Published in final edited form as:

J Health Commun. 2012 ; 17(3): 356–371. doi:10.1080/10810730.2011.585696.

Social and Psychological Determinants of Levels of Engagement with an Online Breast Cancer Support Group: Posters, Lurkers, and Non-Users

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Abstract

Despite the benefits and growing availability of online cancer support groups, many breast cancer patients still do not actively participate in the support groups. To better understand cancer patients' online information and support seeking behaviors, this study explores how various social and psychological characteristics predict different levels of engagement with an online breast cancer support group: posters, lurkers, and non-users. The study sample included 231 recently diagnosed breast cancer patients. Data included baseline survey scores of demographic, disease-related, and psychosocial factors and automatically collected discussion group use data over the 4-month intervention. Patterns of engagement with the cancer support group differed according to the patients' characteristics, suggesting that (1) cancer patients have very different orientations to and engagement with an online support group, and (2) 'deficits' in social and psychological resources may not be barriers to participation in a cancer support group, but rather motivators to interact with other patients. Theoretical and practical implications of the findings are discussed.

Breast cancer is the most common form of cancer and the second leading cause of cancer-related death among women in the United States (American Cancer Society, 2009). Not surprisingly, past research has shown that, along with the direct physical effects of the disease, breast cancer patients face a variety of psychological challenges related to body image and sexuality (Gustafson et al., 2001; Gustafson et al., 2005), experiences of isolation and loneliness (Anderson, 1992), as well as feelings of anxiety, distress, and depression (Spiegel, 1997). Given the high prevalence of breast cancer and the extent of life trauma associated with the diagnosis and subsequent treatments, it is essential to understand how various coping mechanisms may help reduce anxiety and improve quality of life for cancer patients.

A review of the relevant literature suggests that an increasingly common way women with breast cancer cope with their illness is participation in computer-mediated social support (CMSS) groups (Han, Shaw, Hawkins, Pingree, McTavish, & Gustafson, 2008; Han et al., in press; Shaw, Hawkins, McTavish, Pingree, & Gustafson, 2006). Despite the benefits and growing availability of online cancer support groups, many breast cancer patients still do not actively participate in the support groups. A study on breast cancer support groups showed that, although they were provided with free computer hardware, Internet access, and training, about 54% of the patients either did not participate in the CMSS group or share their feelings and thoughts with others (Shaw et al., 2006). Another study also found that about 58% of breast cancer patients either did not access the online support group or posted messages for other patients to read (Han et al., 2008). The question that rises from these findings is why some women with breast cancer do not show interest in online support groups or do not write messages to others even after they have been provided with necessary tools and training. A closer observation into the factors that determine these different engagement types may lead to insights in patients' social and psychological barriers for participation in online support groups.

To better understand the patterns of online information and support seeking/avoiding behaviors among breast cancer patients, this study explores how various demographic, disease-related, and psychosocial characteristics predict different levels of engagement in an online support group: posters, lurkers, and non-users. For this purpose, this study incorporates three theoretical frameworks: Johnson's (1997) Comprehensive Model of Information Seeking (CMIS) and the competing models on online engagement (i.e., social compensation versus social enhancement). The CMIS model identifies several antecedent factors relevant to health information seeking behavior but the directions of these relationships are unclear. Justifications for the directions are to be offered by the social compensation and social enhancement models. To address our questions, we draw upon two types of data collected from a large-scale eHealth intervention study of breast cancer patients which includes: (a) action log data analysis of the message relevant behaviors (i.e., posting vs. reading messages) within the CMSS group, and (b) survey data collected before the intervention.

The CMSS group examined in this study was part of the XXXX system. The discussion group functioned as a text-based, asynchronous bulletin board, and not as an e-mail system. That is, all messages were available to and widely read by all participants, not just those addressed in a given sentence or in the 'subject' tag. Further, the discussion group was monitored by a trained facilitator to ensure that discussions were supportive and did not contain unchallenged inaccurate or harmful information, though the facilitator did not take an active role in guiding the topics of communication and rarely intervened. The CMSS group was limited to women who were diagnosed with breast cancer.

Who Engages More and Why? Two Competing Explanations

Two competing perspectives have been proposed as frameworks for explaining why breast cancer patients show different levels of participation in online cancer support groups. These two frameworks had been originally used for explaining uses and effects of the Internet (Kraut, Kiesler, Boneva, Cummings, Helgeson, & Crawford, 2002) and some specific online services, such as social network websites. The social enhancement model (the "Rich get richer" model) (Kraut et al., 2002) posits that individuals who have more social resources in their daily lives will use and benefit more from using the Internet compared to those who do not have many offline social resources. Having strong social support offline can make people feel comfortable exploring online world without much concern, since they know they already have their "safety net" offline. Knowing that they do not have to make up for what

they lack offline provides them with confidence and easiness in using diverse online services. According to this perspective, such comfort and confidence would encourage those with more resources to actively engage in online social support groups.

Alternatively, the social compensation model (the “Poor get richer” model) (McKenna & Bargh, 1998) posits that individuals who are shy and do not have sufficient offline social resources will use and benefit more from participating in diverse online activities through connecting with people and obtaining supportive communications. According to this perspective, individuals who do not have much social support offline might be more active in participating in online activities or services, since they have more time to spare and be more eager to develop new relationships online. On the other hand, using online services might rather interfere with real-world relationships for those who already have satisfactory offline resources. This hypothesis has been applied to the cancer patient support group context, showing that cancer patients with emotionally supportive spouses were rather harmed by participating in peer support group (Helgeson, Cohen, Schulz, & Yasko, 2000).

Using the CMIS to Predict Online Support Group Participation

Since information seeking is considered as one of the vital reasons for participating in an online support group (e.g., factual information seeking, seeking for different viewpoints, and access to others’ personal experiences) (Han et al., 2010), the current study seeks to apply the CMIS framework in examining the antecedents to online support group participation. The two competing models of social enhancement and social compensation allow us to predict in either (or both) direction(s) with each antecedent variable.

Demographic Factors

Within the CMIS framework, demographic factors are considered essential in predicting the use of health information resources, including participation in online support groups. Recent studies have found that factors such as age, race, living situation, and education predicted differential use of various health information resources (Freimuth, Stein, & Kean, 1989; Leydon et al., 2000). Internet usage studies have reported that the older the person, the less likely he/she would be actively engaging in Internet activities; the propensity to use the Internet for health information was also found to decrease with increase in age (Ybarra & Suman, 2006); and a study specifically focusing on lurking in an online support group found that lurkers were relatively older than active participants (van Uden-Kraan et al., 2008).

Racial differences have been observed in using the Internet for health information. African Americans were less likely to turn to the Internet for information than Whites (Ybarra & Suman, 2006). More specifically with online cancer support group participation, past research has found that Caucasians produce greater volumes of writing than African Americans (Shaw et al., 2006). One reason for this discrepancy may be that African Americans were found to be less willing to share cancer information beyond their family boundary.

Online patient support group participation can also be linked with living conditions and education level (Assael, 2005; Ybarra & Suman, 2006). Patients who are living alone may be more likely to actively participate in an online support group since without the support of family or friends living together in the household, they might be motivated to turn to online, especially if the option is readily available, as a way of receiving alternative social support (McKenna & Bargh, 1998). Past research has also found that both Internet usage and health information seeking online increases with higher levels of education.

Disease-Related Factors

According to the CMIS, the level of individuals' direct experience with the disease will predict their health information seeking behaviors (Johnson, 1997). For example, cancer stage is a key factor, as treatment choices, side effects, and prognosis are very different for patients with early-stage vs. advanced breast cancer (Czaja, Manfredi, & Price, 2003; Johnson, 1997). In addition, each phase of the cancer journey comes with its own set of concerns and thus may influence the type (Mills & Sullivan, 1999) and extent of using health information resources (Czaja et al., 2003; Leydon et al., 2000). From this information, we expect that the motivation to participate in an online social support group may be different depending on the patient's disease progress, thus influencing participation levels in an online support group.

Psychosocial Factors

The CMIS points out that individual's health beliefs and perceived salience of the information influence information seeking. First, an individual's "perception of the extent to which he or she can shape or control events" (Johnson, 1997, p. 73), has been found to enhance the ability to seek out and use cancer information in making a health care decision (Leydon et al., 2000). Thus, patients with higher information competence may be more likely to seek out relevant information and engage more within an online support group (Kraut et al., 2002; Valkenburg et al., 2005). Alternatively, it is possible that patients with low information competence may use this eHealth resource to augment their competence in dealing with their cancer and treatment decisions (Shaw et al., 2008).

Second, according to the CMIS, psychological salience, or "the personal significance of cancer-related information to the individual" (Johnson, 1997, p. 72), is an underlying motivation to seek out information. Applying this framework to our discussion, one possibility is that people who report lower levels of social support, quality of life, and confidence in physician-patient communication may turn to an online support group and engage more in order to compensate for the lack of those resources (Shaw et al., 2008). Similarly, higher levels of need for information can be a motivator to seek out needed information in support of lifestyle and cognitive/emotional adjustments. Another possibility is that those with higher levels of social support and quality of life at baseline may be best able to engage in and thus benefit from a new information resource such as online support groups (Kraut et al., 2002).

Methods

Participants

The data analyzed in this study were collected as a part of a larger Digital Divide Pilot Project (DDPP), in which underserved women with breast cancer in rural Wisconsin and Detroit, Michigan were given access to the XXXX "*Living with Breast Cancer*" program for 4 months (Gustafson et al., 2005). Although both the pretest and a 4-month posttest surveys were conducted with a sample of 231, the current study analyzed the baseline survey data only to explore the relationship between patient's characteristics and different levels of engagement in an online support group. Detroit recruitment started in June 2001 and ended in April 2003 and Wisconsin recruitment began in May 2001 and ended in April 2003.

Eligibility criterion required that participants were at or below 250% of the federal poverty level, not homeless, within one year of diagnosis with early-stage breast cancer or within one year of a diagnosis of metastatic breast cancer, and able to read and understand an informed consent letter. After submitting their pre-test, all study participants were loaned a computer and given Internet access for 4 months. Over 80% of those who joined the study

(more than 185 women) did not have a computer at home and they had very limited experience in both the computer and the Internet (Han, Hawkins, Shaw, Pingree, McTavish, & Gustafson, 2009). All study participants also received personal training to learn how to use the computer and the Internet, but the majority of time was spent on teaching participants how to use XXXX, including how to post messages in the CMSS group.

Action Log Data Action log tracking data on whether and how women used the discussion group for 4-months were also collected. Action log data files contain the unique identifier for each action, individual participants' online handle and numerical ID, and the message relevant behavior (i.e., post, read). This enabled us to monitor whether participant joined the CMSS group or not and which participant wrote and/or read each message.

From this we could generate our measures of levels of engagement with the CMSS group. If women accessed the discussion group and wrote/read at least one message during the four-month intervention period, we categorized them as 'users'. If they did not, they were assigned to the 'non-users' category. Among 'users', 'posters' were operationalized as women who wrote at least two messages during the study period. A woman was considered to be a 'lurker' if she read messages but never wrote at least two messages over the course of the study. We selected this criterion since as part of the training process women were encouraged to write a message introducing themselves to the rest of the group, which provided the participant the opportunity to show during the in-house training that she could use the communication function that allowed her to participate in the computer support group. Finally, these measures of engagement generated from action log analysis were combined with pre-test survey data to examine how demographics, disease status, and psychosocial needs related to different levels of participation in the online breast cancer support group.

Survey Data

Guided by the CMIS framework, we focus on antecedents of three categories: demographic, disease-related, and psychosocial factors.

Demographic factors—Surveys administered at pre-test included demographic factors of age, race (a dummy variable with African American coded 0 and Caucasian coded 1), whether or not patients live alone (a dummy variable with 'no' coded 0 and 'yes' coded 1), and education.

Disease-related factor—Surveys also included disease-related measure of stage of cancer (a dummy variable with early stage (stage 0, 1, 2) coded 0 and late stage (3, 4, or inflammatory) coded 1) (Gustafson et al., 2005). This roughly defines a medical boundary at which treatment choices and prognosis differ considerably.

Psychosocial factors—Measures of seven psychosocial factors at pre-test included: information competence, need for information, social support, functional well-being, emotional well-being, breast cancer-related concerns, and confidence in physician-patient communication. See Appendix for the exact wording of all the items belonging to these scales. For all measures, scale scores are calculated as averages across scale items.

Social Support and Information: A health information competence scale ($M=2.96$, $SD=.87$) assessed a woman's perception that she could get and use health information (Gustafson et al., 2005). The five-point scale ranging from 0 to 4 asked whether participants agreed or disagreed with statements such as "I can figure out how and where to get the information I need" (Cronbach's $\alpha=.74$). A five-item need for information scale ($M=2.90$, $SD=.76$)

assessed the extent to which a woman lacked information about her health or health care (Gustafson et al., 2001). Respondents were asked, on a five-point scale ranging from 0 = not at all to 4 = very much, if, for instance, they “needed more information about latest breast cancer news” (Cronbach’s $\alpha=.84$). Lastly, a social support scale ($M=2.93$, $SD=.86$) used six items (Cronbach’s $\alpha=.87$) on a five-point scale ranging from 0 to 4 to assess how true statements such as “There are people I could count on for emotional support” were (Gustafson et al., 2005). Social support assessed the informational and emotional support of friends, family, co-workers, and others.

Quality of Life: The five-item functional well-being subscale ($M=2.35$, $SD=1.00$) of the Functional Assessment of Cancer Therapy-Breast (FACT-B) was used to assess the impact of breast cancer on quality of life (Brady, Cella, Mo et al., 1997). Respondents were asked, on a five-point scale ranging from 0 = not at all to 4 = very much, if, for example, they are “able to work (including working in home)” (Cronbach’s $\alpha=.84$). A six-item emotional well-being subscale of the FACT-B ($M=2.44$, $SD=1.00$) used a five-point scale ranging from 0 to 4 how often participants had felt, for example, “sad”. These items were reversed so that higher score means higher level of emotional well-being (Cronbach’s $\alpha=.86$). Finally, we used the breast cancer-related concerns subscale of the FACT-B ($M=1.49$, $SD=.72$) to assess the degree of concern about potential emotional, physical, and body image consequences of cancer, its treatments and their side effects (Gustafson et al., 2005). Respondents were asked, on a five-point scale ranging from 0 = not at all to 4 = very much, how much they agreed or disagreed with the statements such as “I worry about the effect of stress on my health” (Cronbach’s $\alpha=.72$).

Participation in health care: A six-item confidence in physician-patient communication scale ($M=3.00$, $SD=.62$) developed in our previous research (Shaw, Han, Hawkins, Stewart, McTavish, & Gustafson, 2007) measured women’s comfort and confidence dealing with physicians, other medical personnel, and health-care situations. We asked, on a five-point scale ranging from 0 = disagree very much to 4 = agree very much, whether they agreed or disagreed with statements such as “I am comfortable discussing my treatment choices with my doctor” (Cronbach’s $\alpha=.81$).

Analytic Approach

To uncover dynamic relationships between antecedent factors and different engagement types, two analytic procedures were employed. To examine how demographic and disease-related factors are associated with different levels of engagement with the online cancer support group, differences in the demographic and disease-related characteristics between users and non-users, and among posters, lurkers, and non-users were first examined by using chi-square and analysis of variance test. Following this analysis, we examined how psychosocial factors are related with different engagement types. To do so, we employed analysis of covariance to determine if there were differences between users and non-users, and among posters, lurkers, and non-users regarding their baseline psychological needs. For this analysis, we adjusted for statistically significant covariates from the previous analysis. Analyses were followed by multiple comparisons using the Bonferroni method to identify the significant differences between engagement types.

Results

Descriptive statistics

The study sample of 231 women had a mean age of 51 years and more than half of them reported at least some college education. On average, more than two thirds of them were in the relatively early stages (I or II) of cancer. The racial characteristics of the sample were

62.3% Caucasian and 35.9% African American. In addition, about a quarter of them lived alone. Table 1 presents patient characteristics of the study sample by engagement types.

Of the 231 participants, about 23% ($N=54$) either did not write or read messages during the four-month study period and thus were classified as *non-users*. Among the 177 *users* (posting $M=15.1$, $SD=43.1$; reading $M=269.6$, $SD=548.9$), 103 women wrote at least two messages (i.e., 'posters', posting $M=25.4$, $SD=54.3$; reading $M=435.2$, $SD=663.9$), while 74 women read messages but never wrote more than one message over the course of the study (i.e., 'lurkers', posting $M=0.7$, $SD=0.5$; reading $M=39.1$, $SD=134.5$).

Factors predicting levels of engagement with a CMSS group

Statistical analyses were conducted to examine whether there were significant differences in patients' social and psychological characteristics (1) between *users* (including *posters* and *lurkers*) and *non-users*, and then (2) among *posters*, *lurkers*, and *non-users*. As shown in Table 1, chi-square and analysis of variance (ANOVA) suggested that *users* were more likely to be Caucasian ($\chi^2=63.3$, $p<.001$) than *non-users*. When all of the three user types were considered, race clearly played a role in which user type the patients were more likely to be ($\chi^2=74.5$, $p<.001$). After adjusting the alpha level for multiple comparisons, post hoc chi-square analyses revealed that significantly more Caucasian women were *posters*, followed by *lurkers*, and then *non-users*. In contrast, African American women were more likely to be *non-users*, followed by *lurkers*, and then *posters*. Additionally, ANOVA showed that age ($F(2,228)=3.78$, $p<.05$) was a significant predictor and post hoc analysis indicated that *posters* were significantly younger than *lurkers*. Whether or not patients lived alone ($\chi^2=7.05$, $p<.05$) was another significant predictor, with post hoc chi-square suggesting that *posters* were more likely to live without friends/family than *lurkers*. However, we found no difference in the stage of cancer among different user types.

To determine which psychosocial factors predict different engagement types, analysis of covariance (ANCOVA) was employed and all analyses were adjusted for statistically significant covariates from Table 1. After controlling for age, education, race, and living situation, ANCOVA and following post hoc analyses suggested that patients who had a lack of competence in health information ($F(1,220)=8.95$, $p<.01$) and confidence in physician-patient communication ($F(1,220)=3.90$, $p<.05$) at pretest were more likely to be *users* than *non-users*. When all of three user types were considered, analyses revealed that information competence ($F(2,219)=4.74$, $p<.01$), social support ($F(2,219)=4.74$, $p<.05$), and need for information ($F(2,219)=6.52$, $p<.01$) were only significant predictors determining different engagement types. As shown in Table 2, post hoc analysis using the Bonferroni method indicated that *non-users* and *lurkers*' social support level was significantly greater than that of *posters*, respectively. Similarly, *non-users*' competence in health information was greater than that of *posters*. There was also a significant difference between *lurkers* and *posters* in terms of their need for information, suggesting that *posters*' need for information was greater than that of *lurkers*' at pretest. Overall, these results suggest a trend that those who were in worse conditions regarding their perceived state of affairs were likely to engage more in the discussion group for information and support.

Discussion

This study incorporated the CMIS and the competing models on online engagement into an overarching theoretical framework to examine how cancer patients' background characteristics, disease-related factors, and psychosocial factors predict different types of engagement with an online cancer support group. Previous studies have found that support groups play a significant role in improving cancer patient's emotional and physical health by providing diverse informational, instrumental, and emotional support (Dumont & Provost,

1999; Shaw et al., 2006). For those who do not have strong support from their family members/friends, it is comforting and almost therapeutic (Walther, Pingree, Hawkins, & Buller, 2005) to be a part of the online group that consists of individuals who share similar concerns. For those who already have good offline support resources, they can share their physical or psychological concerns with more confidence.

Even with such benefits breast cancer patients can gain from online support groups, our findings suggest that many of them still do not actively participate in sharing their concerns or issues by posting messages, but rather choose to remain as lurkers. Only 44.6% actively posted messages while 32% lurked and the remaining 23.4% did not log in to the system. Some of the possible explanations behind lurking behavior might be that certain members think that posting takes up too much time, have concerns about privacy or safety issues, feel uncomfortable using the user-interface of discussion boards, or still can feel a strong sense of community just from reading others' postings without writing anything (Nonnecke & Preece, 1999). However, there is little empirical research examining why some breast cancer patients lurk and do not actively engage in online support group activities. Our finding clearly shows that patients have different orientations to and engagements with an online cancer support group and research efforts to examine what factors potentially determine their levels of engagement with the online system are warranted.

Our results suggest that the CMIS is a useful framework for understanding cancer patient's diverse patterns of engagement with an online support group. Demographic variables had some predictive value in this study. It is worth reiterating that participants were provided free computers, Internet service and individualized computer training. By removing the barrier of access to technology, we posit that demographic characteristics might reflect differences in experience, preferences, and comfort with a mouse-driven medium and on-screen text. Thus, the fact that posters were younger than lurkers suggests that older women may have been less comfortable in typing and sharing their personal experiences with anonymous others beyond their family boundaries (Squires et al., 2005). Posters were also more likely to live alone than lurkers, signifying that those who live alone might have greater motivations to express their problems online as an alternative way of receiving feedback and support from their offline peers (McKenna & Bargh, 1998). Equally interesting is the finding that the majority of African Americans were non-users whereas the majority of Caucasian women participated in the online group and posted messages for others to read. This is in line with the past findings that African American women may have been reluctant to share their cancer experiences in a predominantly white and anonymous discussion group (Freimuth, 1993; Shaw et al., 2006).

In addition to the CMIS, this study relied on two competing perspectives on online engagement – the social compensation model and the social enhancement model – as complementary frameworks that provide more insights into how cancer patient's social and psychological resources can affect their engagement types in the support group. Of the two models, the social compensation model (McKenna & Bargh, 1998) gained greater support by the data. Specifically, those who did not use the online support system at all and those who were only lurking had had more offline social support from their close friends or family than those who were actively posting messages. The application of the social compensation model is not limited only to social support. Those who were highly competent in their ability to deal with information about breast cancer did not participate in online social support discussions as much as those who lacked in their competence. Also, posters had higher levels of need for information than lurkers. Taken together, these results suggest that these “deficits” in psychosocial resources may not be barriers to participation in an online support group, but rather motivators to use more demanding and engaging communication tool. This is particularly noteworthy because participation in an online support group requires

substantial thoughts and input, often over time, in order to receive/provide needed support and feedback from/to other group members.

Notably, the findings of this study have implications for research on computer-mediated communication. One interesting aspect of lurkers worth further investigation is whether they have a strong group identity and attachment to online support groups although they do not actively post. According to the social identity model of deindividuation effects (Lea & Spears, 1992), deindividuated members of online groups are expected to not only identify with other members, but also show their attachment to the group by explicitly agreeing with other members or conforming to group norms. If lurkers identify strongly with other breast cancer patients, but do not engage in posting activities, can we say that they are contributing to the group's cohesion? In this sense, the existence of lurkers in online communities can be an interesting new domain for testing boundary conditions of the model.

This study has several limitations and suggestions for future research. Given the somewhat dated nature of the data presented here, it seems to be necessary to replicate our findings with a more recent collection. The CMSS group examined here was text-based, asynchronous bulletin boards, but given the rapid advances in technology, it is likely that CMSS groups accommodating photo sharing, real-time chat, audio, and video are not far off. Then it is suggested that future research should examine preference of and familiarity with advanced technology as important factors predicting different engagement types. Notably, while our study attends to antecedent factors that might explain different engagement types with the CMSS group, it is quite possible that simply reading others' messages while not actively contributing to the group could have benefits for lurkers in terms of understanding their illness and situation. Thus, future study should extend our inquiry and examine the effects of engagement types on various outcomes.

The findings of this study provide several important practical implications for health informatics. First, we found that there was a significant gap in usage of online support systems between different race and age groups. Although various factors may attribute to these differences, one reason may be the perceived lack of commonality between cancer patients (Andrews, Preece, & Turoff, 2002). Especially for racial minority group members, interacting with those belonging to a majority group can be a barrier that can keep them from greater participation. One way to solve this issue may be to create subgroups in terms of race and age, so that people would be more comfortable in sharing their feelings and experiences (Pettigrew & Tropp, 2006). Another way is to increase understanding and familiarity among members by encouraging them to create online profiles containing their information and interests (Andrews et al., 2002) but also holding offline meetings with relevant experts and organizations to increase trust and intergroup interaction (Pettigrew & Tropp, 2006). These efforts would help reduce barriers among participants and increase active participation.

Second, we found greater lack of participation among patients with more resources and support in their daily life. This is an important matter since they could potentially contribute more with the knowledge and experience they gain from their strong offline support systems. One reason for their lack of participation may be that they find online participation takes time away from their time with doctors or caregivers (Helgeson et al., 2000). Then it is suggested that future online support groups provide means of communication that allows caregivers, doctors, and family members to participate together with the patient. This could decrease potential conflict between offline and online support systems and create a synergy effect between the two. Finally, given that the patients with the greatest deficits in their resources and psychosocial competence were likely to be more active in online support

groups, screening for and giving access to patients who are more socially isolated and lacking in offline resources could result in meaningful outcomes.

In closing, the current study contributes to our understanding of why breast cancer patients do or do not actively participate in online support groups. There are some studies that compare online support group participants and non-participants (e.g., Hoybye, Dalton, Christensen, Ross, Kuhn, & Johansen, 2010). To our knowledge, however, this is the first research to conceive both *non-users* and *lurkers* as another form of engagement and examine different factors in their relationships, resulting in deeper knowledge about cancer patient's preferences with a coping resource. To accomplish our goal, this study merged survey data collected from an eHealth intervention with action log data on whether and how participants used the discussion group. From a methodological standpoint, our approach offers an avenue to explore the nature of the exchanges occurring within the CMSS group and their antecedents previously inaccessible for testing due to the limits of extant research methodologies.

Acknowledgments

The Digital Divide Pilot Project study was funded by grants from the National Cancer Institute and the John and Mary Markle Foundation (RFP No. NO2-CO-01040-75). The authors would like to thank Haile Berhe, Helene McDowell, and Gina Landucci for their central role in conducting the operational aspects of this study. We would also like to thank the women who agreed to participate in our study.

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Appendix: Question Wording

Confidence in physician-patient communication, a 6-item scale. All items were scored on a 5-point scale ranging from 0= *disagree very much* to 4= *agree very much*.

1. I am comfortable discussing my treatment choices with my doctor
2. I am able to be assertive with my doctor
3. I feel comfortable in asking the physician or nurse a lot of questions
4. I understood what doctor told me
5. I have confidence in my doctors
6. I know what questions to ask my doctor.

Health information competence, a 5-item scale. All items were scored on a 5-point scale ranging from 0 = *never* to 4 = *always*.

1. I know exactly what it is that I want to learn about my health care
2. I can figure out how and where to get the information I need
3. Health information is more difficult for me to obtain than other types of information (reverse coded)
4. I am satisfied with the way I currently learn about health issues
5. I feel that I am in control over how and what I learn about my health.

Social support, a 6-item scale. All items were scored on a 5-point scale ranging from 0= *not at all* to 4= *very much*.

1. There are people they could count on for emotional support
2. There are people who will help them understand things they are finding out about their illness
3. There are people they could rely on when they need help doing something
4. There are people who can help them find out the answers to their questions
5. There are people who will fill in for them if they are unable to do something
6. I am pretty much all alone (reversed).

Emotional well-being, a 6-item scale. All items were scored on a 5-point scale ranging from 0= *not at all* to 4= *very much*.

1. I feel sad (reversed)
2. I feel nervous (reversed)
3. I am worried about dying (reversed)
4. I am worried that my illness will get worse (reversed)
5. I feel like my life is a failure (reversed)
6. I feel like everything is an effort (reversed).

Functional well-being, a 5-item scale. All items were scored on a 5-point scale ranging from 0= *not at all* to 4= *very much*.

1. I am able to work (including working in home).
2. My work (including work in home) is fulfilling.
3. I am able to enjoy life “in the moment”.
4. I am sleeping well.
5. I am enjoying the things I usually do to relax.

Breast cancer-related concerns, a 10-item scale. All items were scored on a 5-point scale ranging from 0= *not at all* to 4= *very much*.

1. I was self conscious about the way I dress.
2. I was bothered by swollen or tender arms.
3. I worried about the risk of cancer in other family members.
4. I worry about the effect of stress on my health.
5. I was short of breath.
6. My change in weight bothered me.
7. I feel sexually attractive.
8. My hair loss bothered me.
9. My skin bothered me as a result of radiation.
10. I am fatigued.

Need for information, a 5-item scale. All items were scored on a 5-point scale ranging from 0= *disagree very much* to 4= *agree very much*.

1. I needed more information about breast cancer from the point of view of women who have had breast cancer.
2. I needed more understandable information about breast cancer.
3. I needed more information about the latest breast cancer news.
4. I needed more contact with people who understood what I was going through.
5. I needed help making decisions.

Table 1Characteristics of Patients by their Levels of Engagement with an Online Support Group ($N = 231$)

Patient Characteristics	Non-Users (n=54)	Users (n=177)		
		All (n=177)	Lurkers (n=74)	Posters (n=103)
Age				
Mean (SD)	52.24 (11.86)	51.37 (11.82)	54.18 _a (11.86)	49.36 _b (11.43)
Race				
African American	44 _a (83.0%)	40 (22.9%)	27 _b (37.5%)	13 _c (12.6%)
Caucasian	9 _{A_a} (17.0%)	135 ^B (77.1%)	45 _b (62.5%)	90 _c (87.4%)
Live alone				
Yes	16 (29.6%)	47 (26.6%)	12 _a (16.2%)	35 _b (34.0%)
Education				
Some junior high	1 (1.9%)	1 (0.6%)	1 (1.4%)	0 (0.0%)
Some high school	11 (20.4%)	13 (7.3%)	4 (5.4%)	9 (8.7%)
High school degree	17 (31.5%)	55 (31.1%)	27 (36.5%)	28 (27.2%)
Some college	15 (27.8%)	54 (30.5%)	19 (25.7%)	35 (34.0%)
Associate or technical degree	3 (5.6%)	25 (14.1%)	11 (14.9%)	14 (13.6%)
Bachelor’s degree	5 (9.3%)	23 (13.0%)	9 (12.2%)	14 (13.6%)
Graduate degree	2 (3.7%)	6 (3.4%)	3 (4.1%)	3 (2.9%)
Stage of cancer				
Early stage (stage 0,1,2)	41 (75.9%)	121(68.4%)	55 (74.3%)	66 (61.4%)

Note: Different superscripts mean there are significant differences in corresponding variables between users and non-users. Subscripts are based on analysis among posters, lurkers, and non-users. Cells with different subscripts differ at $p < .05$ at the minimum.

Table 2Group Differences on Support, Participation, and Quality of life at Pre-test ($N = 231$)

Variables	Non-Users (n=54)	Users (n=177)		
		All (n=177)	Lurkers (n=74)	Posters (n=103)
Social support & information				
Social support	3.13 _a (.82)	2.93 (.88)	3.12 _a (.87)	2.79 _b (.87)
Information competence	3.25 ^A _a (.95)	2.87 ^B (.82)	2.88 (.81)	2.86 _b (.83)
Need for information	3.05 (.77)	3.01 (.78)	2.84 _a (.94)	3.13 _b (.64)
Quality of life				
Emotional well-being	2.60 (1.02)	2.39 (1.00)	2.49 (1.05)	2.32 (.95)
Functional well-being	2.30 (1.15)	2.36 (.97)	2.44 (1.01)	2.30 (.93)
Breast cancer concerns	1.47 (.83)	1.48 (.71)	1.45 (.70)	1.50 (.66)
Participation in health care				
Confidence in physician- patient communication	3.19 ^A (.60)	2.94 ^B (.62)	2.98 (.60)	2.91 (.64)

Note: Entries refer to means and standard deviations are in parentheses. Different superscripts mean there are significant differences in corresponding variables between users and non-users. Subscripts are based on ANCOVA analysis among posters, lurkers, and non-users. Cells with different superscripts/subscripts differ at $p < .05$ at the minimum by post hoc tests. All analyses adjusted for statistically significant covariates from Table 1.