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Lurking as an Active Participation Process: A Longitudinal Investigation of Engagement with an Online Cancer Support Group

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Abstract

To better understand participation in computer-mediated social support (CMSS) groups for breast cancer patients, this study examines two overarching questions of: 1) who are posters, lurkers, or non-users? and 2) what role do these different types of engagement play in explaining psychosocial health outcomes? This study incorporates the comprehensive model of information seeking and two competing models of social enhancement and social compensation, as well as the literature of lurking and posting behaviors in online groups to answer research questions. Our findings suggest that patterns of engagement in a CMSS group differed according to patients' socio-demographic characteristics and psychosocial factors. In addition, we found that lurkers have a higher level of perceived functional well-being than posters at 3 months post-baseline. Theoretical and practical implications for effective online cancer support group campaigns are discussed.

Keywords

Lurking; Posting; Computer-mediated support group (CMSS); eHealth; Cancer; Quality of life

More than 50% of American adults living with chronic disease are using the Internet for health issues, and 8% of this population is using online support groups for seeking health information and online support (Fox & Purcell, 2010; Zickuhr & Smith, 2012). Online support groups are commonly referred to as forums where informational, emotional, and instrumental support can be exchanged through various forms of computer-mediated communication, including bulletin boards, email, instant messaging, or voice and video interactions (Wright & Muhtaseb, 2010). For women with breast cancer, there are currently many online support groups operated by either professionals or cancer survivors (e.g., The Cancer Support Community, breastcancer.org, and SHARE cancer support). Although overall rates of participation in online support groups are low (Nagler et al., 2010), when

women with breast cancer are given access and necessary training on how to use online support groups, they were more likely to take advantage of this opportunity, with participation rates reaching 40% or above (Shaw, Hawkins, McTavish, Pingree, & Gustafson, 2006; Han et al., 2008).

In fact, online support groups play a significant role in improving patients' emotional and psychological health by providing diverse informational, instrumental, and emotional support (Dumont & Provost, 1999; Shaw et al., 2006). A review of the literature suggests that women with breast cancer can obtain a variety of positive outcomes through active participation (e.g., information seeking and sharing, and emotional disclosure), including perceived social support, reduction in breast cancer-related concerns, competence in healthcare and information, and emotional well-being (Baker et al., 2011; Han, 2012; Han et al., 2008; Han et al., 2012; Shaw et al., 2006; Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000; Shim, Cappella, & Han, 2011).

However, despite the benefits of online support groups, many breast cancer patients choose to be lurkers or not participate in online support groups at all (Han et al., 2008; Han et al., 2012; Shaw et al., 2006). A widely accepted definition of lurkers includes "anyone who reads but seldom if ever publicly contributes to an online group" (Nonnecke & Preece, 2003, p. 110). Lack of prior experience and comfort in using a computer and the Internet might be one reason why patients lurk or do not engage with online support groups. However, there is a research gap examining why patients demonstrate different engagement behaviors (such as lurking, posting, or non-using) even after they have been provided with necessary tools and training, such as a free computer and internet connection, and instruction on how to use a computer and online support groups. More importantly, to our knowledge, there is no extant research that explores the potential impacts of such behaviors on breast cancer patients' short- and long-term disease experience and quality of life.

Accordingly, this study draws upon two types of data collected from a large-scale eHealth intervention study of breast cancer patients which includes: (a) longitudinal survey data collected before, during, and after the intervention involving a CMSS group, and (b) action log data analysis of the message relevant behaviors occurring within the CMSS group (i.e., posting vs. reading messages). Our aim here is to advance research on the antecedents and consequences of participation in CMSS groups.

Predicting Engagement with an Online Cancer Support Group

To understand cancer patients' levels of engagement—posting, lurking, or non-using—within online support groups, we incorporate three theoretical frameworks to identify demographic and psychosocial factors as antecedents to cancer-related information seeking behaviors. These three theoretical frameworks are Johnson's (1997) comprehensive model of information seeking (CMIS) and the two competing models of social enhancement (Kraut et al., 2002) and social compensation (McKenna & Bargh, 1998).

CMIS Model

The CMIS model identifies various antecedent factors relevant to health information seeking behaviors (Johnson, 1997). Within the CMIS framework, demographic factors are considered important to predict the use of health information resources, including participation in online support groups. Previous research documented that factors such as age and race predicted differential use of various health information resources (Carlsson, 2000; Freimuth, Stein, & Kean, 1989; Johnson, 1997; Leydon et al., 2000). With age, comfort with using technology (Assael, 2005) and the propensity to use the Internet for health information (Ybarra & Suman, 2006) tend to decrease, which will likely make older patients less active in online support groups. Past research has also found that Caucasians are more likely to be active in online support groups than African Americans, spending more time in online support groups and producing greater volumes of writing (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 (Johnson, 1997).

Online patient support group participation can also be linked to living conditions, education level, and time since cancer diagnosis (Assael, 2005; Caplan, 2003; Shotton, 1991; Johnson, 1997). Previous research found that patients who are living alone may be more likely to be active in online support groups since they might be motivated to turn to the Internet, especially if the option is readily available, as a way of receiving alternative social support (Han et al., 2012). Education can be another factor predicting different levels of online support group participation since both Internet usage and health information seeking online increases with higher levels of education (Assael, 2005; Ybarra & Suman, 2006). As noted by the CMIS, the level of individuals' direct experience with the disease will predict their health information seeking behaviors (Johnson, 1997; Johnson & Meischke, 1993). For example, time since cancer diagnosis is a key factor, as treatment choices, side effects, and prognoses are very different for patients in each phase of the cancer journey, thus influencing the type of health information resources they turn to (Mills & Sullivan, 1999; Luker, Beaver, Leinster, Owens, & Glynn, 1996) and the extent to which they use these resources (Leydon et al., 2000).

Cancer-related information seeking can be also triggered by an individual's level of experience with technology. Although the CMIS does not explicitly consider it, previous research suggests preference of and familiarity with advanced technology as important factors predicting different engagement types since limited keyboarding skills might inhibit some individuals' propensity to type and engage in text-based communication (Han et al., 2012). The current study expands the CMIS to the eHealth research domain and looks into how users' prior experience and comfort level with using a computer and the Internet might affect their level of engagement with an online cancer support group.

Two Competing Models

Although the CMIS identifies various factors as antecedents to cancer-related information seeking behaviors, two competing perspectives have been proposed as frameworks for explaining why breast cancer patients show different levels of participation in online cancer support groups. First, the social enhancement model (Kraut et al., 2002; Valkenburg,

Schouten, & Peter, 2005) suggests that those with more resources (e.g., availability of professional healthcare, access to health and cancer information, support from family and friends) in their daily life will engage more with online resources (e.g., online health and cancer information, emotional support from other members in online support groups) since those additional resources provide an added avenue for augmenting their total resources. According to this model, having a strong support network offline may make them feel comfortable in not only using online resources but also in engaging more deeply with others by sharing their own concerns and emotions.

On the other hand, the social compensation model (McKenna & Bargh, 1998) suggests that those with fewer resources in their daily life will engage more with online resources since connecting with people and receiving supportive communications through online activities will allow them to compensate for the lack of resources in daily life. According to this perspective, individuals who do not have much support offline might be more active in participating in online activities, since they have more time to spare and may be more eager to develop new relationships online. Both of these perspectives can be applied to the online support group context and will help us better understand who engages more and why.

The CMIS suggests that an individual's "perception of the extent to which he or she can shape or control events" (Johnson, 1997, p. 73), can influence the ability to seek out and use cancer information in making a healthcare decision (Leydon et al., 2000; Lichter, 1987). From the perspective of the social enhancement model, patients with higher healthcare competence or breast cancer knowledge may be more likely to seek out relevant information and engage more within the online support group (Kraut et al., 2002; Valkenburg et al., 2005). Alternatively, it is also possible that patients with low competence or knowledge may use this eHealth resource to augment their competence in dealing with their cancer and treatment decisions (McKenna & Bargh, 1998; Shaw et al., 2008). Furthermore, 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 support and quality of life may turn to an online support group and engage more in order to compensate for the lack of those resources (McKenna & Bargh, 1998; Shaw et al., 2008). Another possibility is that those with higher levels of support and quality of life may be best able to engage in, and thus benefit from, a new information resource such as online support groups (Kraut et al., 2002; Valkenburg et al., 2005).

To summarize, CMIS frameworks indicate that patients' demographic and psychosocial characteristics are expected to predict different levels of engagement in an online support group. The two competing models also suggest different influencing mechanisms of predictors. Thus, we compare the differences in these predictors between users and non-users, and, more importantly, between posters and lurkers. In the absence of strong prior expectations, the following research questions are proposed:

RQ1a: In an online breast cancer support group, how do users and non-users differ in their baseline demographic and psychosocial characteristics?

RQ1b: In an online breast cancer support group, how do posters and lurkers differ in their baseline demographic and psychosocial characteristics?

In addition to exploring who engages in a CMSS group and why, it is crucial to examine the consequences of those different levels of engagement on psychosocial health outcomes. In the section below, we start with a literature review of online lurking and posting behaviors and then focus on potential mechanisms behind such behaviors in producing health outcomes. The research questions are then articulated.

Lurking as an Active Participation Process

Research on Lurking Behavior in Online Groups

How to conceptualize the nature of online lurking has been a debatable issue in the literature. A widely accepted definition of lurkers is “anyone who reads but seldom if ever publicly contributes to an online group” (Nonnecke & Preece, 2003, p. 110). This definition reflects a traditional perspective about online lurking, which is perceived negatively as ‘good for nothing free-riding’ behavior (Preece, Nonnecke, & Andrews, 2004). Early work from Nonnecke and Preece has challenged this traditional perspective of lurking behavior and argued that online lurking should be viewed as a highly active and goal-driven participation process (Preece et al., 2004). Nonnecke and Preece (1999) redefined online lurking behavior as “prolonged periods of receiving communications without posting” (p. 2). Lurking is a strategic activity that allows lurkers to maximize their return on participating effort and strategically manage available online information (Nonnecke & Preece, 2003).

To date, lurking and posting behaviors have been widely studied in different types of online groups, but empirical research comparing the characteristics and outcomes of lurking and posting in online breast cancer support groups is still limited. The existing literature indicates that lurkers and posters do not differ significantly in most of their health-related psychosocial outcomes. For example, in Mo and Coulson’s (2010) study of empowering processes in online HIV/AIDS support groups, survey results show that, although lurkers received less social support and felt less satisfied with their relationship with group members, they were more competitive in social function and higher in energy than posters. Similarly, there were no significant differences in a majority of variables, including self-care, self-efficacy, loneliness, depression, or optimism between posters and lurkers. Mo and Coulson (2010) therefore argued that those lurking in the online support groups “seem to profit to the same extent from accessing online support groups as posters” (p.1191). van Uden-Kraan, Drossaert, Taal, Seydel, and van de Laar (2008) also found that although posters visited online health support groups for social interaction reasons more often than lurkers, they did not differ in most empowering outcomes, such as “being better informed,” “feeling more confident in the relationship with their physician,” “improved acceptance of the disease,” “feeling more confident about the treatment,” and “enhanced self-esteem, increased optimism and control.”

Setoyama, Yamazaki, and Namayama (2011) have surveyed lurkers and posters to study the perceived differences of peer support gained from participation in the online health support group. Among the five support categories that include emotional support, emotional

expression, conflict, advice, and insight/universality, posters' emotional support and emotional expression were significantly higher than those of lurkers. There were no significant differences between lurkers and posters in the other three types of support functions.

Posting, Lurking, and their Potential Benefits

Writing about traumatic experience has long been regarded as a critical part of the research and practice of health psychology (Pennebaker & Chung, in press). As Smyth's (1998) meta-analysis of the writing paradigm suggested, most studies on the efficacy of writing interventions during periods of emotional upheavals have focused on the role of expressing emotions and associated physical and mental benefits. This is particularly relevant to research on online cancer support groups. Previous studies by Shaw et al. (2006, 2007) have found that breast cancer patients who post about their experience can have a range of psychosocial benefits. More recent work suggests that it is the mental processes underlying the actual composition of language that produces the benefits (Han et al., 2011; Pennebaker, 1997). Expression's health benefits may in fact not be effects of disclosure in the literal sense of revealing pre-existing memory contents. Instead, they may result from the creation of new understanding during language composition, the outcome of a self-reflexive process. The use of one's own personal experiences to help and support others can lead to increased feelings of competence, strength, and independence (Roberts et al., 1999), help patients feel less isolated and avoid self-focused preoccupations with their own illness (Yalom, 1970), and can also help them reappraise and assimilate painful experiences, and cope more effectively with the traumatic event (Pennebaker, 1997).

However, writing is not the only mechanism to potentially contribute to improved mental health outcomes. In the context of online environments, lurking behavior is a 'reception-only' participation, which allows lurkers to gain better and deeper understanding of online peers' views and to be able to learn from reading different perspectives (Mazuro & Rao, 2011). Lurking may let people develop a sense of community with the group, and the value derived from belonging to the online group could have long-term effects on lurkers themselves (Nonnecke & Preece, 2000, 2003). In fact, having a consistent and committed lurking behavior could educate and prepare lurkers for a more active participation and eventually allow them to engage in posting behaviors (Rafaeli, Ravid, & Soroka, 2004; Yeow, Johnson, & Faraj, 2006).

At the onset of their illness, most cancer patients typically do not have anyone within their personal networks who shares a similar experience. Thus, consuming supportive messages written by similar others may be linked to positive benefits (Shaw et al., 2000). In a CMSS group study interviewing 12 breast cancer patients, Shaw et al. (2000) found that patients attributed the benefits to emotional support and encouragements from others who were experiencing similar struggles. Indeed, consuming messages containing information, understanding, affective response, and support may help people learn about many different perspectives on a given problem. This may also help patients feel less isolated and increase their understanding about the illness and treatment processes, thus reducing the worry and distress that is often part of living with a cancer diagnosis.

As the previous findings are mixed regarding the effects of lurking and posting on health outcomes, this study examines the effects of different levels of engagement on breast cancer patients' psychosocial health outcomes by comparing users and non-users, as well as posters and lurkers. Thus, the following research questions are proposed:

RQ2a: In an online breast cancer support group, how do users and non-users differ in their 6 weeks and 3 months psychosocial health outcomes?

RQ2b: In an online breast cancer support group, how do posters and lurkers differ in their 6 weeks and 3 months psychosocial health outcomes?

Method

Procedures

The data analyzed in this study were collected as a part of two larger clinical trials in which 661 women with breast cancer were recruited from three cancer institutions: Hartford Hospital's Helen and Harry Gray Cancer Center, The University of Texas M.D. Anderson Cancer Center, and the University of Wisconsin Paul P. Carbone Comprehensive Cancer Center. Eligibility criterion required that participants were more than 17 years old, within 2 months of a diagnosis of primary breast cancer or recurrence at the time of recruitment, and able to read and understand English. Once a patient was referred to the study, a research team member explained the purpose of the study, reviewed eligibility criteria with the patient, explained the risks and benefits of being involved, including that their computer use would be monitored, obtained written consent, and provided patients the baseline questionnaires. The recruitment started on April 1, 2005, and ended on May 31, 2007.

After content and the baseline survey were received, participants were randomized to one of six different combinations of the Comprehensive Health Enhancement Support System (CHESS) "*Living with Breast Cancer*" program: (1) Internet only (control condition), (2) CHESS Information, (3) CHESS Information + Support, (4) CHESS Information, Support, and Coaching (or Full CHESS), (5) Cancer Information Mentor only, and (6) Full CHESS + Mentor. The purpose of the two original clinical trials was to test how women with breast cancer respond to different configurations of CHESS tools. Internet only and Full CHESS conditions were shared by two studies. The CHESS breast cancer module is an Internet-based integrated eHealth system that provides patients and their families with a range of conceptually distinct services (See a detailed description of the original study from Baker et al., 2011; Hawkins et al., 2011).

Any patient who did not have access to a computer with Internet access was provided a computer and access by the research program. 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 CHESS, including how to post messages in the online support group. Of 661 women recruited, we limited our analysis to the 325 women assigned to three conditions that shared a component of an online support group (i.e., CHESS Information + Support, Full CHESS, and Full CHESS + Mentor conditions). The other three conditions did not have access to the support group and thus were excluded from the current analysis. The discussion group functioned as a text-based, asynchronous bulletin board and

not as an e-mail system. It 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.

Besides the baseline survey, three follow-up posttest surveys were administered to participants at 6 weeks, 3 months, and 6 months. Patient attrition rates were about 6%. To determine differences in baseline scores (i.e., demographic and psychosocial factors) between those who are included in our analysis and those who are not, we performed both t-tests and chi-square tests. The results revealed no statistically significant differences between our sample and those who are not retained in the sample.

To gauge the predictors of engagement types and their effects on patients' outcomes, we decided to use the baseline survey, 6-week, and 3-month follow-ups only because (a) the original clinical trial demonstrated significant intervention effects primarily at 6-week or 3-month follow-up intervals (Baker et al., 2011), and (b) overall system usage after the 3-month follow-up was minimal.

Action Log Data

Action log tracking data on whether and how women used the discussion group for 3 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 participants joined the online support group or not and who wrote and/or read each message.

From this we could generate our measures of levels of engagement with the support group. If women accessed the discussion group and wrote/read at least one message between the baseline survey and each follow-up period, we categorized them as 'users' for each follow-up period. 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 did not write at least two messages between the baseline and each follow-up. This criterion is not only consistent with previous studies (Han et al., 2009; Han et al., 2012) but also based on several observations that emerged from both qualitative and quantitative analyses of the messages that occurred following data collection. 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 (Han et al., 2009; Han et al., 2012). This training message was typically a short introduction about her background, and posting merely one short message and not writing again might be insufficient for users to be considered posters (Shim et al., 2011). Notably, these measures of engagement generated from action log analysis were combined with survey data to examine the predictors of different levels of participation and their effects on patients' outcomes in the online breast cancer support group.

Survey Data

We focus on antecedents and consequences related to two broad categories: demographic and psychosocial factors (Johnson, 1997). These measures were selected to reflect predictors and outcomes that were both suggested by prior research (e.g., Han et al., 2011) and that were intended to reflect the effects of the engagement types.

Demographic factors

The baseline survey included demographic factors of age (measured as a continuous variable), race (African American, a dummy variable with ‘no’ coded 0 and ‘yes’ coded 1; and Caucasian, a dummy variable with ‘no’ coded 0 and ‘yes’ coded 1), whether or not patients live alone (a dummy variable with ‘no’ coded 0 and ‘yes’ coded 1), education, and a disease-related measure of time since cancer diagnosis (months). Two questions related to participants’ comfort in using a computer and the Internet were also considered. For both questions respondents were asked, on a five-point scale ranging from 0 = *not at all comfortable* to 4 = *very comfortable*, how comfortable they were at using a computer (or the Internet).

Psychosocial factors

Measures of seven psychosocial factors at the baseline, 6 week, and 3 month surveys included: Quality of Life (depression, functional well-being, and breast cancer-related concerns), Participation in Healthcare (healthcare competence and breast cancer knowledge), and Support (bonding and social support). 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. Quality of life measures have been widely tested and demonstrated in terms of reliability, validity, and responsiveness to clinical change. Other scales were developed for previous CHES studies and extensively published elsewhere (Baker et al., 2011; Han et al., 2012; Hawkins et al., 2011). Given that specific indicators are specified a priori to measure only one factor, confirmatory factor analysis (CFA) was used to determine the unidimensionality of those scales. For the seven outcome variables, data were found to be consistent with the proposed factors.

Quality of Life—The seven-item functional well-being subscale ($M = 2.59$, $SD = .79$) of the Functional Assessment of Cancer Therapy-Breast (FACT-B) was used to assess a woman’s ability to carry out everyday activities (Brady et al., 1997; Cella et al., 2003). This scale was used as a latent construct and CFA results suggest that all seven indicators load on a single factor ($\alpha = .86$, CFI = .95, TLI = .93). An eight-item CES-D (Center for Epidemiologic Studies Depression) scale (Radloff, 1977) was used to measure symptoms of depression ($M = .87$, $SD = .64$). Test-retest reliability and validity of this scale have been well established. Respondents were asked, on a four-point scale ranging from 0 = *rarely or none of the time* to 3 = *most or all of the time*, items such as “I felt depressed” ($\alpha = .87$, CFI = .94, TLI = .92). Finally, we used the breast cancer-related concerns subscale of the FACT-B ($M = 1.12$, $SD = .63$) to assess the degree of concern about nine individual physical or social consequences of breast cancer and its treatment. This scale lacks high internal

consistency because the concerns are partially independent, but it is nonetheless useful as a measure of overall degree of concern ($\alpha = .65$, CFI = .93, TLI = .91).

Participation in Healthcare—A breast cancer knowledge scale ($M = 2.43$, $SD = .75$) assessed a woman's perception that she could understand treatment options, side effects, and pros and cons of various approaches to the disease (Gustafson et al., 2001). The five-point scale ranging from 0 to 4 asked whether participants agreed or disagreed with statements such as "I understand the effect my treatment will have on my quality of life" ($\alpha = .88$, CFI = .94, TLI = .92). A five-item healthcare competence scale ($M = 2.94$, $SD = .74$) developed in our previous research (Gustafson et al., 2001; Gustafson et al., 2005) measured women's comfort and confidence dealing with physicians, other medical personnel, and healthcare situations. We asked, on a five-point scale ranging from 0 = *strongly disagree* to 4 = *agree very much*, whether they agreed or disagreed with statements such as "I felt comfortable with how actively I participated in my care." All items were averaged to construct an index for healthcare competence ($\alpha = .83$, CFI = .98, TLI = .97).

Support—A social support scale ($M = 3.42$, $SD = .63$), developed to assess perception of emotional and instrumental support (Gustafson et al., 2005), was created using six items ($\alpha = .88$, CFI = .96, TLI = .94) on a five-point scale ranging from 0 = *not at all* to 4 = *very much* to assess how true statements such as "There are people I could count on for emotional support" were. A perceived bonding scale ($M = 2.42$, $SD = 1.02$) developed in previous research (Hawkins et al., 2010) measured women's attachment and social integration with other breast cancer patients. We asked, on a five-point scale ranging from 0 = *never* to 4 = *always*, whether they agreed or disagreed with statements such as "I am building a bond with other women with breast cancer" ($\alpha = .92$, CFI = .98, TLI = .97).

Analytic Framework

To uncover the dynamic relationships among different engagement types and their antecedents and consequences, two analytic procedures were employed. To examine how demographic and psychosocial factors are associated with different levels of engagement with an online cancer support group, differences in the demographic characteristics between users and non-users, and between posters and lurkers were first examined by using chi-square and analysis of variance tests. Following this analysis, we examined how psychosocial factors at baseline are related to different engagement types assessed at two follow-up periods. To do so, we employed analysis of covariance (adjusting for demographics) to determine if there were differences between users and non-users and between posters and lurkers regarding their baseline psychological needs.

To examine the effects of engagement types on subsequent changes in psychosocial needs at two follow-ups, analysis of covariance was employed. Covariates include demographics and pretest counterparts of the dependent variables, which allowed us to examine changes in each dependent variable from the baseline to each follow-up. To rule out the confounding effect from writing/reading more or less, we controlled for the amount of messages posted and read when testing the effect of engagement types on the outcomes. We also controlled for total time spent with the whole system since women's access to other components within

the system may confound our results. Since we combined three conditions that shared a component of an online support group, a dummy variable for conditions was created and included as a covariate.

Results

Descriptive statistics

The study sample of 325 women had a mean age of 51 years, and about half of them reported at least a bachelor's degree. On average, less than two months had passed since women were diagnosed with cancer. The racial characteristics of the sample were 88.2% Caucasian, 4.4% African American, 2.5% Asian, and 4.9% others. In addition, about 13% lived alone. On average, women reported that they are "quite comfortable" using a computer ($M = 3.04$, $SD = 1.05$) and the Internet ($M = 2.98$, $SD = 1.16$), each of which was scored on a five-point scale (not at all comfortable, a little bit comfortable, somewhat comfortable, quite comfortable, very comfortable). Patient characteristics of the study sample were further divided by engagement types and two time periods (see Table 1).

Of the 325 participants, about 40% ($N = 131$) neither wrote nor read messages during the first 6-week study period. About 37.5% ($N = 122$) never engaged in the discussion group during the 3-month period. Therefore, they were classified as *non-users* for each period. Among the 6-week *users* ($N = 194$), 95 women wrote at least two messages (i.e., '*posters*,' posting $M = 18.16$, $SD = 24.04$; reading $M = 222.10$, $SD = 18.33$), while 99 women read messages but never wrote more than one message (i.e., '*lurkers*,' reading $M = 148.79$, $SD = 17.88$). Among the 3-month *users* ($N = 203$), 104 women wrote at least two messages (i.e., '*posters*,' posting $M = 29.08$, $SD = 43.95$; reading $M = 374.31$, $SD = 37.55$), while 99 women read messages but never wrote more than one message (i.e., '*lurkers*,' reading $M = 280.34$, $SD = 38.65$). After 6 weeks, 3.9% of non-users ($N=9$) began to use the online support group while 34.5% of users ($N=81$) did not use it anymore. For the same time period, 1.7% of lurkers ($N=4$) became posters while 8.1% of posters ($N=19$) became lurkers.

Factors predicting different engagement types

Statistical analyses were conducted to examine whether there were significant differences in patients' social and psychological characteristics (1) between *users* and *non-users* (RQ1a), and (2) between *posters* and *lurkers* (RQ1b). As shown in Table 1, engagement types were divided by each follow-up period to gauge how demographics predict both short- and long-term engagement with the online support group. For the first 6-week period, chi-square and analysis of variance (ANOVA) tests suggested that *users* were more likely to live with someone else ($\chi^2 = 5.26$, $p < .05$) and be more comfortable using a computer ($F(1,319) = 4.63$, $p < .05$) and the Internet ($F(1,317) = 4.29$, $p < .05$) than *non-users*. When the two user types were considered, Caucasian women were also more likely to be *posters* than their non-Caucasian counterparts ($\chi^2 = 8.16$, $p < .01$). When considering 3-month engagement types, whether or not patients lived alone ($\chi^2 = 5.74$, $p < .05$) was a significant predictor, suggesting that *non-users* were more likely to live without friends/family than *users*. However, we found no difference in age, education, and time since cancer diagnosis among different user types.

To determine which psychosocial factors predict different engagement types during each follow-up (RQ1a & RQ1b), analysis of covariance (ANCOVA) was employed and all analyses were adjusted for the seven covariates from Table 1. As shown in the left column of Table 2, there were significant differences between *users* and *non-users* in their baseline depression, knowledge, and social support levels. Patients who had a higher level of depression ($F(1,300) = 6.96, p < .05$) and lower levels of breast cancer knowledge ($F(1,295) = 9.17, p < .01$) and perceived social support ($F(1,302) = 5.19, p < .05$) at pretest were more likely to be *users* than *non-users* during the first 6-week period (RQ1a). When two user types were considered, analyses also revealed that there was a significant difference between *lurkers* and *posters* in terms of their depression level ($F(1,178) = 4.92, p < .05$), breast cancer knowledge ($F(2,180) = 6.85, p < .01$), and perceived bonding ($F(1,173) = 4.58, p < .05$), implying that *posters'* depression level at pretest was greater than that of *lurkers'* while their knowledge and perceived bonding were lower (RQ1b).

Looking at significant psychosocial predictors determining more long-term 3-month engagement types, the right column of Table 2 presents a similar pattern. Although perceived social support and bonding were no longer significant predictors, depression level at pretest was significantly higher for both *users* ($F(1,300) = 4.57, p < .05$) and *posters* ($F(1,178) = 3.97, p < .05$) than their respective counterparts. Breast cancer knowledge level at pretest was significantly lower for *users* ($F(1,295) = 5.24, p < .05$) and *posters* ($F(1,189) = 11.25, p < .01$). Overall, these results suggest a trend that those who were in worse condition regarding their perceived state of affairs were likely to engage more in the discussion group for information and support.

Effects of engagement types on psychosocial outcomes

To investigate whether there were significant differences in patients' social and psychological outcomes (1) between *users* and *non-users* (RQ2a), and (2) between *posters* and *lurkers* (RQ2b) at 6-week and 3-month follow-ups, a series of ANCOVA tests were performed. As shown in Table 3, there were no significant differences between *users* and *non-users*, or between *posters* and *lurkers* at the 6-week follow-up. However, at the 3-month follow-up, *lurkers'* perceived functional well-being was significantly greater than *posters'* ($F(1,157) = 6.24, p < .05$), and there were also trends toward significance that *lurkers* are more likely to have lower levels of depression ($F(1,159) = 3.73, p < .10$) and higher levels of perceived social support ($F(1,230) = 3.10, p < .10$) than their respective counterparts. There was also a trend that *users* are more likely to have higher level of perceived social support than *non-users* ($F(1,229) = 3.80, p < .10$).

Discussion

Previous studies have found that support groups play a significant role in improving cancer patients' emotional and physical health by providing diverse support (Han et al., 2011; Shaw et al., 2006). Nevertheless, our findings suggest that many breast cancer patients still do not actively engage in sharing their concerns and experiences, but rather choose to remain as non-users or lurkers. Given that patients were given access to the cancer support group with free computer hardware, Internet service, and training, more empirical research is needed to

examine (1) why some breast cancer patients lurk and do not actively engage in online support group activities and (2) especially the effects of such differing engagement on their health outcomes. This study examined these questions by analyzing a longitudinal survey involving an online support group intervention, resulting in deeper knowledge about cancer patients' preferences with a coping resource and related benefits.

This study first incorporated the CMIS and the competing models on online engagement into an overarching theoretical framework to examine how cancer patients' background characteristics and psychosocial factors predict different types of engagement with an online cancer support group (RQ1a & RQ1b). In terms of patients' characteristics (Table 1), age is not a significant barrier for them to go online and use a health support group. Consistent with the previous study (Han et al., 2012), Caucasians were more likely to be posters than lurkers during 6-week period. Living alone was another significant predictor of engagement types. In line with the social enhancement model (Kraut et al., 2002), for both 6-week and 3-month periods, non-users are more likely to live alone than users. As expected, patients' comforts in using computers and the Internet can significantly predict their engagement types in 6-week but not in 3-month periods. Specifically, those who have higher levels of comfort in using computers and the Internet are more likely to be users than non-users, supporting the social enhancement model (Kraut et al., 2002). The same is not true for more long-term 3-month engagement types. It may be due to non-users spending a good amount of time using computers and also accessing other parts of the online system, which may allow them to gain experience on both computers and Internet.

Besides patients' demographic characteristics, several social and psychological resources have been found to affect patients' engagement types (see Table 2). Supporting the social compensation model (McKenna & Bargh, 1998), patients experiencing more depression initially were more likely to use the online health support group and to become posters rather than lurkers. Similarly, those who have less knowledge on breast cancer were more likely to use the online group and post messages to others. Both depression and knowledge levels assessed at pretest consistently predicted short- and long-term engagements with the system, implying that both are key factors differentiating patients' level of participation in these types of online communication interventions.

Other psychosocial variables such as perceived bonding and social support mainly predicted 6-week engagement types. In line with the social compensation model (McKenna & Bargh, 1998) and consistent with previous literature (Han et al., 2012), patients with a higher level of perceived bonding were more likely to be lurkers than posters; and patients who experienced a lack of social support from family or friends were more likely to become users of the online cancer support group for the same period. However, the differences were no longer significant in the 3-month period. As indicated by Table 2, the gap in perceived bonding levels between posters and lurkers seemed to be shrinking since posters improved their bonding level over time while lurkers did not. The same is true for social support levels between users and non-users, although the change in their scores was very small. Overall, these results suggest that an initial deficit in patients' psychosocial resources may not be a barrier to participation but rather provide greater motivation to join an online support group or even express their problems as an alternative way of receiving feedback and support from

their peers (Han et al., 2012; McKenna & Bargh, 1998). The social enhancement model (Kraut et al., 2002) also had some predictive power, especially explaining the role of demographic factors such as patients' living status and computer and Internet experience. In this sense, the CMIS and two competing perspectives on online engagement are useful frameworks for understanding cancer patients' diverse patterns of engagement with the system.

Since it is clear that patients have different orientations to and engagements with the online cancer support group, we further examined the effect of engagement types on health outcomes by drawing on the emotional writing paradigm (Pennebaker, 1997) and previous literature on lurking behavior in online environments (Mazuro & Rao, 2011; Nonnecke & Preece, 2000, 2003) (RQ2a & RQ2b). In terms of 6-week effects, there were no significant differences between users and non-users, and between lurkers and posters in terms of quality of life, participation, and support. Given that posters had more depression, less knowledge, and lower levels of perceived bonding than lurkers in their pretest scores (Table 2), it is interesting to see that the differences between lurkers and posters were gradually narrowing, although this pattern was not statistically significant. This narrowing gap indicates that in a relatively short period of time, posters had gained more knowledge, coped with their emotional stress, and built their bonds with other similar patients through active participation in an online support group.

With regard to the outcomes of 3-month participation, however, lurkers appeared to benefit more than posters in terms of their functional well-being, depression, and perceived social support. We also found that non-users' perceived social support level dropped sharply after the first 6-week period, implying that participation in an online support group at least helps patients maintain their perceived support level for a longer period, which was not the case for non-users. It is worth noting that within a relatively short period of time (i.e., 6 weeks), differences between lurkers and posters were not significant, but after 3 months of participation lurkers began to show greater improvement in these psychosocial outcomes. These results suggest that, unlike posters who had to spend a lot of time learning to use this demanding and engaging communication tool, (a) lurkers were able to focus on reading other patients' messages and finding answers to their questions, (b) they may have become familiar with the group environment and its members, which may have helped them develop a sense of efficacy and caring, and attachment to the group (Walther, Pingree, Hawkins, & Buller, 2005); or (c) it is also possible that the value (e.g. sense of belonging, self-efficacy) lurkers obtained in early days could have long-term effects on these outcomes (Nonnecke & Preece, 2000, 2003). Overall, the findings suggest that lurkers and posters do not differ in their short-term health outcomes, but lurkers tend to perform better in certain outcomes than posters with their long-term engagement in online support group participation. Consistent with past studies, lurking can help patients focus on the content and topics without having the stress of posting messages, thus allowing them to better understand their diseases and evaluate their situations from different perspectives (Dennen, 2008; McKendree, Stenning, Mayes, Lee, & Cox, 1998).

There are several reasons that may explain why we found modest effects of posting. First of all, it is clear from Table 1 that the majority of study participants are both Caucasian and

highly educated, as more than 80% of them are Caucasian and half of them earned a bachelor's degree. While the nature of this sample suggests that the degree of generalization to other populations remains to be tested, it also suggests that patients with higher education can understand and process health information obtained more efficiently, which may explain why lurkers may perform as well as or sometimes even better than posters in certain outcomes. It is also possible that the role of motivation might have affected the results of this study. Since the online support group examined here was a part of larger experimental studies, we cannot entirely rule out the possibility that the external expectation - patients are anticipated to participate and contribute content - might have decreased positive benefits of use, especially posting, for some. Notably, when assessing the potential effect of posting, we didn't consider the actual content of messages. For example, simply writing about a daily issue may not be as beneficial for patients as other types of expression that contain relevant information, understanding, and empathy (Han et al., 2011; Shaw et al., 2006). Future study must consider the content of messages when assessing the benefit of posting behaviors.

Along this line, future study should extend our inquiry and examine how both quantity and quality of online interactions contribute to emotional and psychological benefits for patients. Although this study controlled for the quantity measure (such as number of messages posted and read) to distinguish it from the effect of engagement types, it would be an interesting next step to combine the quantity measure with content coding of individual messages posted or read and further identify the conditions under which online support groups may serve as a viable place for communicating about illness experiences.

Nonetheless, there are some caveats. First, breast cancer-related concerns, one of the psychosocial variables of this study, had a relatively low consistency alpha of .65. Although the scale has been validated and widely applied to understand breast cancer patients' quality of life, future research should focus on building a more reliable scale for this dimension. Furthermore, this study did not collect measures of other communication resources that cancer patients may have used outside of ones that the current intervention provided. Although our analyses tried to rule out as many covariates as possible, future research should assess patients' use of other psychosocial resources to reduce possible confounding effects of such use. Last, we assessed cancer patients' engagement over the entire 6-week or 3-month periods. However, cancer patients need to deal with various physical and emotional challenges, which likely shape their engagement with CMSS groups more discrete and dynamic (Han, 2012). Future research should also examine how engagement types change over time, what factors predict such change, and, more importantly, how patterns of change affect patients' health outcomes.

In closing, the current study contributes to our understanding of antecedents and consequences with regard to levels of participation in an online cancer support group. This is, to our knowledge, the first longitudinal study to examine the potential impacts of online engagement among cancer patients. To achieve our aim, this research merged longitudinal survey data collected from an eHealth intervention with action log data on whether and how participants used the discussion group. Methodologically, this approach offers a more valid way to investigate the nature of the exchanges occurring within the online cancer support group and their antecedents and consequents.

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References

- Assael H. A demographic and psychographic profile of heavy Internet users and users by type of Internet usage. *Journal of Advertising Research*. 2005; 45:93–123.
- Baker TB, Hawkins RP, Pingree S, Roberts L, McDowell H, Shaw B, Gustafson DH. Optimizing eHealth Breast Cancer Interventions: Which Types of eHealth Services are Effective? *Translational Behavioral Medicine*. 2011; 1(1):134–145. [PubMed: 21709810]
- Brady MJ, Cella DF, Mo F, Bonomi AE, Tulskey DS, Lloyd SR, Shiimoto G. Reliability and validity of the functional assessment of cancer therapy-breast quality-of-life instrument. *Journal of Clinical Oncology*. 1997; 15(3):974–986. [PubMed: 9060536]
- Caplan SE. Preference for online social interaction: A theory of problematic Internet use and psychosocial well-being. *Communication Research*. 2003; 30:625–648.
- Carlsson M. Cancer patients seeking information from sources outside the health care system. *Support Care Cancer*. 2000; 8:453–457. [PubMed: 11094989]
- Cella D, Paul D, Yount S, Winn R, Chang CH, Banik D, Weeks J. What are the most important symptom targets when treating advanced cancer? A survey of providers in the National Comprehensive Cancer Network (NCCN). *Cancer Investigation*. 2003; 21(4):526–535. [PubMed: 14533442]
- Dennen VP. Pedagogical lurking: Student engagement in non-posting discussion behavior. *Computers in Human Behavior*. 2008; 24:1624–1633.
- Dumont M, Provost MA. Resilience in adolescents: Protective role of social support, coping strategies, self-esteem, and social activities on experience of stress and depression. *Journal of Youth and Adolescence*. 1999; 28:343–363.
- Fox, S.; Purcell, K. Chronic disease and the Internet. Pew Internet & American Life Project; 2010. Retrieved from <http://pewinternet.org/Reports/2010/Chronic-Disease.aspx> [March 24 2010]
- Freimuth, VS.; Stein, JA.; Kean, TJ. Searching for health information: the cancer information search model. Philadelphia: University of Pennsylvania Press; 1989.
- Gustafson DH, McTavish FM, Stengle W, Ballard D, Hawkins R, Shaw B, Landucci G. Use and impact of eHealth system by low-income women with breast cancer. *Journal of Health Communication*. 2005; 10(1):194–218.
- Gustafson DH, Hawkins RP, Pingree S, McTavish F, Arora N, Mendenhall J, Salner A. Effects of computer support on younger women with breast cancer. *Journal of General Internal Medicine*. 2001; 16:435–445. [PubMed: 11520380]
- Han JY. A longitudinal study of use of an interactive health communication system. *Health Communication*. 2012; 29(4):319–330. [PubMed: 21916702]
- Han JY, Hawkins RP, Shaw B, Pingree S, McTavish F, Gustafson D. Unraveling Uses and Effects of an Interactive Health Communication System. *Journal of Broadcasting & Electronic Media*. 2009; 53(1):112–133. [PubMed: 23172985]
- Han JY, Kim J-H, Yoon HJ, Shim M, McTavish F, Gustafson D. Social and Psychological Determinants of Levels of Engagement with an Online Breast Cancer Support Group: Posters, Lurkers, and Non-Users. *Journal of Health Communication*. 2012; 17(3):356–371. [PubMed: 22085215]
- Han JY, Shah DV, Kim E, Namkoong K, Lee SY, Moon TJ, Gustafson DH. Empathic Exchanges in Online Cancer Support Groups: Distinguishing Message Expression and Reception Effects. *Health Communication*. 2011; 26(2):185–197. [PubMed: 21318917]
- Han JY, Shaw BR, Hawkins RP, Pingree S, McTavish F, Gustafson DH. Expressing positive emotions within online support groups by women with breast cancer. *Journal of Health Psychology*. 2008; 13(8):1002–1007. [PubMed: 18987072]

- Hawkins RP, Pingree S, Baker TB, Roberts LJ, Shaw BR, McDowell HE, Gustafson DH. Integrating eHealth with Human Services for Breast Cancer Patients. *Translational Behavioral Medicine*. 2011; 1(1):146–154. [PubMed: 22496712]
- Hawkins RP, Pingree S, Shaw B, Serlin R, Swoboda C, Han JY, Salner A. Mediating Processes and Effects of Two Communication Interventions for Breast Cancer Patients. *Patient Education and Counseling*. 2010; 81:S48–S53. [PubMed: 21081261]
- Johnson, DJ. *Cancer-related Information Seeking*. Cresskill, NJ: Hampton Press; 1997.
- Johnson JD, Meischke H. A comprehensive model of cancer-related information seeking applied to magazines. *Human Communication Research*. 1993; 19:343–367.
- Kraut R, Kiesler S, Boneva B, Cummings J, Helgeson V, Crawford A. The Internet paradox revisited. *Journal of Social Issues*. 2002; 58:49–74.
- Leydon GM, Boulton M, Moynihan C, Jones A, Mossman J, Boudioni M, McPherson K. Cancer patients' information needs and information seeking behavior: in-depth interview study. *British Medical Journal*. 2000; 320:909–913. [PubMed: 10742000]
- Lichter, I. *Communication in Cancer Care*. New York, NY: Churchill-Livingstone; 1987.
- Luker K, Beaver K, Leinster SJ, Owens R, Glynn B. Information needs and sources of information for women with breast cancer: A follow-up study. *Journal of Advanced Nursing*. 1996; 23(3):4887–4895.
- Mazuro C, Rao N. Online discussion forums in higher education: Is lurking working? *International Journal for Cross-Disciplinary Subjects in Education*. 2011; 2(2):364–371.
- McKendree J, Stenning K, Mayes T, Lee J, Cox R. Why observing a dialogue may benefit learning. *Journal of Computer Assisted Learning*. 1998; 14:110–119.
- McKenna KYA, Bargh JA. Coming out in the age of the internet: Identity “demarginalization” through virtual group participation. *Journal of Personality and Social Psychology*. 1998; 75:681.
- Mills ME, Sullivan K. The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *Journal of Clinical Nursing*. 1999; 8(6):631–642. [PubMed: 10827609]
- Mo PKH, Coulson NS. Empowering processes in online support groups among people living with HIV/AIDS: A comparative analysis of ‘lurkers’ and ‘posters’. *Computers in Human Behaviors*. 2010; 26:1183–1193.
- Nagler RH, Gray SW, Romantan A, Kelly BJ, DeMichele A, Armstrong K, Hornik RC. Differences in information seeking among breast, prostate, and colorectal cancer patients: Results from a population-based survey. *Patient Education and Counseling*. 2010; 81S:S54–S62. [PubMed: 20934297]
- Nonnecke, B.; Preece, J. Shedding light on lurkers in online communities. Paper presented at the *Ethnographic Studies in Real and Virtual Environments*; Edinburgh. *Inhabited Information Spaces and Connected Communities*; 1999.
- Nonnecke, B.; Preece, J. Proceedings of the SIGCHI conference on Human factors in computing systems. New York: 2000. Lurker demographics: counting the silent; p. 73-80.
- Nonnecke, B.; Preece, J. Silent participants: Getting to know lurkers better. In: Lueg, C.; Fisher, D., editors. *From Usenet to CoWebs: Interacting with Social Information Spaces*. London: Springer-Verlag; 2003.
- Pennebaker, JW. *Opening up: The healing power of expressing emotions*. New York: The Guilford Press; 1997.
- Pennebaker, JW.; Chung, CK. Expressive writing, emotional upheavals, and health. In: Friedman, H.; Silver, R., editors. *Handbook of health psychology*. New York: Oxford University Press; in press
- Preece J, Nonnecke B, Andrews D. The top five reasons for lurking: improving community experiences for everyone. *Computers in Human Behavior*. 2004; 20:201–223.
- Rafaeli S, Ravid G, Soroka V. De-lurking in virtual communities: A social communication network approach to measuring the effects of social and cultural capital. *Proceeding of the 37th Annual Hawaii International Conference on System Sciences*. Big Island, Hawaii. 2004:70203.
- Radloff LS. The CES-D Scale: a self-report depression scale for research in the general population. *Applied Psychological Measurement*. 1977; 1:385–401.

- Roberts LJ, Salem D, Rappaport J, Toro PA, Luke DA, Seidman E. Giving and receiving help: Interpersonal transactions in mutual-help meetings and psychosocial adjustment of members. *American Journal of Community Psychology*. 1999; 27:841–868. [PubMed: 10723537]
- Setoyama Y, Yamazaki Y, Namayama K. Benefits of peer support in online Japanese breast cancer communities: Differences between lurkers and posters. *Journal of Medical Internet Research*. 2011; 13(4):e122. [PubMed: 22204869]
- Shaw BR, DuBenske L, Han JY, Cofta-Woerpel L, Bush N, Gustafson DH, McTavish F. Antecedent characteristics of online cancer information seeking behaviors among rural breast cancer patients: An application of the Cognitive-Social Health Information Processing (C-SHIP) model. *Journal of Health Communication*. 2008; 13(4):389–408. [PubMed: 18569368]
- Shaw B, Han JY, Hawkins RP, Stewart J, McTavish F, Gustafson D. Doctor-patient relationship as motivation and outcome: Examining uses of an interactive cancer communication system. *International Journal of Medical Informatics*. 2007; 76:274–282. [PubMed: 16460995]
- Shaw BR, Hawkins R, Arora N, McTavish F, Pingree S, Gustafson D. An exploratory study of predictors of participation in a computer support group for women with breast cancer. *CIN: Computers, Informatics, Nursing*. 2006; 24:18–27.
- Shaw B, Hawkins RP, McTavish F, Pingree S, Gustafson D. Effects of insightful disclosure within computer mediated support groups on women with breast cancer. *Health Communication*. 2006; 19(2):133–142. [PubMed: 16548704]
- Shaw B, McTavish F, Hawkins RP, Gustafson D, Pingree S. Experiences of women with breast cancer: Exchanging social support over the CHESS computer network. *Journal of Health Communication*. 2000; 5:135–149. [PubMed: 11010346]
- Shim M, Cappella Han JY. How does insightful and emotional disclosure bring potential health benefits? Study based on online support groups for women with breast cancer. *Journal of Communication*. 2011; 61:432–454. [PubMed: 25568496]
- Shotton MA. The costs and benefits of computer addiction. *Behavior and Information Technology*. 1991; 10:219–230.
- Smyth JM. Written emotional expression: effect sizes, outcome types, and moderating variables. *Journal of Consulting and Clinical Psychology*. 1998; 66:174–184. [PubMed: 9489272]
- Valkenburg PM, Schouten AP, Peter J. Adolescents' identity experiments on the internet. *New Media & Society*. 2005; 7(3):383–402.
- van Uden-Kraan CF, Drossaert CHC, Taal E, Seydel ER, van de Laar MAFJ. Self-reported differences in empowerment between lurkers and posters in online patient support groups. *Journal of Medical Internet Research*. 2008;10.
- Walther JB, Pingree S, Hawkins RP, Buller DB. Attributes of Interactive Online Health Information Systems. *Journal of Medical Internet Research*. 2005; 7(3):e33. [PubMed: 15998624]
- Wright, KB.; Muhtaseb, A. Personal relationships and computer-mediated support groups. In: Wright, KB.; Webb, LM., editors. *Computer-Mediated Communication in Personal Relationships*. New York: Peter Lang Publishing; 2010. p. 135-155.
- Yalom, ID. *The theory and practice of group psychotherapy*. New York: Basic Books; 1970.
- Ybarra ML, Suman M. Help seeking behavior and the Internet: A national survey. *International Journal of Medical Informatics*. 2006; 75:29–41. [PubMed: 16129659]
- Yeow, A.; Johnson, SL.; Faraj, S. Proceeding of the 27th International Conference on Information System. Milwaukee: Wisconsin; 2006. Lurking: Legitimate or illegitimate peripheral participation?.
- Zickuh, K.; Smith, A. Digital differences. Pew Internet & American Life Project; 2012. Retrieved from http://pewinternet.org/~media/Files/Reports/2012/PIP_Digital_differences_041312.pdf [April 13 2012]

Appendix: Question Wording

Breast Cancer Knowledge, an 8-item scale. All items were scored on a 5-point scale (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree). At this time I feel I understand...

1. The effect my treatment will have on my quality of life.
2. How to deal with breast cancer in my work and with my family.
3. What my treatments will be like.
4. The pros and cons of various treatment approaches.
5. How to know if a healthcare provider is good.
6. How to get through my treatments and their side effects.
7. How to get a second opinion if I want one.
8. I knew what the side effects of my treatment would be, before I started.

Healthcare competence, a 5 item scale. All items were scored on a 5-point scale (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree).

1. I thought about what was going to happen ahead of time
2. I felt comfortable with how actively I participated in my care.
3. I understand what was going on.
4. I knew the right questions to ask.
5. I went to the right healthcare provider at the right time.

Social Support, a 6 item scale. All items were scored on a 5-point scale (not at all, a little bit, somewhat, quite a bit, very much).

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

CES-D, an 8 item scale. All items were scored on a 4-point scale (rarely or none of the time, some or a little of the time, occasionally or a moderate amount of the time, most or all of the time).

1. I felt that I could not shake off the blues even with help from my family or friends.
2. I felt depressed.

3. I thought my life had been a failure.
4. I felt fearful.
5. My sleep was restless.
6. I felt lonely.
7. I had crying spells.
8. I felt sad.

Functional Well-Being, a 7 item scale. All items were scored on a 5-point scale (not at all, a little bit, somewhat, quite a bit, very much).

1. I am able to work (including working in home).
2. My work (including work in home) was fulfilling.
3. I was able to enjoy life “in the moment”.
4. I accepted my illness.
5. I was sleeping well.
6. I was enjoying my usual leisure pursuits.
7. I was content with the quality of life.

Breast Cancer Related Concerns, a 9 item scale. All items were scored on a 5-point scale (not at all, a little bit, somewhat, quite a bit, very much).

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

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

1. I can get information from other women with breast cancer.
2. I am building a bond with other women with breast cancer.
3. I feel stronger knowing that there are others in my situation.
4. I've been getting emotional support from other women with breast cancer.

5. It helps me to be able to share my feelings and fears with other women with breast cancer.

Table 1
 Characteristics of Patients by their Levels of Engagement with an Online Support Group (N = 325)

Patient Characteristics	6 Week				3 Month			
	Non-Users (n=131)	Users (n=194)		Non-Users (n=122)	Users (n=203)		Posters (n=104)	
		All (n=194)	Lurkers (n=99)		All (n=203)	Lurkers (n=99)		
Age								
Mean (SD)	52.22 (10.86)	50.77 (8.86)	50.56 (8.89)	51.00 (8.87)	52.39 (10.82)	50.73 (8.97)	50.60 (9.24)	50.86 (8.75)
Race								
African American	8 (6.3%)	6 (3.1%)	5 (5.1%)	1 (1.1%)	7 (5.9%)	7 (3.5%)	5 (5.1%)	2 (1.9%)
Caucasian	108 (84.4%)	175 (90.7%)	84 _b (84.8%)	91 _c (96.8%)	100 (84.0%)	183 (90.6%)	84 (84.8%)	99 (96.1%)
Live alone								
Yes	24 ^A (18.8%)	19 ^B (9.8%)	8 (8.1%)	11 (11.7%)	23 ^A (19.3%)	20 ^B (9.9%)	8 (8.1%)	12 (11.7%)
Education								
Less than high school	4 (3.1%)	4 (2.1%)	2 (2.0%)	2 (2.1%)	4 (3.4%)	4 (2.0%)	2 (2.0%)	2 (1.9%)
High school degree	21 (16.4%)	25 (13.0%)	12 (12.1%)	13 (13.8%)	18 (15.1%)	28 (13.9%)	15 (15.2%)	13 (12.6%)
Some college	23 (18.0%)	35 (18.1%)	17 (17.2%)	18 (19.1%)	22 (18.5%)	36 (17.8%)	16 (16.2%)	20 (19.4%)
Associate/technical degree	13 (10.2%)	19 (9.8%)	8 (8.1%)	11 (11.7%)	10 (8.4%)	22 (10.9%)	8 (8.1%)	14 (13.6%)
Bachelor's degree	28 (21.0%)	52 (26.9%)	25 (25.3%)	27 (28.7%)	27 (22.7%)	53 (26.2%)	26 (26.3%)	27 (26.2%)
Graduate degree	39 (30.5%)	58 (30.1%)	35 (35.4%)	23 (24.5%)	38 (31.9%)	59 (29.2%)	32 (32.3%)	27 (26.2%)
Time since diagnosis								
Months (Mean (SD))	2.67 (15.20)	1.24 (3.54)	1.21 (1.72)	1.27 (3.54)	2.78 (15.79)	1.24 (3.46)	1.19 (1.72)	1.28 (4.54)
Comfort in a computer: Mean(SD)	2.89 ^A (1.17)	3.15 ^B (.96)	3.20 (.97)	3.10 (.96)	2.92 (1.15)	3.12 (.99)	3.14 (1.01)	3.10 (.98)
Comfort in the Internet: Mean(SD)	2.82 ^A (1.25)	3.09 ^B (1.08)	3.14 (1.07)	3.04 (1.10)	2.86 (1.22)	3.05 (1.12)	3.08 (1.11)	3.03 (1.13)

Note. Different superscripts mean there are significant differences in corresponding variables between users and non-users. Subscripts are based on analysis between posters and lurkers. Cells with different superscripts/subscripts differ at $p < .05$ at the minimum. Table 2

Table 2
Group Differences on Information, Support, and Quality of life at Pre-test (N = 325)

Variables	6 Week				3 Month			
	Non-Users (n=131)	Users (n=194)			Non-Users (n=122)	Users (n=203)		
		All (n=194)	Lurkers (n=99)	Posters (n=95)		All (n=203)	Lurkers (n=99)	Posters (n=104)
Quality of Life								
Depression	.77 ^A (.62)	.95 ^B (.64)	.86 ^a (.65)	1.05 ^b (.61)	.77 ^A (.62)	.86 ^a (.66)	.94 ^B (.64)	1.04 ^b (.61)
Functional well-being	2.64 (.78)	2.55 (.79)	2.55 (.80)	2.55 (.79)	2.65 (.78)	2.56 (.81)	2.55 (.79)	2.55 (.77)
Breast cancer concerns	1.17 (.67)	1.11 (.60)	1.10 (.57)	1.12 (.63)	1.17 (.65)	1.08 (.57)	1.11 (.61)	1.14 (.65)
Participation								
Competence	3.00 (.69)	2.91 (.78)	2.90 (.82)	2.92 (.73)	3.00 (.70)	2.91 (.82)	2.92 (.77)	2.92 (.71)
Knowledge	2.59 ^A (.76)	2.33 ^B (.75)	2.46 ^a (.73)	2.19 ^b (.75)	2.57 ^A (.76)	2.53 ^a (.67)	2.36 ^B (.75)	2.19 ^b (.79)
Support								
Bonding	2.41 (1.06)	2.44 (1.02)	2.61 ^a (1.06)	2.27 ^b (.95)	2.38 (1.06)	2.54 (1.03)	2.46 (1.02)	2.38 (1.02)
Social support	3.51 ^A (.54)	3.40 ^B (.68)	3.41 (.64)	3.38 (.72)	3.50 (.55)	3.44 (.64)	3.41 (.67)	3.39 (.71)

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 between posters and lurkers. Cells with different superscripts/subscripts differ at $p < .05$ at the minimum. All analyses adjusted for seven baseline characteristics from Table 1.

Table 3
Group Differences on Information, Support, and Quality of life at 6 Week and 3 Month (N = 325)

Patient Characteristics	6 Week				3 Month			
	Non-Users (n=131)		Users (n=194)		Non-Users (n=122)		Users (n=203)	
	All (n=194)	Lurkers (n=99)	Posters (n=95)	All (n=203)	Lurkers (n=99)	Posters (n=104)	All (n=203)	Lurkers (n=99)
Quality of Life								
Depression	.70 (.63)	.73 (.60)	.69 (.66)	.78 (.53)	.64 (.59)	.57 _a (.50)	.67 (.56)	.75 _a (.60)
Functional well-being	2.62 (.77)	2.50 (.79)	2.59 (.78)	2.42 (.79)	2.57 (.81)	2.77 _a (.81)	2.62 (.84)	2.49 _b (.84)
Breast cancer concerns	1.28 (.74)	1.26 (.63)	1.22 (.68)	1.31 (.58)	1.26 (.69)	1.11 (.74)	1.18 (.70)	1.23 (.66)
Participation								
Competence	3.07 (.85)	3.03 (.71)	3.01 (.73)	3.05 (.70)	3.06 (.68)	2.99 (.80)	3.06 (.71)	3.12 (.62)
Knowledge	2.85 (.78)	2.80 (.62)	2.80 (.66)	2.80 (.59)	2.86 (.57)	2.98 (.56)	2.93 (.59)	2.89 (.62)
Support								
Bonding	2.59 (.96)	2.73 (.90)	2.64 (.94)	2.81 (.85)	2.35 (.95)	2.60 (.97)	2.71 (.95)	2.80 (.93)
Social support	3.39 (.62)	3.32 (.65)	3.37 (.61)	3.28 (.69)	3.21 ^A (.70)	3.44 _a (.53)	3.33 ^A (.63)	3.23 _a (.70)

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 between posters and lurkers. Cells with different superscripts/subscripts differ at $p < .05$ at the minimum. Cells with the same superscripts/subscripts differ at $p < .10$. All analyses adjusted for seven baseline characteristics from Table 1, total writing and reading, time spent with the system, group assignment, and pretest counterpart of the dependent variable.