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# Writing to Connect

## CAN CREATING A PERSONAL WEBSITE IMPROVE ADJUSTMENT TO BREAST CANCER?

BY LAUREN HARRIS

**A**PPROXIMATELY one in eight women in the United States will be diagnosed with breast cancer at some point during her life (Howlader et al., 2012). In 2014 alone, more than 232,000 American women were diagnosed with the disease (DeSantis et al., 2014). Diagnosis and treatment of breast cancer, which can include surgery, radiation, chemotherapy, and/or endocrine therapy, can profoundly impact a woman's physical, psychological, and social functioning.

Although most women diagnosed with breast cancer adjust well over time, breast cancer patients do have elevated rates of depression and anxiety disorders compared with the general population (Mitchell et al., 2011; Fann et al., 2008). Depression in cancer patients is associated with lower participation in medical care, longer hospital stays, and, perhaps, lower survival (Colleoni et al., 2000; Prieto et al., 2002; Fann et al., 2008; Pinguart & Duberstein, 2010a). Breast cancer patients are

also faced with social concerns, including managing communication with loved ones about their health and having less energy to engage in valued social activities.

Many studies demonstrate that traditional types of therapy, such as cognitive behavioral therapy and supportive-expressive therapy, can improve emotional distress and quality of life in cancer patients (Faller et al., 2013; Naaman et al., 2009). However, some breast cancer patients may be unable to participate in therapy in a traditional, face-to-face setting due to side effects of treatment (for example, fatigue and pain), intensive medical treatment schedules, and unavailability of therapy services in their communities. Therefore, it is crucial to identify resources that are both effective and accessible to address the difficulties women face following a breast cancer diagnosis.

A large body of research demonstrates that strong social ties can improve both psychological and physical health during the cancer

experience (Nosarti et al., 2002; Pinguart & Duberstein, 2010b) and that social isolation is associated with poor health outcomes (Widows et al., 2000; Lutgendorf & Sood, 2011). Despite the importance of social support, fostering communication between women with breast cancer and their social network can be challenging. Women may be hesitant to ask others for help, lack the energy to seek support, or feel burdened by having to repeat the same information over and over. Family and friends may want to offer support, but may not know what to say or do.

Personal websites provide a central space for women to share their cancer experience and communicate their needs, bridging the potential gap in communication between the patient and her support system. Online journaling may help women to create a story of their experience with breast cancer, express emotions, and boost confidence in their ability to cope with the cancer experience, factors

that can promote positive adjustment in women with breast cancer (Howsepian & Merluzzi, 2009; Stanton et al., 2000). However, very little research has examined whether using a personal website can improve breast cancer patients' psychological health and bolster social support. Our research group at UCLA developed and tested a program called Project Connect Online (PCO) to evaluate whether women with breast cancer could benefit from creating and maintaining a personal website to share their experience and communicate with family and friends (Stanton et al., 2013; Cleary & Stanton, 2014).

### *The Project Connect Online Study*

In the randomized controlled trial of PCO, 88 women diagnosed with breast cancer were assigned to create a personal website or to a waiting-list control condition. Women assigned to create a personal website attended a three-hour workshop for hands-on creation of the website, whereas the waitlisted group was invited to attend the workshop and create a website after the study's conclusion. Both groups completed questionnaires about their psychological and social functioning when they enrolled in the study and six months later.

The primary feature of each woman's personal website was a journal; websites also included a "How You Can Help" feature, where women could post their wishes for specific kinds of support. During the workshop, mem-

bers of the research team led a discussion about potential uses for personal websites (for example, communicating with friends and family), proactively addressed common concerns about personal website use (such as pressure to post frequently), and helped women create their websites and initiate their first journal post. Women were encouraged to invite family and friends to visit their website; website visitors could subscribe for automatic email notifications whenever the woman posted a journal entry on her website.

Women randomly assigned to create personal websites benefitted significantly on measures of depressive symptoms, positive mood, and life appreciation at six-month follow-up compared with control participants (Stanton et al., 2013). PCO promoted these adaptive changes through increased perceived social support from friends, decreased loneliness, and increased confidence in the ability to cope with the cancer experience (Cleary & Stanton, 2014). These results demonstrate that personal website use can improve psychological well-being among women with breast cancer. Interestingly, the websites were most helpful for women who were currently undergoing treatment for their breast cancer (for example, chemotherapy and/or radiation) compared with women who had already completed treatment. The researchers suggested that women in current treatment may have more need to process their cancer experience and garner social support from

friends and family.

Given the promising results of the PCO study, we were interested in characterizing women's experiences of using their personal websites and identifying elements of online journaling that were particularly helpful in improving psychosocial well-being (Harris et al., 2014). Women reported on their website use one and six months after attending the workshop. We also asked family and friends who visited the websites for feedback about their experience viewing the women's websites. Identifying effective components of personal website use for women with breast cancer will help researchers refine future studies to be maximally effective, efficient, and tailored to women's needs.

Most women's website content described the story of their diagnosis and treatment and discussed their emotional experience. A few women wrote about disappointment when others failed to provide effective support. More often, however, women expressed gratitude for guidance from their medical team and for support from family, friends, colleagues, and other breast cancer survivors. Reflecting a mixed experience with receipt of social support, one woman wrote, "people you know and love can disappoint you when you need them the most... and it is equally astonishing the people who [step] up to help."

Many women also wrote about spirituality and finding benefit in the cancer experience. For instance, some women wrote that

cancer had given them a better understanding of what was truly important in their lives, had helped them treasure family and friends, and had prompted engagement in meaningful activities.

Overall, women who created personal websites as part of the PCO study reported that their experience using the websites was positive. Women found the websites most useful in terms of giving them a place to express emotions and tell the story of their experience. As one woman wrote, “I am alive and I have a story to tell.” Despite their positive experiences using their personal website, women noted some barriers to website use. The most common barrier was lacking time to contribute to their website due to other obligations and stressors (for example, work and illness).

We collected data from 66 visitors to the websites, most of whom were female friends of the breast cancer patients. Visitors found the websites most helpful for providing updates on the patient’s health and emotional state and for helping the visitor feel close to the patient.

When we asked about actions that website visitors intended to take as a result of reading the website, they reported that they planned to visit the website again, contact the patient, and offer help. One visitor wrote, “I did not see [the patient] often, and 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.” Our findings suggest that website

visitors can provide a valuable source of information about the ways in which personal websites can bolster communication and support between breast cancer patients and their loved ones.

In order to identify subgroups of women who were highly engaged in contributing to their websites, we examined predictors of website use. We found that women with more advanced breast cancer (stages 3 and 4) were more likely to post to their websites than women with earlier-stage cancer, suggesting that women with advanced cancer may have perceived more need for a platform to share their experience and garner support from others.

We were also interested in identifying specific components of women’s writing as “active ingredients” of online journaling that could help explain the improved depressive symptoms, positive mood, and life appreciation observed in the PCO study. Previous research has demonstrated that use of positive emotion words (for example, “joy”), negative emotion words (for example, “angry”) and words that reflect cognitive processing (for example, “realize”) in written emotional disclosure tasks predicts improvement in psychological functioning (Pennebaker & Chung, 2007).

We used Linguistic Inquiry and Word Count (LIWC; Pennebaker et al., 2007), a computer program designed to analyze the content of text files, to examine whether women’s use of positive emotion words, negative emotion words,

and cognitive processing words in their journal posts was associated with improved psychological functioning. Consistent with findings from previous studies, we found that higher use of positive emotion words was significantly associated with an increase in positive mood over the study period, and higher use of negative emotion words was significantly associated with a decrease in depressive symptoms over the study period. These results suggest that emotional expression was an important aspect of journaling that may have led to psychological benefit.

### *Conclusions and Future Directions*

Personal website use may help women with breast cancer create a narrative of their experience, express emotions, bolster support from friends and family, and improve psychological well-being. Our findings suggest that personal websites may be particularly useful for women with advanced breast cancer and/or women currently undergoing breast cancer treatment. The next iteration of PCO will recruit women with metastatic (stage 4) breast cancer in order to address the needs of this group of women who often experience profound impact on physical, psychological, and social functioning as a consequence of the disease.

Future research should also explore the potential for personal websites to improve adjustment to other types of cancer as well as other illnesses and stressors. With Internet access expanding rapidly

in the United States and around the world, online journaling is a potentially low-cost, accessible way for individuals to chronicle stressful experiences and garner effective social support.

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