or mild agreement or disagreement).

Please note the options ***D. No opinion*** and ***H. Does not apply [to me]***. Both, Women Conquering Cancer and CIN/VIN/VaIN members, will be answering the same questionnaire. Since there are so many different situations in the two groups, not everyone will have had the same experience. If you have HAD the experience referenced in a question, but you do not agree or disagree, then **D. No opinion** is the answer to choose. If you have NOT had the experience in the question, and therefore, you can not make a decision one way or the other, then please choose **H. Does not apply**. In order to report the answers accurately, it makes a difference if a woman does not have an opinion about an experience she has had or if she did not answer because she has never had the experience.

Please know that you do not have to answer any question that you do not want to answer. Option **Z. Pass** is for any question you choose not to answer. Any questions you do answer will be counted no matter how many you to choose to pass.

If you click on an answer and then change your mind, all you have to do is click on another answer in that same question and it automatically changes your answer to your new choice. You can change any answer at any time until you click the Submit button.

The Reset button will clear ALL your answers and leave you with a blank form. Click this button ONLY if you want to clear the entire form and start all over.
Thank you for taking your time to participate in this study.

Sincerely,

Elaine Parrish
Doctoral Candidate

APPENDIX G

URL EMAIL

URL Email to Research Study Participants

CIN/VIN/VaIN Cancer Support Group

Elaine Parrish
P.O. Box 2821
Columbus, MS 39704

October 24, 2010

Dear Ladies:

I am a doctoral candidate in the department of Instructional Systems and Workforce Development at Mississippi State University. I am conducting a research study that is designed to describe the personal perceptions of women diagnosed with gynecological cancers or pre-cancers regarding participation in an online support group.

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. The results of this study will increase the base of information and knowledge and should also benefit caregivers and loved ones.

The Institutional Review Board (IRB) at Mississippi State University has approved this study. If you have any questions about your rights as a research subject in this study, you may contact the Office for Regulatory Compliance at Mississippi State University at 662-325-5220.

The population for this study will include all of the members, past and present, of CIN/VIN/VaIN. So, you are invited to participate. I realize that your professional and personal duties, as well as other responsibilities demand a great deal of your time and that your participation in this study will require additional time. However, your responses to the survey form, which will take approximately 30 minutes of your time, will be very important to this research study. Your participation is strictly voluntary and you may withdraw at any time. Please know that your name and other identifying information will not be included in the questionnaire and even I will not know which questionnaire is yours. The responses will be summarized along with others who respond. One code number for the group will be issued to access to the website, but individual forms will not be marked with any other identifying information.

The survey is starting and this is the information you will need to access it.

At the top of the survey there is a box for a code number. The box is labeled “My group code number”. Please put the code number below in the box. This is a security measure so that only members of the CVV group will be counted in the CVV category. Please don't give this code number to any non-member of CVV, because it is important that all answers reflect just the CVV members. If you have a friend that you want to participate who is not a member of CVV, then give her the code number, 9292P. This way we can keep the results accurate for each group. I really appreciate your cooperation with these code numbers.

The web address for the survey is: http://www.projectesp.org/index.html

The code number is **555cvv (c v v)**.

The survey will be active for 2 weeks starting today, October 24, 2010, and ending November 8, 2010.

Please don't discuss the actual survey questions in the group until the survey is closed. Each woman should be free to make her own decisions about how to answer without influence. If you have a question that you do not understand or with which you need assistance, please contact me privately at the address listed below.

Again, I want to thank you for your participation in this project. If you have any questions, you may contact me privately at esp@ebicom.net or 1-662-327-4009.

Sincerely,

Elaine Parrish
Doctoral Candidate

URL Email to Research Study Participants
Women Conquering Cancer Support Group

Elaine Parrish
P.O. Box 2821
Columbus, MS 39704

October 24, 2010

Dear Ladies:

I am a doctoral candidate in the department of Instructional Systems and Workforce Development at Mississippi State University. I am conducting a research study that is designed to describe the personal perceptions of women diagnosed with gynecological cancers or pre-cancers regarding participation in an online support group.

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. The results of this study will increase the base of information and knowledge and should also benefit caregivers and loved ones. The Institutional Review Board (IRB) at Mississippi State University has approved this study. If you have any questions about your rights as a research subject in this study, you may contact the Office for Regulatory Compliance at Mississippi State University at 662-325-5220.

The population for this study will include all of the members, past and present, of Women Conquering Cancer. So, you are invited to participate. I realize that your professional and personal duties, as well as other responsibilities demand a great deal of your time and that your participation in this study will require additional time. However, your responses to the survey form, which will take approximately 30 minutes of your time, will be very important to this research study. Your participation is strictly voluntary and you may withdraw at any time. Please know that your name and other identifying information will not be included in the questionnaire and even I will not know which questionnaire is yours. The responses will be summarized along with others who respond. One code number for the group will be issued to access to the website, but individual forms will not be marked with any other identifying information.

The survey is starting and this is the information you will need to access it.

At the top of the survey there is a box for a code number. The box is labeled "My group code number". Please put the code number below in the box. This is a security measure so that only members of the WCC group will be counted in the WCC category. Please don't give this code number to any non-member of WCC, because it is important that all answers reflect just the WCC members. If you have a friend that you want to participate who is not a member of WCC, then give her the code number, 9191C. This way I can keep the results accurate for each group. I really appreciate your cooperation with these code numbers.

The web address for the survey is: http://www.projectesp.org/index.html

The code number is **wcc333**

The survey will be active for 2 weeks starting today, October 24, 2010, and ending November 8, 2010.

Please don’t discuss the actual survey questions in the group until the survey is closed. Each woman should be free to make her own decisions about how to answer without influence. If you have a question that you do not understand or need assistance, please contact me privately at the address listed below.

Again, I want to thank you for your participation in this project. If you have any questions, you may contact me privately at esp@ebicom.net or 1-662-327-4009.

Sincerely,

Elaine Parrish
Doctoral Candidate

APPENDIX H

PERMISSION TO SURVEY

(The following are copies of the emails requesting permission to survey the online cancer support group, Women Conquering Cancer, and its sub-group, CIN/VIN/VaIN.)

Date: Wed, 25 Mar 2009 16:37:42 -0700 (PDT)
From: "Marie :>)" <marie_parrish@yahoo.com>
To: Elaine Parrish <esp@ebicom.net>
Subject: Re: permission to survey.
Parts/Attachments:

Hi Elaine,

Your research sounds very interesting. If you can guarantee that the identities of the members will be protected so that they can not be identified, you have my permission.

Marie

Marie [07.gif]

Cervical/Vulvar Cancer Survivor
Progressive MS & Founder of:

Http://www.womenconqueringcancer.org
http://www.myspace.com/iammariehearmeroar

--- On Wed, 3/25/09, Elaine Parrish
<esp@ebicom.net> wrote:
From: Elaine Parrish
<esp@ebicom.net>
Subject: permission to survey.

To: "Marie :>)"

<marie_parrish@yahoo.com>
Date: Wednesday, March 25, 2009,
7:08 PM

Hi Marie,

As you know, I am working on my dissertation at
Mississippi State University. I would like to
conduct a survey with the members of WCC and
CVV regarding online support and gyne cancers and
pre cancers. I would like to have your permission
to do this research. May I have your
permission to conduct this study?

Elaine

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Elaine Parrish
esp@ebicom.net

APPENDIX I

REMINDER LETTER

Reminder Email to Research Study Participants

CIN/VIN/VaIN Cancer Support Group

Elaine Parrish
P.O. Box 2821
Columbus, MS 39704

October 31, 2010

Dear Ladies:

I am a doctoral candidate in the department of Instructional Systems and Workforce Development at Mississippi State University. I am conducting a research study that is designed to describe the personal perceptions of women diagnosed with gynecological cancers or pre-cancers regarding participation in an online support group.

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. The results of this study will increase the base of information and knowledge and should also benefit caregivers and loved ones.

The Institutional Review Board (IRB) at Mississippi State University has approved this study. If you have any questions about your rights as a research subject in this study, you may contact the Office for Regulatory Compliance at Mississippi State University at 662-325-5220.

The population for this study will include all of the members, past and present, of CIN/VIN/VaIN. So, you are invited to participate. I realize that your professional and personal duties, as well as other responsibilities demand a great deal of your time and that your participation in this study will require additional time. However, your responses to the survey form, which will take approximately 30 minutes of your time, will be very important to this research study. Your participation is strictly voluntary and you may withdraw at any time. Please know that your name and other identifying information will not be included in the questionnaire and even I will not know which questionnaire is yours. The responses will be summarized along with others who respond. One code number for the group will be issued to access to the website, but individual forms will not be marked with any other identifying information.

There is only one (1) week left to complete and submit your survey. If you have not had an opportunity to complete your survey, I would appreciate it if you would take a few minutes of your time to complete the survey and submit it online. Please do so within the next 7 days.

The web address is http://www.projectesp.org/index.html

The code number for your group is **555cvv** (that is c v v)

If you have questions, you may contact me at esp@ebicom.net or 1-662-327-4009**.**

Thank you for your help in this project.

Sincerely,

Elaine Parrish
Doctoral Candidate

Reminder Email to Research Study Participants
Women Conquering Cancer Support Group

Elaine Parrish
P.O. Box 2821
Columbus, MS 39704

October 31, 2010

Dear Ladies:

I am a doctoral candidate in the department of Instructional Systems and Workforce Development at Mississippi State University. I am conducting a research study that is designed to describe the personal perceptions of women diagnosed with gynecological cancers or pre-cancers regarding participation in an online support group.

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The population for this study will include all of the members, past and present, of Women Conquering Cancer. So, you are invited to participate. I realize that your professional and personal duties, as well as other responsibilities demand a great deal of your time and that your participation in this study will require additional time. However, your responses to the survey form, which will take approximately 30 minutes of your time, will be very important to this research study. Your participation is strictly voluntary and you may withdraw at any time. Please know that your name and other identifying information will not be included in the questionnaire and even I will not know which questionnaire is yours. The responses will be summarized along with others who respond. One code number for the group will be issued to access to the website, but individual forms will not be marked with any other identifying information.

There is only one (1) week left to complete and submit your survey. If you have not had an opportunity to complete your survey, I would appreciate it if you would take a few minutes of your time to complete the survey and submit it online. Please do so within the next 7 days.

The web address is http://www.projectesp.org/index.html

The code number for your group is **wcc333**

If you have questions, you may contact me at esp@ebicom.net or 1-662-327-4009**.**

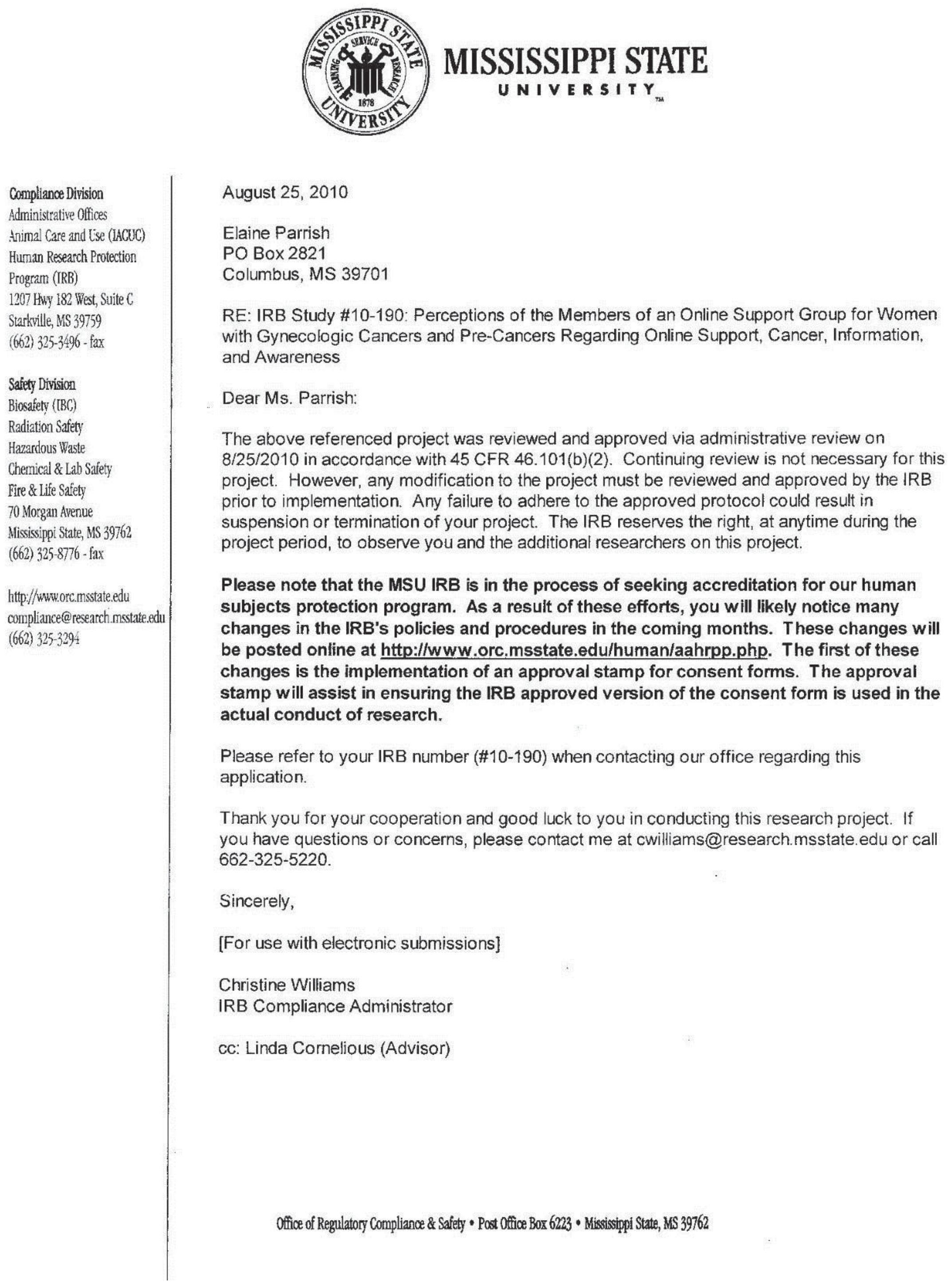
Thank you for your help in this project.

Sincerely,

Elaine Parrish
Doctoral Candidate

APPENDIX J

INSTITUTIONAL REVIEW BOARD (IRB) APPROVAL



MISSISSIPPI STATE
UNIVERSITY

Compliance Division
Administrative Offices
Animal Care and Use (IACUC)
Human Research Protection
Program (IRB)
1207 Hwy 182 West, Suite C
Starkville, MS 39759
(662) 325-3496 - fax

Safety Division
Biosafety (IBC)
Radiation Safety
Hazardous Waste
Chemical & Lab Safety
Fire & Life Safety
70 Morgan Avenue
Mississippi State, MS 39762
(662) 325-8776 - fax

http://www.orc.msstate.edu
compliance@research.msstate.edu
(662) 325-3294

August 25, 2010

Elaine Parrish
PO Box 2821
Columbus, MS 39701

RE: IRB Study #10-190: Perceptions of the Members of an Online Support Group for Women with Gynecologic Cancers and Pre-Cancers Regarding Online Support, Cancer, Information, and Awareness

Dear Ms. Parrish:

The above referenced project was reviewed and approved via administrative review on 8/25/2010 in accordance with 45 CFR 46.101(b)(2). Continuing review is not necessary for this project. However, any modification to the project must be reviewed and approved by the IRB prior to implementation. Any failure to adhere to the approved protocol could result in suspension or termination of your project. The IRB reserves the right, at anytime during the project period, to observe you and the additional researchers on this project.

Please note that the MSU IRB is in the process of seeking accreditation for our human subjects protection program. As a result of these efforts, you will likely notice many changes in the IRB's policies and procedures in the coming months. These changes will be posted online at http://www.orc.msstate.edu/human/aahrpp.php. The first of these changes is the implementation of an approval stamp for consent forms. The approval stamp will assist in ensuring the IRB approved version of the consent form is used in the actual conduct of research.

Please refer to your IRB number (#10-190) when contacting our office regarding this application.

Thank you for your cooperation and good luck to you in conducting this research project. If you have questions or concerns, please contact me at cwilliams@research.msstate.edu or call 662-325-5220.

Sincerely,

[For use with electronic submissions]

Christine Williams
IRB Compliance Administrator

cc: Linda Cornelious (Advisor)

Office of Regulatory Compliance & Safety • Post Office Box 6223 • Mississippi State, MS 39762