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M. Bunde

J. Suls

Rene' Martin  
*University of Iowa*

*Please see article for additional authors.*

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## Online Hysterectomy Support: Characteristics of Website Experiences

MALI BUNDE, Ph.D. (C), JERRY SULS, Ph.D., RENÉ MARTIN, Ph.D., RN, and  
KATHERINE BARNETT, B.S.

### ABSTRACT

This descriptive study examines the use of an Internet information and chat website, *hystersisters.com*, which allows women to communicate with others who are contemplating or have recently had a hysterectomy. This study had three aims: (1) to determine if the site is successful in providing information and support, (2) to assess why particular Hystersisters were perceived to be helpful, and (3) to describe what, if anything, women found to be unhelpful about the site. Women ( $n = 137$ ), aged 25–65 years ( $M = 39.8$ ,  $SD = 7.54$ ) responded to a mail survey. The site was perceived to provide positive informational support (chi square  $= 13.46$ ,  $p = 0.000$ ) more than esteem or emotional support. Women found discussing recovery issues (chi square  $= 5.727$ ,  $p = 0.017$ ) to be most helpful. Thirty-nine percent indicated that something on the site was unhelpful. The website seems to accomplish the provision of positive informational support; however, this site was not always seen as helpful.

### INTRODUCTION

THE INTERNET is an important source of health information.<sup>1</sup> There have been concerns regarding the quality of the information available to the public<sup>2</sup> and potential misunderstandings about that information.<sup>3</sup> However, two systematic reviews found little evidence of harm.<sup>3,4</sup> The potential benefits of these virtual communities,<sup>5</sup> or chat rooms, are similar to support groups, and are designed to offer their members not only health information but also emotional support.<sup>6,7</sup> Zrebiec and Jacobson<sup>8</sup> conducted an extensive investigation into individual participation in an on-line support group for patients with diabetes and their families. A large proportion of the 569 support group users reported that site participation positively affected their diabetes coping with 40% reporting favorably about the information and 25% about the peer response.<sup>8</sup> However, not all studies show benefits,<sup>9</sup> and it is acknowledged that more

work is needed to examine both informational and emotional support in medical samples before we can be certain about the benefits, if any, of virtual patient communities.<sup>5</sup>

The present paper examines the use of an Internet information and chat website especially designed for women who were scheduled for or had recently had a hysterectomy. In 2000, approximately 633,000 hysterectomies were performed in the US,<sup>10</sup> but relatively little is known about the quality or quantity of social communication, informational or emotional support experienced by women who undergo hysterectomy and there have been no prior studies of their use of Web site support resources.

Prior research examining perceived social support in women post-hysterectomy has focused on their relationships with their partners<sup>11</sup> and communications.<sup>12</sup> One study<sup>13</sup> showed that a perception of low social support, in addition to negative expectancies about the consequences of hysterectomy (e.g., loss of uterus will negatively effect sexual

pleasure), predicted high post-hysterectomy distress.<sup>13</sup> Thus, perceived support<sup>11,13</sup> and adequate communication<sup>12</sup> may facilitate women's adjustment and recovery; however, more research is necessary to understand the impact of social support in women who are facing or have had a hysterectomy.

The purpose of this study is to explore how women utilize a popular website for women who have had or will undergo a hysterectomy. In addition to exploring how women utilize this site, we wanted to determine if this site is successful in providing information and support; why particular Hystersisters were perceived to be helpful for specific issues and problems; and to describe what, if anything, women found unhelpful about the site.

## METHODS

### *Participants*

Women ( $N = 144$ ) who were visitors to the Hystersisters.com website responded to an advertisement posted on the site for 8 weeks, in order to complete a self-administered mail survey. Of these, 7 women reported that they had not visited the Hystersisters site prior to their surgery and were therefore excluded from all analyses. Ages ranged from 25 to 65 years ( $M = 39.8$ ,  $SD = 7.54$ ). The majority ( $n = 109$ ) were married (74%) or living with a life partner (6%). Seventeen were single (12%) and 11 were divorced (8%). The majority had children (77%) and no significant demographic differences were found between women who had children and those who did not.

The sample was 90% Caucasian, 4% mixed ethnicity, 2% Hispanic, 2% American Indian or Alaskan Native, 1% African American and 1% other. This sample was well educated, with 30% completing high school, 49% completing college and 22% indicating that they had obtained a post-graduate degree.

The majority (88%) were post- versus pre-operative at survey completion. When describing their diagnoses, 45% reported uterine fibroids, 29% hypermenorrhea, 28% endometriosis, 24% ovarian cysts or non-cancerous tumors, 8% uterine prolapse, 7% cancer, 14% adenomyosis, 6% pelvic adhesions, and 24% had another condition that led to their surgery. As women were allowed to report all of their diagnoses, percentages summed to more than 100%.

The majority had undergone or were planning to undergo a total abdominal hysterectomy (61%), another 18% a total vaginal hysterectomy, 15% a laparoscopically assisted vaginal hysterectomy, and 6% had undergone or were planning to undergo a

different relevant procedure. With regard to age and diagnosis, this sample was comparable to a national sample of hysterectomy patients that used U.S. census data from the National Hospital Discharge Survey.<sup>14</sup> The present sample had a slightly larger proportion of Caucasians, as compared to African Americans, than would be expected given the national rates of hysterectomy.

### *Website*

"Hystersisters.com" ([www.hystersisters.com](http://www.hystersisters.com)) was begun by one woman who wanted a place for hysterectomy patients to share their stories, to collect correct information, and to feel comfortable. Each member of the site has the capability to post messages and communicate with any of the other members. Women have access to a "mini-biography" of each member, which lists their handle, or login name, and any other personal information the woman would like to share with the other members (e.g., marital status, age, children).

### *Measures*

Participants completed a survey concerning (a) demographic information (age, diagnosis, type of surgery, marital status, sexual orientation, parental status, ethnicity, religion, education, income), (b) time spent on the site (less than 1 h, 1–3 h, 4–6 h, 7–10 h, 10+ h), (c) the type of support the site provided to them (i.e., participants were asked to check either informational/advice support or emotional support as the primary type of support provided), (d) the number and purpose of posts made on hystersisters.com (i.e., to get information, to offer advice, or to share their experience), (e) what had been most helpful about the website prior to surgery, (f) if there had been a particular Hystersister whose posts were most helpful, (g) what it was about this person's posts that had made them particularly helpful, (h) if this individual's posts had been particularly helpful with regard to a particular issue or problem, (i) what had been most unhelpful about the site prior to surgery, (j) if there had been a particular Hystersister whose posts were most unhelpful, and (k) if these posts were unhelpful with regard to a particular issue or problem. Questions e–k were open-ended. Items are available from the authors upon request.

### *Coding*

Content analysis was performed on the responses to five questions: (1) What was most helpful about the website prior to surgery? (2) Thinking about the

Hystersister whose posts were most helpful, what was it about her posts that made them especially helpful? (3) Were her posts most helpful with regard to particular issues and problems and if yes, what issues or problems? (4) What was most unhelpful about the website prior to surgery? (5) If a particular Hystersister was unhelpful, with what issues or problems was she particularly unhelpful?

Responses to the questions regarding the helpful and unhelpful nature of the site prior to surgery were classified by coders as representing esteem-emotional, informational or tangible support. This system was developed by Schaefer et al.<sup>15</sup> and was modified by Dakof and Taylor.<sup>16</sup> Esteem-emotional support was defined by Schaefer et al.<sup>15</sup> as a pattern of behaviors conveying love and acceptance, informational support as information or advice aimed at problem solving or feedback, and tangible support as the provision of assistance or goods. Martin et al. further described these social support behaviors as helpful (positive) or unhelpful (negative).<sup>17</sup>

Responses to the question asking what had been most helpful about the site prior to surgery were coded as a positive esteem-emotional response if their descriptions included any of the following: (a) expressing concern, empathy or affection, (b) expressing special understanding from being in similar circumstances, or (c) general pleasantness and kindness. Providing useful information or advice, showing optimism about the patient's situation, and serving as a positive role model were behaviors that were coded as positive informational support. Women had only virtual contact with other Hystersisters; hence, tangible support included site characteristics, such as being able to obtain answers to questions quickly and viewing site checklists.

Responses were coded as unhelpful esteem-emotional support if they (a) expressed excessive worry or pessimism, (b) inadequately demonstrated concern, empathy or affection, (c) avoided posting a response, or (d) described rude or inappropriate behavior. Responses that criticized adjustment to hysterectomy, minimization of the impact of this procedure, service as a poor role model, and inadequate offers of information or bad advice were coded as unhelpful informational support. Annoying or frustrating Web site characteristics such as an overuse of icons or responses that were difficult to read were coded as unhelpful tangible support.

Responses to the item regarding the most helpful posts were coded into one of six categories: (1) being in the same situation (i.e., undergoing the same procedure, having the same diagnosis), (2) quality of advice, (3) providing encouragement, (4) honesty, (5) humor, and (6) other. These categories were

formulated after a thorough reading of the completed questionnaires. Responses to the item requesting participants to report on the issues or problems for which this Hystersister was most helpful were coded into the following six categories: (1) preparation for surgery, (2) recovery expectations (e.g., pain, symptom control), (3) someone to relate to, (4) sexual issues, (5) questions that the participant was unwilling to ask her doctor, and (6) other. These categories were also developed after a thorough reading of the completed questionnaires.

Participants who indicated that a particular Hystersister had been unhelpful were asked to indicate for which issues or problems. Responses to this item were coded into the following five categories: (1) too emotional, (2) lacked helpful information, (3) overly negative or pessimistic, (4) irrelevant topics, and (5) other.

#### *Procedure*

Participants were recruited via an advertisement placed on the Hystersisters site. Women who were scheduled for or had recently undergone a hysterectomy were asked to e-mail the researchers if they were interested in participating in a mail survey inquiring about the type of information found to be helpful prior to their surgery, both on the website and from other sources. Those women who contacted the laboratory were given further information regarding the study and were told to send their name and mailing address; following the receipt of this information, an informed consent form and survey was sent. Participants were compensated \$10 for their time.

#### *Statistical analysis*

Data were analyzed with chi-square statistics.

## **RESULTS**

Preliminary analyses revealed no significant differences in helpful or unhelpful responses with respect to demographics, diagnosis, type of procedure, number of children, and operative status; these factors were not considered further.

#### *Website use*

The largest percentage (35%) of Hystersisters spent approximately 4–6 h per week on the site preoperatively. Another 29% used the site 1–3 h per week; 16% spent more than 10 h per week, 15%

7–10 h per week, and 5% less than 1 h per week pre-operatively. The majority (77%) had posted messages on the bulletin boards, with the median number of posts being six.

*Purpose of website use*

Most reported visiting the site for informational or advice (61%), as opposed to emotional or esteem purposes (31%). Women indicated that they posted messages to obtain information (87%), share their own experience (76%), or to offer advice or information (70%). Because more than one reason for posting messages could be selected, the percentages could sum to more than 100%.

*Most helpful and unhelpful aspects of website*

Open-ended questionnaire responses were classified by two coders; kappas ranged from 0.73 to 0.99, with an average of 0.86. Discrepancies were resolved by a third coder.

*Helpful aspects of website.* Sixty percent of responses reflected positive informational support, 27% as positive esteem/emotional support, and 16% as positive tangible support. Positive informational support was mentioned more frequently than positive esteem/emotional support or positive tangible support (Table 1), but the comparison was not statistically significant.

TABLE 1. SIGNIFICANT CONTRASTS<sup>a</sup> BETWEEN MOST HELPFUL AND MOST UNHELPFUL ASPECTS OF SITE

<i>Category (%)</i>	<i>Category (%)</i>	$\chi^2$	<i>p</i>
Most helpful aspect of site			
Positive informational support (60%)	Positive esteem/emotional support (27%)	13.460	<0.000
Positive informational support (60%)	Positive tangible support (16%)	29.775	<0.000
Most helpful aspects of Hystersister's posts			
Gone through or currently in the same situation (43%)	Honesty (12%)	18.286	<0.000
Gone through or currently in the same situation (43%)	Encouragement (8%)	24.923	<0.000
Gone through or currently in the same situation (43%)	Quality of advice (7%)	26.483	<0.000
Gone through or currently in the same situation (43%)	Sense of humor (6%)	28.880	<0.000
Issues for which Hystersister's posts were most helpful			
Preparation (23%)	Recovery expectations (40%)	5.727	<0.017
Recovery expectations (40%)	Someone to relate to (4%)	35.482	<0.000
Preparation (23%)	Someone to relate to (4%)	16.030	<0.000
Preparation (23%)	Sexual issues (3%)	18.000	<0.000
Preparation (23%)	Questions the participant did not want to ask her doctor about (2%)	22.533	<0.000
Recovery expectations (40%)	Questions the participant did not want to ask her doctor about (2%)	43.314	<0.000
Recovery expectations (40%)	Sexual issues (3%)	38.208	<0.000
Most unhelpful aspects of website			
Negative esteem/emotional support (57%)	Negative informational support (22%)	8.395	<0.004
Negative esteem/emotional support (57%)	Negative tangible support (17%)	12.100	<0.001

<sup>a</sup>Due to space limitations, only significant contrasts are reported.

When asked why they selected a particular Hystersister's posts as most helpful, 43% indicated that she had either gone through or was currently in the same situation. Twelve percent of women's responses reflected honesty, 8% encouragement, 7% the quality of advice the Hystersister provided, 6% the fact that the Hystersister had a sense of humor, and 25% indicated other reasons that her posts were most helpful. "Having gone through or currently in the same situation" was mentioned significantly more often than all other categories (Table 1). No other significant contrasts were found.

Forty percent of women's responses indicated that their most helpful Hystersister was most helpful for recovery issues, 23% regarding preparation for surgery, 4% as having someone to relate to, 3% for sexual issues, 2% for questions the participant did not want to ask her doctor, and 29% for other issues or problems. Significant contrasts are reported in Table 1.

*Unhelpful aspects of website.* Thirty-nine percent of participants indicated that they found a particular aspect of the Web site to be unhelpful. The majority (57%) of these responses were coded as reflecting negative esteem/emotional support, 22% as negative informational support and 17% as negative tangible support. Significant contrasts were found between negative esteem/emotional support and negative informational support and between negative esteem/emotional support and tangible support (Table 1).

Fourteen percent indicated that a particular Hystersister had been unhelpful. The majority (32%) of these responses indicated the posts were not positive. Twenty-one percent were coded as indicative of irrelevant topics, 11% as providing encouragement without any helpful information, 5% as being too emotional, and 32% were coded as giving other issues or problems for which the particular Hystersister's posts were unhelpful.

## DISCUSSION

This study suggests that the Hystersisters.com website is successful in providing information and support. Women indicated that informational support was the primary reason for visiting the site. Furthermore, when posting messages on the site, the majority of women appear to be providing informational support as well. These findings also suggest that women visiting the site are most concerned with obtaining information related to recovery and preparation issues. This may be because women view other site visitors as the best source of

information on this topic; this hypothesis is supported by the result that women reported finding a particular Hystersister to be most helpful because she had gone through or was currently going through the same situation herself.

Although women found this site helpful, 39% of women indicated that they had found some aspect of the site unhelpful. When asked what was most unhelpful about the site, women described situations of negative esteem/emotional support. Furthermore, 14% of participants indicated that a particular Hystersister had been unhelpful, with responses indicating that these posts were perceived as unhelpful because they were not positive. This suggests that it is perhaps unavoidable that, in an online environment such as Hystersisters.com, community members will say things that are interpreted as excessively negative by other members. Although prior reviews have reported little evidence for negative effects of health-related virtual communities,<sup>5</sup> these authors noted that in the majority of studies an intention to treat analysis was not conducted. Thus, it is possible that when an individual encounters an aspect of the virtual community or a particular individual perceived as unhelpful, this individual simply stops visiting that particular community. Although we asked women what they perceived to be unhelpful about this website, we did not inquire as to what effect these perceptions had on their subsequent website usage.

As the Internet continues to become a leading source of information on health issues, longitudinal research will be necessary to determine causal relationships between Internet use and health outcomes. Although this study is a first-step, more knowledge is needed to determine how women use the information they receive from the Internet. In particular, research is needed to address how perceptions of helpful or unhelpful behavior by other members affects an individual's use of that virtual community.

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Address reprint requests to:  
 Mali Bunde  
 Department of Psychology  
 University of Iowa  
 E11 Seashore Hall  
 Iowa City, IA 52242

E-mail: mali-bunde@uiowa.edu

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