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Project Connect Online: User and visitor experiences of an Internet-based intervention for women with breast cancer

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Abstract

Objective—This study's purpose was to characterize the experience of breast cancer patients randomly assigned to the intervention arm of Project Connect Online (PCO), a randomized controlled trial of an Internet-based intervention, and to examine relationships between website use variables and psychosocial outcomes.

Methods—In the larger PCO trial, breast cancer patients ($N = 88$) were randomly assigned to an intervention or a waiting-list control. This report pertains to the 46 women in the intervention arm, a three-hour workshop for creation of personal websites with a blog function to communicate with their interpersonal network and chronicle their experience. Participants completed assessments at one and six months. Visitors to the websites ($N = 66$) completed an online questionnaire.

Results—Reactions to website use were positive, although lack of time was a barrier for some. Women with advanced cancer were more likely to use their websites. Women found the websites useful for telling the story of their experience and expressing emotions. Positive word use was associated with heightened positive mood at six months; negative word use was associated with improved depressive symptoms. Visitors were most commonly female friends of participants who valued the websites as a way to connect emotionally with participants and receive information about their health.

Conclusions—Specific aspects of patients' blogs predicted improvements in psychosocial functioning. Personal websites can help women with breast cancer construct a narrative of their experience, express emotions, and receive the social support they need, particularly from friends and extended family.

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Keywords

breast cancer; oncology; psychosocial intervention; emotional expression; social support

Background

Strong social ties can improve psychological and physical adjustment to cancer [1-4], and isolation is associated with poor health outcomes [5-6]. Communication between cancer patients and their social network can be challenging, however. Cancer patients may face barriers that inhibit receipt of social support including lack of energy, fear of burdening others, and anticipation of unsupportive responses. Furthermore, members of a patient's social network may be unsure of how to help or fear imposing on the patient. The current report aims to characterize the experience of women who participated in the intervention arm of Project Connect Online (PCO), a randomized controlled trial designed to facilitate communication of women with breast cancer with supportive others [7], as well as the experience of visitors to the websites (i.e., family and friends the patients invited to view their websites)

In the larger PCO trial, women diagnosed with breast cancer were randomly assigned to a waiting-list control condition or to a three-hour workshop for hands-on creation of a personal website to communicate with their social network. In addition to providing a channel for communication and support, PCO was designed to help women create a narrative of their experience with breast cancer, bolster coping self-efficacy, express emotions, and decrease loneliness, factors that can promote adjustment to breast cancer [e.g., 8-9]. In intent-to-treat analyses, women randomized to PCO evidenced significant benefit six months later on depressive symptoms, positive mood, and life appreciation relative to control participants [7]. Women currently undergoing medical treatment for breast cancer benefitted significantly more from the intervention on depressive symptoms and positive mood than did women not receiving treatment. PCO did not demonstrate significant effects on negative mood, perceived strengthened relationships, or intrusive thoughts.

Research identifying efficacious elements of psychosocial interventions for cancer patients is limited [e.g., 10]. Given the success of PCO in improving psychosocial outcomes, examination of elements of PCO website use associated with positive adjustment is warranted in order to refine future interventions for cancer patients. Furthermore, understanding the experiences of visitors may provide insight into the efficacy of PCO to facilitate communication and strengthen social support. Findings will inform the development of Internet-based psychosocial interventions tailored to the needs of breast cancer patients.

The primary aim of the current report was to characterize the experience of PCO participants and visitors. Second, we examined predictors of website use. Women with advanced disease and those undergoing current medical treatment are likely to have greater need to process and share their cancer experience than women with early stage disease and those who have completed treatment. We therefore hypothesized that advanced cancer stage and current treatment status would predict higher website use. Third, we examined predictors of

significant outcomes in order to identify “active ingredients” of PCO. We predicted that benefit would be greatest when women used more positive emotion (PE) words, negative emotion (NE) words, and cognitive processing (CP) words in their posts [11-12].

Methods

Participants

PCO participants—Women were recruited from a community medical oncology practice specializing in the treatment of breast cancer to participate in the randomized controlled trial [7]. Eligibility criteria included: (1) at least 18 years old; (2) diagnosis of invasive or metastatic breast cancer; (3) able to complete questionnaires in English; (4) no existing personal website.

Of 440 women approached, 8% ($n = 37$) were ineligible, 72% ($n = 315$) declined to hear more about the study or were unreachable by telephone, and 20% ($n = 88$) were randomized and included in analyses for the randomized controlled trial. See Stanton et al. for a flow chart [7]. Of the 88 participants randomized, 86% ($n = 76$) completed the one-month assessment and 86% ($n = 76$) completed the six-month assessment. The present report pertains to the 46 women assigned randomly to the intervention arm of PCO.

Visitors—Data were collected online from 66 visitors to participants' websites to examine who visited and perceived website usefulness.

Procedure

The UCLA Institutional Review Board approved all study procedures. For a detailed description of study procedures, intervention, and measures, see Stanton et al. [7]. The oncology clinic's research coordinator approached potentially eligible participants at the clinic. Women who met eligibility criteria completed informed consent forms and questionnaires. Research staff then called to schedule the workshop or inform the participant that she would continue assessments and be offered the workshop in six months. Women completed follow-up questionnaires one and six months after the workshop.

Data were collected from visitors to PCO websites via an online questionnaire. The websites included a section titled “Please Help by Taking Our Survey” with a link to a consent form and brief survey. Visitors were informed that PCO participants would not have access to their responses.

PCO intervention—Intervention sessions lasted approximately three hours and were conducted at the oncology practice. Led by two researchers, the sessions were delivered in groups of one to five participants. Participants' significant others were invited to attend. Women were introduced to website functions and engaged in discussion regarding topics including common concerns about maintaining a personal website and how to introduce the website to others. The session involved creation of the website (i.e., selecting a website template, creating a title, initiating the first post). The primary function of the websites was a journal (i.e., blog). Other website features included a section for links to other websites, to

be populated by each participant; a How You Can Help page, in which participants would convey actions visitors to the website could undertake; and a choice of privacy settings.

Women were given support materials (i.e., printed manual, toll-free phone number for technical support). Wireless access was available at the oncology clinic; cameras and laptops were available for check-out. Participants were called one week after the workshop to answer questions. Phone calls lasted no more than 15 minutes.

Waiting-list control—Women assigned to the waiting-list control condition (not included in the present analyses) completed baseline and follow-up assessments and otherwise received standard medical care. After they had completed the six-month assessment, eight women chose to participate in PCO.

Measures

Demographic (i.e., age, education, ethnicity, employment, partner status, familial/social network data) and cancer-related (i.e., diagnosis date, stage of cancer, treatment status, specific treatments) variables were assessed at baseline. A measure of website use was administered at one- and six-month follow-up. Outcome variables were assessed at baseline and one- and six-month follow-up.

Objective website data—Objective website data included website use within one month of the workshop (yes/no), total number of posts, and total word count of posts.

Website content—All website content posted within six months of the workshop was analyzed with the computerized text analysis program, Linguistic Inquiry and Word Count (LIWC) [13]. The LIWC program is designed to analyze text files and compute the percentage of words in various content categories. The linguistic content categories examined in the current study were PE words (e.g., “joy”), NE words (e.g., “angry”), and CP words (e.g., “realize”).

All website content posted within six months of baseline also was coded into 27 categories generated by the authors after reading all PCO website content. Categories were coded yes/no for whether women mentioned a given category at least once in their writing. All websites were coded separately by two trained raters. Inter-rater reliability for the 27 yes/no categories of website content was high (89%). Inconsistencies were resolved by a third rater.

Website use questionnaire—An author-constructed website use questionnaire was administered at one- and six-month follow-up. At one month, women indicated how much total time they spent on their website during the past four weeks and how often they logged in to their website. Participants also rated website usefulness on ten potential uses (e.g., “allowing you to tell the story of your experience”) on a scale ranging from 1 (*not at all useful*) to 5 (*extremely useful*). In free-response format, women described the most useful consequence of the website and offered additional feedback.

The questionnaire was re-administered at six months with the addition of three items. First, women rated how positive or negative their experience with the website had been on scale

ranging from 1 (*very negative*) to 7 (*very positive*). Second, in a yes/no format, women indicated any technical difficulties and barriers to website use. Third, women were asked in a free response format to describe any technical difficulties and/or barriers to website use.

Visitor questionnaire—An author-constructed questionnaire was available on each website for visitors to complete throughout the study; visitors were instructed to complete the questionnaire only once. Visitors indicated their sex, the number of times they had visited the website, and their relationship to the author. Visitors also rated the usefulness of the website on six categories (e.g., “providing an update on the author’s health”) on a scale ranging from 1 (*not at all useful*) to 5 (*extremely useful*). In free-response format, visitors commented on their experience visiting the website. In analyses, visitors’ responses were not connected to authors’ responses.

Dependent variables—Completed at each assessment point, dependent variables in the current study were outcomes associated with significant main and/or moderated effects in the PCO trial [7]. Depressive symptoms were assessed using the Center for Epidemiologic Studies Depression Scale (CES-D) [14]. Positive affect during the past week (e.g., “cheerful”) was assessed using the Profile of Mood States (POMS) Vigor subscale [15]. The Posttraumatic Growth Inventory (PTGI) [16] Appreciation of Life subscale assessed perceived increase in life appreciation since cancer diagnosis.

Statistical Analysis

Descriptive statistics on major variables and dependent *t*-tests to assess change across time were computed. To evaluate predictors of three indices of website use (i.e., posting to website [yes/no], number of posts, total word count), chi-square tests, independent-samples *t*-tests, and regressions were computed. Results are reported for the sample regardless of medical treatment status; subsample size was insufficient to yield reliable findings as a function of current treatment ($n = 10$) versus completed treatment ($n = 36$). Sample size varies somewhat across analyses owing to nonresponse to particular items.

Multiple regression analyses were conducted to examine the influences of PE, NE, and CP word use separately on change in outcomes from baseline to six months. Multiple regressions for each dependent variable controlled for the initial value on the relevant dependent variable (to evaluate change in the variables across time) by entering the initial value as a predictor. Predictors were centered to reduce multicollinearity.

Results

Participant Characteristics

PCO participants—Of the 46 women randomly assigned to the PCO intervention, six did not attend the workshop. Most of the 46 women were married (74%), college graduates (63%), non-Hispanic white (87%), and had been diagnosed more than two years earlier (85%). Approximately half were employed outside the home (46%). On average, women were 55 years old ($SD = 12$, range = 28-76 years). Ten women were in current medical treatment, and nine had metastatic disease.

Visitors—Self-report data were collected online from 66 visitors to the websites, of whom 73% were first-time visitors. Returning visitors had viewed the website on average 4.53 times previously (range = 1-20). Most visitors reported knowing the website author personally (83%) and were female (92%). Approximately half (49%) were friends of participants; 14% were extended family; 11% were siblings; 11% were acquaintances; 11% were other women with breast cancer (no relationship with participant); 3% were children; fewer than 2% were co-workers; and fewer than 2% selected an “other” category.

Website Use

As indicated by objective website data, 80% of women who participated in a workshop posted a blog entry during the following month. Website users had posted an average of 3.00 entries to their blogs ($SD = 3.99$, range = 0-17 posts) at one month and an average of 5.28 entries ($SD = 6.57$, range = 0-28 posts) at six months.

At both one month and six months, 33 women completed the website use questionnaire. Women reported spending an average of 3.03 hours ($SD = 4.83$, range = 0-25 hours) on their website during the first month and an average of 1.27 hours ($SD = 2.44$, range = 0-8 hours) on their website during the four weeks prior to six-month follow-up. At one month, most women (69%) reported logging in to their website once a week or less during the past month; 28% logged in a few times a week, and 3% logged in every day. At six months, most women (91%) indicated that they logged in to their website less than once a week and 9% reported that they logged in about once a week.

Website Usefulness at One- and Six-month Follow-up

At one month (see Table 1), women ($n = 27$) reported that the websites were “very useful” on average in terms of giving them a place to express emotions (77% rated this item “very useful” or “extremely useful”) and tell the story of their experience (66% rated this item “very useful” or “extremely useful”). Women reported that the websites were “a little useful” on average in terms of letting others know what would be helpful for them and helping them feel cared for by others (69% rated these items “not at all useful” or “a little useful”). Women reported that the websites were significantly more useful at one month than at six months on three of ten items.

At six months, women on average reported that their experience was positive ($M = 5.20$, $SD = 1.54$). A majority of women (80%) reported experiencing barriers to website use. Over half ($n = 14$) of women who commented ($n = 24$) reported that they lacked time to contribute to their websites due to other obligations and stressors (e.g., work, illness). Four women who had completed medical treatment for breast cancer did not perceive a need for the website. Three women reported lack of comfort with computers, two had difficulty accessing the website, two received fewer responses from visitors than anticipated, two experienced physical limitations (e.g., eye problems), and one woman reported lack of computer access.

Visitor Questionnaire

Visitors reported that the websites were “very useful” for providing updates on the PCO participant's health and emotional state and for helping the visitor feel close to the participant (see Table 2).

Predictors of Website Use

Chi-square tests for categorical variables (i.e., cancer stage, ethnicity, employment status, marital status, treatment status) and independent samples t-tests for continuous variables (i.e., age, education, income, months since breast cancer diagnosis) were performed in order to examine whether demographic and cancer-related variables predicted website use (i.e., posting to website [yes/no], number of posts, total word count). Cancer stage predicted posting to websites, $X^2(1, N = 38) = 5.70, p = .017$. Women with more advanced cancer (stages 3 and 4) were more likely to post than women with early-stage cancer. No other significant relationships emerged.

Website Content

Number and percentage of women who mentioned each category in their blog posts are displayed in Table 3. Most women described the story of their diagnosis and treatment, their emotional experience, spirituality, positive interactions with medical care providers, support received from others, benefits in the cancer experience, and their involvement in PCO.

Predictors of PCO Outcomes

On average, 3.83% of total words used in posts over the six months were classified as PE words ($SD = 1.35$), 1.50% were NE words ($SD = 0.76$), and 15.41% were CP words ($SD = 2.16$) [13]. Linguistic content categories were examined for association with change in outcomes from baseline to six months. Because number of posts and total word count were not associated with change in depressive symptoms, positive affect, or life appreciation, they were not included as covariates.

Higher use of PE words was significantly associated with an increase in positive mood ($b = 3.37, 95\% \text{ CI } [.26, 6.49], p = .036$). PE word use was not significantly associated with depressive symptoms ($b = -.60, 95\% \text{ CI } [-2.69, 1.48], p = .55$) or life appreciation ($b = -.21, 95\% \text{ CI } [-1.01, .592], p = .59$). Higher use of NE words was significantly associated with a decrease in depressive symptoms ($b = -2.87, 95\% \text{ CI } [-5.72, -.028], p = .048$). NE word use was not significantly associated with positive mood ($b = -4.05, 95\% \text{ CI } [-9.96, 1.87], p = .17$) or life appreciation ($b = .31, 95\% \text{ CI } [-1.05, 1.66], p = .63$). Further, CP word use was not significantly associated with depressive symptoms ($b = -.09, 95\% \text{ CI } [-1.36, 1.18], p = .88$), positive mood ($b = .14, 95\% \text{ CI } [-2.27, 2.55], p = .90$), or life appreciation ($b = .06, 95\% \text{ CI } [-.51, .62], p = .83$).

Discussion

The current study aimed to characterize PCO participant and visitor experience, examine predictors of website use, and identify “active ingredients” of the effects of blogging about the cancer experience in improving psychosocial outcomes [10]. PCO participants indicated

that using their websites was a positive experience and found the websites most useful as an avenue for telling the story of their experience and expressing emotions. As one woman wrote, “I am alive and I have a story to tell.”

PE, NE, and CP word use was more similar to a large collection of publicly available blogs examined with LIWC than to a collection of expressive writing studies [13], although direct comparisons with other samples are not possible because variability is not reported in the comparison samples. The similarity of website content in the current study to public blogs suggests that writing for an audience may influence how women choose to portray their cancer experience. Consistent with research suggesting that individuals who benefit most from expressive writing tend to use high rates of PE words [12], in the current study PE word use was significantly associated with an increase in positive affect. In addition, NE word use was significantly associated with a decrease in depressive symptoms. Processing and expressing emotions related to a stressor (i.e., emotional approach coping) predicts improvement in psychological health [17-18] and, more specifically, positive adjustment to cancer [9, 19-20]. It is possible that associations between word usage and outcomes in the current study might reflect changing mood states (e.g., heightened positive mood may have led to more positive word usage). However, in the current study, more negative word use was associated with a *decrease* in depressive symptoms.

Most women wrote about finding benefit in the cancer experience. For instance, women stated that cancer had given them a better understanding of what was truly important in their lives and prompted involvement in meaningful activities. Most women also expressed gratitude for guidance from their medical team and support from family, friends, colleagues, other breast cancer patients, and strangers. One woman wrote, “The pain was not the cancer, but a life unexpectedly in shambles. And for that pain my primo friend and my kids have been there and listened and listened and listened and continue to do so.”

Although women wrote about receiving support from their interpersonal networks during the cancer experience, items evaluating website usefulness in terms of promoting interaction with family and friends (e.g., helping them feel cared for by others, letting others know what would be helpful for them) generally received low ratings. Notably, many women in the current study were not undergoing current medical treatment for their breast cancer and therefore may not have felt a need for support in relation to their cancer. Future Internet-based interventions aimed at women undergoing current medical treatment could include more explicit features promoting interaction between participants and visitors in order to bolster social support.

Interestingly, women with more advanced cancer were more likely to post to their websites, suggesting that they perceived more need to share their experience with and garner support from others and/or that they had more time to do so. This finding points to a potentially unmet need among women with advanced breast cancer that future Internet-based psychosocial interventions could address.

Although women used their websites often during the month following the workshop, website use tapered during the following months. This pattern is consistent with other

Internet-based interventions that have evidenced relatively modest engagement [21-22]. However, unlike interventions that require maintenance of health behavior changes to confer benefit (e.g., smoking cessation), even brief engagement in PCO was sufficient to improve outcomes [7]. Compared with expressive writing tasks that suggest writing for approximately 80 minutes total [12], PCO participants reported spending an average of 180 minutes using their websites during the first month. Perhaps website use was beneficial primarily in the weeks following the workshop, with durable effects at six months. Early PCO use might have mobilized the interpersonal network to provide continuing support. Whether continued high rates of website use would have conferred additional benefit is unknown, although we did not find evidence for a dose-response relationship in number of posts or total words with outcomes.

Our findings point to potential strategies to bolster engagement in future Internet-based interventions. A substantial proportion of women reported lacking adequate time to contribute to their websites. As one woman wrote on her blog, "I have been so busy with work that I haven't had the time to write [in] my journal here." To address this barrier, future interventions could recruit a family member or friend to manage certain website functions or bolster engagement by using automated reminder emails or text messages.

Significant mediators of PCO's effects included an increase in coping self-efficacy, a decrease in loneliness, and an increase in perceived social support from friends [23]. These findings are consistent with the evidence that PCO websites were most commonly read by female friends who valued the websites as a way to connect emotionally with participants and receive information about their health. One visitor wrote, "[I] did not know that my friend had experienced this journey with cancer... I have already written her an email and will continue to check on her." The current research suggests that visitors can provide a valuable source of data about the utility of personal websites to increase social support for cancer patients. In the present study, a self-selected group of visitors responded to the survey offered on women's websites and data regarding number of unique visitors to the websites were not gathered. Future studies should aim to gather data from visitors more systematically.

Limitations of this study warrant discussion. The items assessing website use have not been validated in other samples, and some women did not complete items assessing website usefulness. Upon further examination, the women who did not complete these items posted to their websites zero to two times during the study period. It is conceivable that had they responded, those women would not have found their websites useful. The trial included a sample of predominantly well-educated, non-Hispanic white women with breast cancer. Results may not generalize to men, individuals with other types of cancer, and disadvantaged groups. The current study did not assess writing or social network communication that occurred outside the study. Furthermore, the small sample size in the current study limited our ability to examine predictors of website use and outcomes as a function of medical treatment status.

In conclusion, personal websites can help women with breast cancer construct a narrative of their experience and receive effective social support. Expressing emotions was a particularly

important component of this intervention. Participants reported that the websites were useful as a platform for expressing emotions, and visitors reported that the websites helped them connect emotionally with participants. Additionally, writing about positive and negative emotions was associated with improved psychosocial outcomes. Future Internet-based interventions should investigate the role of emotional expression in improving psychosocial outcomes in more detail. Future studies also should target women with advanced breast cancer and/or women currently undergoing medical treatment, who may find the websites more useful for garnering support from their interpersonal network. Finally, future Internet-based interventions should aim to reduce barriers to website use, gather data from visitors systematically, and include a larger and more diverse sample. Investigation of the “active ingredients” of Internet-based interventions for cancer patients will improve the efficiency and efficacy of future studies. Personal websites are a promising avenue for promoting adjustment among individuals experiencing cancer, and perhaps other serious stressors, by creating a narrative of their experience and connecting with others.

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Table 1

Website Usefulness at One- and Six-Month Follow-up

Items	One-Month Follow-up		Six-Month Follow-up		Dependent <i>t</i> -test
	Mean	SD	Mean	SD	
1. Allowing you to tell the story of your experience	4.00	1.41	3.60	1.57	$t(19) = 1.90, p = .072$
2. Reducing your having to repeat information over and over	3.28	1.64	2.78	1.52	$t(17) = 2.47, p = .024$
3. Making you feel connected to family and friends	2.84	1.50	2.42	1.35	$t(18) = 1.36, p = .19$
4. Keeping others informed about how you're doing	3.00	1.49	2.63	1.50	$t(18) = 1.79, p = .090$
5. Helping you feel cared for by others	2.26	1.20	2.11	1.24	$t(18) = .65, p = .53$
6. Letting others know what would be helpful to you	2.11	1.23	1.94	1.16	$t(17) = .77, p = .45$
7. Allowing you to help the people who care about you	2.53	1.22	2.05	1.13	$t(18) = 1.84, p = .083$
8. Reducing the amount of time you spend on the phone/talking with others	2.72	1.64	2.28	1.53	$t(17) = 1.81, p = .088$
9. Giving you a place to express your emotions	3.95	1.57	2.90	1.59	$t(19) = 3.94, p = .001$
10. Getting the help you need	2.37	1.54	1.89	1.29	$t(18) = 2.14, p = .046$

Items rated on a scale ranging from 1 (*not at all useful*) to 5 (*extremely useful*).

Note. Means and standard deviations listed are for complete data. $N = 18-20$ on dependent *t*-tests.

Table 2
Visitor-rated Website Usefulness

Items	N	Mean	SD
1. Providing an update on the author's health	65	4.29	0.80
2. Providing an update on how the author is doing emotionally	65	4.03	1.02
3. Giving me ideas about how I can help the author	65	3.55	1.12
4. Providing information about breast cancer	65	3.58	1.07
5. Helping me feel close to the author	66	4.18	0.89
6. Giving me ideas about how I want to live my life	66	3.53	1.07

Items rated on a scale ranging from 1 (*not at all useful*) to 5 (*extremely useful*).

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Table 3
Coded Website Categories ($n = 21$)

Categories	No.	%
Diagnosis story	16	76.2
Treatment description	17	81.0
Treatment decision-making	10	47.6
Complications/changes to treatment	10	47.6
Treatment side effects	9	42.9
Emotional experience	15	71.4
Social support	14	66.7
Emotional support	12	57.1
Instrumental support	12	57.1
Failure to receive support	3	14.3
Desire to support others with breast cancer	9	42.9
Medical team	15	71.4
Positive comments	14	66.7
Negative comments	4	19.0
Cancer-related benefit	13	61.9
Relating to others	9	42.9
New possibilities	3	14.3
Personal strength	6	28.6
Spiritual change	1	4.8
Appreciation of life	10	47.6
Health behavior change	3	14.3
Solicitation of help from visitors	8	38.1
Spirituality	16	76.2
Solicitation of prayers from visitors	7	33.3
Bible verses or prayers	3	14.3
Poems/quotations	4	19.0
Mention of PCO	14	66.7
Difficulties with website use	7	33.3

Note. Categories coded for number of participants who mentioned each category in their writing.