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Project Connect Online: Improving Psychosocial Adjustment for Women with Breast Cancer  
with an Internet-Based Intervention

A dissertation submitted in partial satisfaction of the  
requirements for the degree Doctor of Philosophy  
in Psychology

by

Lauren Nicole Harris

2017

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## ABSTRACT OF THE DISSERTATION

Project Connect Online: Improving Psychosocial Adjustment for Women with Breast Cancer  
with an Internet-Based Intervention

by

Lauren Nicole Harris

Doctor of Philosophy in Psychology

University of California, Los Angeles, 2017

Professor Annette Louise Stanton, Chair

**OBJECTIVE:** Emotional expression and receipt of social support can promote psychological and physical health in women diagnosed with breast cancer. Communication between breast cancer patients and their social network can be challenging, however. Study 1 of the current research aimed to characterize the experience of women who participated in the intervention arm of Project Connect Online (PCO), a randomized controlled trial for breast cancer patients to create personal websites to facilitate emotional expression and communication with supportive others. Study 2, a comparative effectiveness trial of PCO for women with metastatic breast cancer (MBC), examined the potential psychosocial and physical health-related benefits of sharing personal websites with other MBC patients, family, and friends (PCO PLUS condition) versus sharing with family and friends only (PCO ONLY condition).

**METHODS:** Study 1 examined the 46 women in the intervention arm of PCO, a three-hour workshop for creation of personal websites with a journal function. Participants completed assessments at baseline, one month, and six months. In Study 2, 30 women with MBC were randomly assigned to PCO PLUS ( $n = 14$ ) or PCO ONLY ( $n = 16$ ) and attended a similar workshop. General and cancer-specific psychosocial and physical functioning was assessed at baseline, two months, and four months. Multilevel models examined comparative effectiveness of the two conditions, potential mediating variables, and predictors of change in outcomes.

**RESULTS:** Women in Study 1 found the websites useful for telling the story of their experience and expressing emotions. Greater use of positive and negative emotion words on the websites was associated with improved psychological functioning at six months. Women with advanced cancer were more likely to use their websites than women with early-stage disease. In Study 2, significant increases in life appreciation, MBC-related altruism, and cancer-related physical symptoms and worsening physical functioning were observed across conditions. Anxiety decreased significantly in PCO PLUS and did not change in PCO ONLY. No significant mediated effects of PCO PLUS versus PCO ONLY on outcomes were observed.

**CONCLUSIONS:** Personal websites can help women with breast cancer, and, in particular, MBC, construct a narrative of their experience and receive support. For women with MBC, personal websites to communicate with family and friends may improve cancer-specific psychosocial adjustment. Communicating with other MBC patients via personal websites, even infrequently, may confer additional psychosocial benefits.

The dissertation of Lauren Nicole Harris is approved.

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2017

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## INVITED PAPERS AND PRESENTATIONS

- Harris, L. N.** (2016, August). Project Connect Online and the benefits of using a personal website during cancer. *Presentation at Cancer Support Community Benjamin Center.*
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- Harris, L. N.** (2015, March). Writing to connect: Can creating a personal website improve adjustment to breast cancer? *Article for UCLA Center for the Study of Women Update.*

## SELECTED CONFERENCE PRESENTATIONS

- Tong, B., **Harris, L. N.**, Moreno, P. I., & Stanton, A. L. (2016, May). *Relationship quality as a moderator of the effect of emotional expression on psychological adjustment.* Talk presented at the annual Stanford Undergraduate Psychology Conference, Palo Alto, California.
- Bauer, M. R., **Harris, L. N.**, Wiley, J. F., Weihs, K. L., & Stanton, A. L. (2015, April). *Role of situational and dispositional coping in physical health-related adjustment to breast cancer.* Poster presentation at the Annual Meeting and Scientific Sessions of the Society of Behavioral Medicine, San Antonio, Texas.
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- Hanover (Harris), L. N.** (2009, May). *Social anxiety, Internet use, and social outcomes.* Poster presentation at the annual Stanford Undergraduate Psychology Conference, Palo Alto, California.

## **General Introduction to the Research**

### **Prevalence and Impact of Breast Cancer**

Breast cancer is the most prevalent invasive cancer among women in the United States, representing 30% of newly diagnosed cases (Siegel, Miller, & Jemal, 2017). In 2016, more than 246,000 women were diagnosed with breast cancer and there were an estimated 3.56 million breast cancer survivors living in the United States (American Cancer Society [ACS], 2016). Due largely to improvements in early detection and treatment, women diagnosed with breast cancer are living longer in the survivorship phase. Indeed, breast cancer mortality rates decreased by 38% from 1989 to 2014 (Siegel et al., 2017).

A breast cancer diagnosis and subsequent treatment significantly influence psychological and physical well-being (Reilly et al., 2013). Treatment for breast cancer, which can include surgery, radiation therapy, chemotherapy, hormonal therapy, and/or biologic therapy, often causes adverse side effects such as pain, fatigue, and insomnia (ACS, 2016; Bower et al., 2000; Shapiro & Recht, 2001). These and other physical symptoms (e.g., sexual dysfunction, neuropathy, nausea, loss of appetite) can diminish quality of life and functioning for some women (Ganz, Kwan, Stanton, Bower, & Belin, 2011; Helgeson, Snyder, & Seltman, 2004). Additionally, psychological well-being is often compromised following a breast cancer diagnosis. Compared with the general population, rates of depression, anxiety, and adjustment disorders among individuals with cancer are elevated (Fann et al., 2008; Mitchell et al., 2011). Furthermore, evidence suggests that depression in cancer patients is associated with reduced participation in medical treatment, longer hospital stays, poorer quality of life, and reduced survival (Colleoni et al., 2000; Fann et al., 2008; Pinguat & Duberstein, 2010a; Prieto et al., 2002).

## **Living with Metastatic Breast Cancer**

Metastatic breast cancer (MBC; i.e., breast cancer that has spread beyond the breast to other organs, most often bone, lung, liver, and brain) occurs in approximately 5% of newly diagnosed breast cancer cases (ACS, 2015). More commonly, MBC diagnoses involve a recurrence of an earlier malignancy; an estimated 30% of women diagnosed with breast cancer will develop recurrent advanced disease (Cheng et al., 2012; O'Shaughnessy, 2005). MBC is incurable and usually life limiting. Patients typically undergo continuous treatment to control the spread of disease and manage symptoms. Treatment is often accompanied by adverse side effects including fatigue, pain, insomnia, sexual dysfunction, and nausea, which can profoundly affect quality of life and ability to perform role functions and activities of daily living (Low, Beran, & Stanton, 2007; Luoma & Hakamies-Blomqvist, 2004; Osse et al., 2002). Many women face financial hardship due to inability to work, high treatment costs, and insufficient insurance (Corneliussen-James, 2011; Low et al., 2007).

Compared to women with earlier-stage disease, rates of depression and anxiety are higher among MBC patients, and clinically significant distress is often underdiagnosed and undertreated (Caplette-Gingras & Savard, 2008; Greenberg, 2004; Okamura, Yamawaki, Akechi, Taniguchi, & Uchitomi, 2005; Turner, Kelly, Swanson, Allison, & Wetzig, 2005). Women often experience concerns about mortality, coping with uncertainty, loss of autonomy, making treatment-related decisions, and the impact of the cancer on loved ones (Low et al., 2007; Turner et al., 2005). Women with MBC also commonly face social challenges including difficulty communicating with loved ones and decreased ability to engage in usual social activities, which can result in social isolation (Low et al., 2007; Luoma & Hakamies-Blomqvist, 2004). Furthermore, lack of

contact with other MBC patients can contribute to feelings of isolation and loneliness (Low et al., 2007).

### **Psychosocial Interventions for Women with Breast Cancer**

In light of the documented negative consequences of breast cancer for psychological and physical health, numerous psychosocial interventions have been designed to address them. A recent systematic review and meta-analysis of 198 psychosocial randomized controlled trials for adults with cancer found small to medium treatment effects on emotional distress and quality of life (Faller et al., 2013). A review of three meta-analyses of psychosocial interventions for breast cancer patients found moderate to strong treatment effects on depression and moderate effects on anxiety and quality of life (Naaman, Radwan, Fergusson, & Johnson, 2009). Few psychosocial randomized controlled trials have specifically targeted individuals with metastatic disease (Moyer, Sohl, Knapp-Oliver, & Schneider, 2009; Uitterhoeve et al, 2004).

Psychosocial interventions for cancer patients typically require multiple in-person sessions extending over weeks or months. Individuals with cancer may have difficulty committing to regularly scheduled intervention sessions due to functional limitations and intensive medical treatment schedules. Thus, effective and efficient psychosocial interventions for cancer patients are needed. Personal websites are widely used by individuals diagnosed with cancer (e.g., [caringbridge.org](http://caringbridge.org), [csn.cancer.org](http://csn.cancer.org), [mylifeline.org](http://mylifeline.org), [carepages.com](http://carepages.com)), and a quantitative content analysis of 50 personal websites written by women with breast cancer demonstrated that they contained detailed narratives of women's experiences and facilitated communication with loved ones and other breast cancer patients (Pitts, 2004).

Project Connect Online (PCO), on which this dissertation is founded, is a psychosocial intervention to help women with breast cancer establish personal websites in order to chronicle

their experience and facilitate communication (Stanton, Thompson, Crespi, Link, & Waisman, 2013). PCO is the first randomized controlled trial examining whether personal websites are effective in promoting positive psychosocial and physical adjustment to breast cancer. In the original randomized controlled trial of PCO, the intervention demonstrated benefits on depressive symptoms, positive mood, and life appreciation (Stanton et al., 2013). As detailed below, PCO is designed to improve adjustment through bolstered social support, emotional expression, coping self-efficacy, and decreased loneliness.

### **Psychological and Physical Health Benefits of Social Support**

Social support (i.e., feeling cared for, esteemed and valued, and part of a social network of mutual assistance; Wills & Fegan, 2001) confers psychological and physical health benefits, both in general and in the context of stress (i.e., circumstances appraised as taxing or exceeding personal resources; Lazarus & Folkman, 1984; Taylor, 2011; Uchino, 2006). Conversely, social isolation and loneliness are detrimental to psychological and physical health outcomes (Hawkey & Cacioppo, 2010; Jaremka et al., 2013; Lutgendorf & Sood, 2011; Widows, Jacobson, & Fields, 2000). The main effect model of social support proposes that social resources have a positive influence on health regardless of the presence of stress (Cohen & Wills, 1985). Social networks can provide health-related information and resources, positive norms regarding health behaviors (e.g., exercise, diet), and a sense of belonging and security, which may reduce distress and motivate engagement in health-promoting behaviors (Cohen, Gottlieb, & Underwood, 2000).

The stress-buffering model posits that perceived availability of social resources prevents health-damaging responses to stressors and enables more effective coping (Cohen & Wills, 1985). Indeed, evidence suggests that social support decreases the negative impact of stressful events ranging from unemployment to bereavement and medical problems (Cutrona & Russell,

1990). Perceived availability of social support during a stressful experience may contribute to a less threatening appraisal of the stressor and bolster confidence in one's ability to cope, leading to lower perceived stress and more adaptive emotional, behavioral, and physiological responses (Lazarus & Folkman, 1984; Taylor, 2011; Thoits, 1986; Uchino, 2006). Although physiological arousal in response to stress (e.g., release of epinephrine and norepinephrine accompanying sympathetic nervous system activity; release of cortisol accompanying hypothalamic-pituitary-adrenocortical axis activity) is adaptive in the short term, recurrent or chronic activation of these systems is associated with negative effects on health (e.g., Seeman & McEwen, 1996; Uchino, Cacioppo, & Kiecolt-Glaser, 1996).

Specific to breast cancer, social support is an important buffer against the negative psychological and physical impact of the disease (Alferi, Carver, Antoni, Weiss, & Duran, 2001; Helgeson & Cohen, 1996; Nosarti, Roberts, Crayford, McKenzie, & David, 2002; Pinguart & Duberstein, 2010b). Evidence suggests that support from friends and family can play an important role in breast cancer patients' well-being (e.g., Arora, Finney-Rutten, Gustafson, Moser, & Hawkins, 2007; Manne et al., 2003). Effective communication between a woman with breast cancer and her social network, however, can be challenging (Helgeson & Cohen, 1996). Women may want to keep family and friends updated on their status, but may lack the energy to do so, fear becoming a burden, or anticipate unhelpful responses. Members of the social network may want to provide support but feel unsure of how to do so. PCO is designed to facilitate communication and support between breast cancer patients and their social network. Indeed, the original PCO trial demonstrated that an increase in social support from friends mediated the intervention's effects on depressive symptoms and life appreciation (Cleary & Stanton, 2015).

According to the matching hypothesis, stress buffering is most effective when the social support perceived or provided is appropriate to the challenges presented by the stressor (Cohen & McKay, 1984; Cutrona & Russell, 1990). Women with breast cancer may be well-suited to provide appropriate social support to one another (Campbell, Phaneuf, & Deane, 2004; Gustafson et al., 2001; Vilhauer, 2009; Winzelberg et al., 2003). The current research aimed to enhance effective social support and reduce loneliness for women with breast cancer by providing a channel for communication between breast cancer patients and their social network.

### **Emotional Expression and Adjustment to Stress**

Functionalist theories of emotion propose that emotions are adaptive responses to problems of physical and social survival and can prompt positive cognitive appraisal, facilitate goal-directed behavior, aid decision-making, and recruit social support to promote health and well-being in response to stressors (Keltner & Gross, 1999; Levenson, 1994). Emotional disclosure translates an individual's experience of a stressor into language, giving meaning to the experience and promoting constructive processing, cognitive reappraisal, and perhaps resolution of distress related to the stressor (Pennebaker & Chung, 2011; Stanton & Low, 2012). Indeed, empirical evidence demonstrates that emotional expression can benefit psychological and physical adjustment in the face of stress (Frattaroli, 2006; Stanton, 2011; Stanton et al., 2000).

Emotion regulation theory highlights the psychosocial benefits of coping with stressful experiences through emotional expression (Gross, 2007) and the negative consequences of emotional dysregulation (Gross & Levenson, 1997). Emotional expression may habituate emotional and physiological reactivity to a stressor through exposure (Foa & Kozak, 1986; Low, Stanton, & Danoff-Burg, 2006; Pennebaker & Chung, 2011); related research demonstrates that simply labeling a feeling can reduce the intensity of the feeling and promote self-regulation

(Lieberman, Inagaki, Tabibnia, & Crockett, 2011). Furthermore, evidence suggests that physiological and emotional habituation to cancer-related emotional disclosure can improve physical symptoms among breast cancer patients (Low et al., 2006).

A large body of experimental and longitudinal research demonstrates that emotional expression, whether verbal or written, promotes psychological and physical adjustment to breast cancer (Frattaroli, 2006; Reynolds et al., 2000; Stanton, 2011; Stanton et al., 2000). The current research aimed to facilitate emotional expression for women with breast cancer by providing an online journaling platform that women were able to access at their convenience.

### **Coping Self-Efficacy and Adjustment to Stress**

Coping processes are attempts to manage stressor-related demands that are perceived as taxing or exceeding personal resources (Lazarus & Folkman, 1984; Taylor & Stanton, 2007). Bandura (1977) suggests that perceived self-efficacy (i.e., the confidence in one's ability to succeed in a given situation) influences how individuals cope with stressors and, in turn, their psychosocial adjustment. Individuals who perceive themselves as capable of managing a particular stressor are expected to employ active, approach-oriented strategies to cope with the stressor and experience positive psychosocial adjustment, whereas those who believe that the stressor exceeds their coping skills are predicted to avoid the stressor and experience poor adjustment (Bandura, 1977).

The link between coping self-efficacy and positive adjustment to cancer is well documented (Arora et al., 2002; Merluzzi, Nairn, Hedge, Martinez-Sanchez, & Dunn, 2001; Penedo et al., 2003), and several psychosocial interventions with adult cancer patients have demonstrated that increased coping self-efficacy mediates intervention effects on outcomes including depressive symptoms, positive affect, benefit finding, and physical functioning (e.g.,

Antoni et al., 2006; Hawkins et al., 2010; Penedo et al., 2004; Penedo et al., 2006; Scheier et al., 2005). The current research aimed to help women develop a new set of skills (e.g., creating a personal website, journaling about the cancer experience, managing communication online), which was hypothesized to increase women's perceived self-efficacy to cope with the demands of the cancer experience, and, in turn, improve adjustment.

### **Aims of the Current Research**

PCO aimed to improve psychosocial and physical adjustment for women with breast cancer by enhancing social support, decreasing loneliness, facilitating emotional expression, and bolstering cancer-related coping self-efficacy. As described above, theory and empirical evidence suggest that these constructs improve adjustment to stressors, and, more specifically, to breast cancer. In the original randomized controlled trial of PCO, 88 women diagnosed with breast cancer (any stage, any interval since diagnosis) were randomly assigned to a waiting-list control condition or to participate in a three-hour hands-on workshop to create personal websites to communicate with family and friends (see Stanton et al., 2013). At six-month follow-up, PCO demonstrated benefits on depressive symptoms, positive mood, and life appreciation, particularly for women undergoing current medical treatment for breast cancer, most of whom had metastatic disease. Change in coping self-efficacy, loneliness, and social support from friends mediated the intervention's effects on depressive symptoms (Cleary & Stanton, 2015). Additionally, change in coping self-efficacy mediated the relationship between PCO and improved positive mood, and change in social support from friends mediated the effect of the intervention on life appreciation.

**Study 1.** The first study aimed to characterize the experience of women who participated in the intervention arm of PCO, as well as the experience of visitors to the websites (i.e., family and friends invited to view the websites). Predictors of website use were also examined to

identify subgroups of women who were highly engaged in the intervention. Additionally, relationships between website content and significant outcomes were examined to identify “active ingredients” of PCO. Identifying elements of website use associated with positive adjustment may help to refine future Internet-based psychosocial interventions for women with breast cancer.

**Study 2.** Given the promising results of the original PCO trial, Study 2, a comparative effectiveness trial, examined the potential psychosocial and physical health-related benefits of sharing personal websites with other women with breast cancer, family, and friends (PCO PLUS condition) versus sharing with family and friends only (PCO ONLY condition) in a sample of women with MBC. Study 2 focused on women with MBC due to the psychosocial and physical burden of MBC, the paucity of evidence-based psychosocial interventions for women with MBC, and findings from the original PCO trial that women undergoing current medical treatment for breast cancer, most of whom had MBC, benefitted most from the trial. In addition to examining psychosocial and physical adjustment, Study 2 investigated website use variables, potential mechanisms of the effects of PCO PLUS, and predictors of change in outcomes in both conditions.

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## **Study 1: Project Connect Online: User and visitor experiences of an Internet-based intervention for women with breast cancer**

Harris, L. N., Cleary, E. H., & Stanton, A. L. (2015). Project Connect Online: User and visitor experiences of an Internet-based intervention for women with breast cancer. *Psycho-Oncology, 24*, 1145-1151. DOI: 10.1002/pon.3734

### **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.

Strong social ties can improve psychological and physical adjustment to cancer (Alferi, Carver, Antoni, Weiss, & Duran, 2001; Helgeson & Cohen, 1996; Nosarti, Roberts, Crayford, McKenzie, & David, 2002; Pinquart & Duberstein, 2010), and isolation is associated with poor health outcomes (Lutgendorf & Sood, 2011; Widows, Jacobson, & Fields, 2000).

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 aimed 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 (Stanton, Thompson, Crespi, Link, & Waisman, 2013), 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., Howsepian & Merluzzi, 2009; Stanton et al., 2000). 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 (Stanton et al., 2013). 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., Andersen, Shelby, & Golden-Kreutz, 2007). 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 (Pennebaker, 1997; Pennebaker & Chung, 2007).

## **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 (Stanton et al., 2013). 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. (2013) for a flow chart. 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. (2013). 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; Pennebaker, Chung, Ireland, Gonzales, & Booth, 2007). 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 (Stanton et al., 2013). Depressive symptoms were assessed using the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). Positive affect during the past week (e.g., “cheerful”) was assessed using the Profile of Mood States (POMS) Vigor subscale (McNair, Lorr, & Droppleman, 1971). The Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) 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 1-1), 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 1-2).

### **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,  $\chi^2(1, N = 38) = 5.70, p = .017$ . 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 1-3. 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 ( $SD = 2.16$ ; Pennebaker, Chung, et al. 2007). 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% CI [.26, 6.49],  $p = .036$ ). PE word use was not significantly associated with depressive symptoms ( $b = -.60$ , 95% CI [-2.69, 1.48],  $p = .55$ ) or life appreciation ( $b = -.21$ , 95% CI [-1.01, .592],  $p = .59$ ). Higher use of NE words was significantly associated with a decrease in depressive symptoms ( $b = -2.87$ , 95% CI [-5.72, -.028],  $p = .048$ ). NE word use was not significantly associated with positive mood ( $b = -4.05$ , 95% CI [-9.96, 1.87],  $p = .17$ ) or life appreciation ( $b = .31$ , 95% CI [-1.05, 1.66],  $p = .63$ ). Further, CP word use was not significantly associated with depressive symptoms ( $b = -.09$ , 95% CI [-1.36, 1.18],  $p = .88$ ), positive mood ( $b = .14$ , 95% CI [-2.27, 2.55],  $p = .90$ ), or life appreciation ( $b = .06$ , 95% 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 (Andersen et al., 2007). 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 (Pennebaker et al., 2007), 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 (Pennebaker & Chung, 2007), 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 (Frattaroli, 2006; Stanton & Low, 2012) and, more specifically, positive adjustment to cancer (Morgan, Graves, Poggie, & Cheson, 2008; Stanton et al., 2000; Stanton et al., 2002). 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 (Christensen &

Mackinnon, 2006; Eysenbach, 2005). 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 (Stanton et al., 2013). Compared with expressive writing tasks that suggest writing for approximately 80 minutes total (Pennebaker & Chung, 2007), 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 (Cleary & Stanton, 2015). 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 1-1. 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 | $t(19) = 1.90, p = .07$  |
| 2. Reducing your having to repeat information over and over               | 3.28                | 1.64 | 2.78                | 1.52 | $t(17) = 2.47, p = .02$  |
| 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 | $t(18) = 1.79, p = .09$  |
| 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 | $t(18) = 1.84, p = .08$  |
| 8. Reducing the amount of time you spend on the phone/talking with others | 2.72                | 1.64 | 2.28                | 1.53 | $t(17) = 1.81, p = .09$  |
| 9. Giving you a place to express your emotions                            | 3.95                | 1.57 | 2.90                | 1.59 | $t(19) = 3.94, p < .01$  |
| 10. Getting the help you need   | 2.37                | 1.54 | 1.89                | 1.29 | $t(18) = 2.14, p = .05$  |

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 1-2. Visitor-Rated Website Usefulness

| Items   | N  | Mean | SD   |
|---|----|------|------|
| 1. Providing an update on the author's health                 | 65 | 4.29 | .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 | .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*).

Table 1-3. 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.

**Study 2: Project Connect Online for women with metastatic breast cancer: A randomized trial of an Internet-based intervention to enhance peer support and facilitate communication**

**Abstract**

**OBJECTIVE:** Evidence suggests that cancer-related emotional expression and receipt of social support can promote psychological and physical health in women diagnosed with breast cancer, but communication between breast cancer patients and their social network can be challenging. A randomized controlled trial of Project Connect Online (PCO), a psychosocial intervention to help women with breast cancer create personal websites to communicate with others and express emotions, demonstrated benefits on psychosocial adjustment (Stanton, Thompson, Crespi, Link, & Waisman, 2013). The current comparative effectiveness trial of PCO for women with metastatic breast cancer (MBC) examined the potential psychosocial and physical health-related benefits of sharing personal websites with other MBC patients, family, and friends (PCO PLUS condition) versus sharing with family and friends only (PCO ONLY condition).

**METHODS:** Thirty women with MBC were randomly assigned to PCO PLUS ( $n = 14$ ) or PCO ONLY ( $n = 16$ ). Both conditions involved a three-hour workshop for creation of personal websites with a journal function. General and cancer-specific psychosocial and physical health-related functioning was assessed prior to the workshop and two and four months later. Multilevel models examined comparative effectiveness of the two conditions, change in outcomes across conditions, potential mediating variables of the effects of PCO PLUS versus PCO ONLY, and predictors of change in outcomes in both conditions. Website use variables also were examined.

**RESULTS:** Anxiety decreased significantly and loneliness decreased marginally in PCO PLUS; no changes in these variables were observed in PCO ONLY. Across both conditions, life appreciation and MBC-related altruism increased significantly, MBC-related universality increased marginally, and physical functioning and cancer-related physical symptoms worsened significantly. No significant mediators of PCO PLUS emerged. Changes in social support from friends, emotional expression, and coping self-efficacy from study baseline to two months were associated with changes in outcomes over the study period, with some differences by condition. Women's engagement with their personal websites was high throughout the study period, although communication among women in PCO PLUS via websites and other forms was infrequent.

**CONCLUSIONS:** Personal websites to communicate with family and friends may improve cancer-specific psychosocial functioning for women with MBC despite worsening physical symptoms and functioning. Communicating with other MBC patients during a one-time intervention session and subsequently via personal websites, even infrequently, may confer additional psychosocial benefits. PCO represents a brief intervention with promise for promoting psychosocial adjustment among women with MBC.

Social support can improve psychological and physical adjustment to breast cancer (Alferi, Carver, Antoni, Weiss, & Duran, 2001; Helgeson & Cohen, 1996; Nosarti, Roberts, Crayford, McKenzie, & David, 2002; Pinqart & Duberstein, 2010). Evidence also suggests that support from other cancer patients (i.e., peer support) can provide support that is well-matched to patients' needs and desires (Campbell, Phaneuf, & Deane, 2004; Gustafson et al., 2001; Rini et al., 2006; Ussher, Kirsten, Butow, & Sandoval, 2006; Winzelberg et al., 2003). However, communication between breast cancer patients and family, friends, and other patients can be challenging. A randomized controlled trial of Project Connect Online (PCO), a psychosocial intervention to help women with breast cancer establish personal websites to communicate with their social network and create a narrative of their experience, demonstrated benefits on depressive symptoms, positive mood, and life appreciation for women in the intervention condition compared with those in a waiting-list control condition (Stanton, Thompson, Crespi, Link, & Waisman, 2013). Women currently undergoing treatment for cancer, most of whom had metastatic disease, benefitted most from the intervention (Stanton et al., 2013), and women with advanced disease were more likely than those with early-stage disease to use their websites following the intervention (Harris, Cleary, & Stanton, 2015).

The current comparative effectiveness trial of PCO examined the potential psychosocial and physical health-related benefits of sharing personal websites with family, friends, and other breast cancer patients (PCO PLUS condition) versus sharing with family and friends only (PCO ONLY condition) in a sample of women with metastatic breast cancer (MBC). We targeted women with MBC in the current study due to the burden of living with metastatic disease (Low, Beran, & Stanton 2007; Luoma & Hakamies-Blomqvist, 2004), the paucity of evidence-based psychosocial interventions for women with MBC (Moyer, Sohl, Knapp-Oliver, & Schneider,

2009), and findings that women with MBC benefitted most from the original PCO trial (Harris et al., 2015; Stanton et al., 2013). In addition to comparing the effects of the two conditions on outcomes, the current study aimed to identify mediators of the effects of PCO PLUS and predictors of change in outcomes in both conditions over the four-month study period. Website use variables also were examined.

### **Burden of Metastatic Breast Cancer**

Breast cancer is the most prevalent invasive cancer among women in the United States, representing 30% of newly diagnosed cases (Siegel, Miller, & Jemal, 2017) and affecting more than 246,000 women in 2016 (American Cancer Society [ACS], 2016). MBC (i.e., breast cancer that has spread beyond the breast to other organs, most often bone, lung, liver, and brain) occurs in approximately 5% of newly diagnosed breast cancer cases (ACS, 2015). More commonly, MBC diagnoses involve a recurrence of an earlier malignancy. Although cancer registries do not collect data on recurrence and therefore the number of women living with MBC is unknown, an estimated 30% of women diagnosed with breast cancer will develop recurrent advanced disease (Cheng et al., 2012; O'Shaughnessy, 2005). MBC is incurable and usually life limiting. Despite modest improvements in survival rates after MBC diagnosis (Dawood et al., 2008; Shigematsu et al., 2011), only 38% and 17% of women diagnosed with stage IV ER+/PR+ and ER-/PR- breast cancer, respectively, are expected to live for at least five years (Chen, Linden, Anderson, & Li, 2014).

Treatment for MBC, which may include surgical resection of lesions, radiation to target metastases, chemotherapy, endocrine therapy, and/or biologic therapy, is often accompanied by adverse side effects such as fatigue, pain, and insomnia (Irvin, Muss, & Mayer, 2011; Low et al., 2007). These and other physical symptoms (e.g., sexual dysfunction, neuropathy, nausea, loss of

appetite) can profoundly affect quality of life and ability to perform role functions and activities of daily living (Low et al., 2007; Luoma & Hakamies-Blomqvist, 2004; Osse et al., 2002).

Financial hardship is common for women with MBC and their families due to inability to work, high treatment costs, and inadequate medical insurance (Corneliussen-James, 2011; Low et al., 2007).

Beyond the physical effects of metastatic disease and its treatment, psychological and social functioning are often compromised (e.g., Low et al., 2007; Northouse et al., 2002). Rates of depression and anxiety are higher among women with MBC compared to those with early-stage disease, and clinically significant distress is often underdiagnosed and undertreated in this population (Caplette-Gingras & Savard, 2008; Greenberg, 2004; Okamura, Yamawaki, Akechi, Taniguchi, & Uchitomi, 2005; Turner, Kelly, Swanson, Allison, & Wetzig, 2005). Notably, depression in MBC patients is associated with decreased quality of life, poorer physical functioning, pain, and fatigue (Caplette-Gingras & Savard, 2008; Low et al., 2007). Women with MBC commonly experience distress related to making treatment-related decisions, coping with uncertainty, mortality, abandonment by close others and the medical team, loss of independence, and the impact of the cancer on loved ones (Low et al., 2007; Turner et al., 2005).

Women with MBC are also faced with social concerns, including managing communication with others regarding their health status and decreased ability to engage in usual social activities (Low et al., 2007; Luoma & Hakamies-Blomqvist, 2004). Women may want to keep close others updated on their status but may lack energy, anticipate unhelpful responses, or fear becoming a burden. Some women may feel the need to maintain a positive attitude and protect family and friends from the reality of their prognosis, suffering, and fears (Low et al., 2007; Osse et al., 2002). Furthermore, pain, fatigue, and other symptoms may prevent women

with MBC from participating in cherished activities with loved ones. These challenges can contribute to social isolation, which is detrimental to health and well-being in cancer (Lutgendorf & Sood, 2011). Additionally, lack of contact with or support from others who also are undergoing MBC can contribute to feelings of isolation (Low et al., 2007; Mayer & Grober, 2006).

### **Need for Evidence-Based Psychosocial Treatments for Women With MBC**

Despite the striking burden of MBC, few psychosocial randomized controlled trials have specifically targeted individuals with metastatic disease (Low et al., 2007; Moyer et al., 2009). Whereas more than 500 intervention studies have been conducted primarily in adults with early-stage cancer (Moyer et al., 2009), a systematic review of psychosocial interventions for patients with advanced cancer conducted between 1990 and 2002 found only 13 trials (Uitterhoeve et al., 2004). These and several more recent trials (e.g., Aranda et al., 2006; Breitbart et al., 2015; Butler et al., 2009; Gotay et al., 2007; Kissane et al., 2007; Northouse, Kershaw, Mood, & Schafenacker, 2005; Rose, Radziewicz, Bowman, & O'Toole, 2008; Savard et al., 2006) used a range of intervention approaches, including cognitive behavioral therapy and supportive expressive therapy, and showed promise for improving psychosocial outcomes. However, the interventions typically involved multiple in-person sessions extending over weeks or months. Physical symptoms, limited mobility, and intensive medical treatment schedules may prevent women with MBC from accessing traditional psychosocial interventions (Low et al., 2007). Indeed, women who may benefit most from in-person psychosocial interventions (i.e., the most distressed; Goodwin et al., 2001) may be unable to participate in them. Thus, efficient and effective evidence-based psychosocial interventions tailored to the concerns and restrictions of women with MBC are urgently needed.

Emotionally expressive writing is an accessible psychosocial intervention for women with MBC with potential for wide dissemination because it can be done at home at the patient's convenience (Corter & Petrie, 2011; Low et al., 2007; Low, Stanton, Bower, & Gyllenhammer, 2010). Research regarding the utility of expressive writing for patients with metastatic disease, however, is limited and results are not entirely consistent (Corter & Petrie, 2011). Expressive writing trials in metastatic cancer patients have demonstrated salutary effects on outcomes such as improved sleep quality and vigor (de Moor et al., 2002), increased utilization of mental health services (Mosher et al., 2012), and reduced intrusive thoughts (among individuals with low levels of emotional support; Low et al., 2010). The current study aimed to provide a vehicle for emotional expression and receipt of social support during MBC using the Internet, a widely utilized resource for health-related information and communication (Murero & Rice, 2013).

### **The Internet and Cancer-Related Communication**

Besides its function as a vast source of cancer-related information, the Internet is a vehicle for bolstering social support from loved ones and other individuals diagnosed with cancer (Bessière, Pressman, Kiesler, & Kraut, 2010; Fogel, Albert, Schnabel, Ann Ditkoff, & Neugut, 2003; Stanton et al., 2013). Online support groups for cancer are much more prevalent than for other illnesses (Davison, Pennebaker, & Dickerson, 2000). Furthermore, evidence suggests that online cancer support groups may improve adjustment (Hoey, Ieropoli, White, & Jefford, 2008; Lieberman & Goldstein, 2005; Ruland et al., 2013). The Comprehensive Health Enhancement and Support System (CHESS), an online program providing information and support for breast cancer patients, has demonstrated psychosocial benefit (Baker et al., 2011; Gustafson et al., 2001; Gustafson et al., 2005). Additionally, a randomized controlled trial of an online support group for women with breast cancer demonstrated significant decreases in

depressive symptoms, perceived stress, and cancer-related intrusive thoughts for women in the intervention group (Winzelberg et al., 2003). Despite these promising results, randomized controlled trials of online cancer support groups and formal evaluation of existing groups are lacking (Beatty & Lambert, 2013; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Klemm et al., 2003).

Although personal websites are widely used by individuals with cancer to manage communication and support (e.g., caringbridge.org, csncancer.org, mylifeline.org, carepages.com), to our knowledge only three studies have examined cancer-related websites written by women with breast cancer, including the original PCO trial (Stanton et al., 2013). A quantitative content analysis of 50 personal websites written by women with breast cancer found that women often provided detailed and emotional narratives of their experience (Pitts, 2004). Another study described the development of a program called Facebook Connect, which was designed collaboratively with breast cancer patients; however, evaluation of the program was not discussed (Skeels, Unruh, Powell, & Pratt, 2010). Personal websites are a potentially highly accessible, low-cost method for facilitating communication and emotional expression and, in turn, promoting positive adjustment to breast cancer.

### **Role of Peer Support in Adjustment to Cancer**

Social support (i.e., feeling cared for, esteemed and valued, and part of a social network of mutual assistance; Wills & Fegan, 2001) is strongly associated with adjustment to breast cancer (Hoyt & Stanton, 2012), and, more specifically, to MBC (Northouse et al., 2002; Widows, Jacobson, & Fields, 2000). This evidence supports the stress-buffering hypothesis, which posits that perceived availability of social resources during the experience of stress prevents health-damaging responses to stressors and enables more effective coping (Cohen &

Wills, 1985). Perceived availability of social support during breast cancer may bolster confidence in one's ability to cope with the challenges of the cancer experience, promote approach-oriented coping, provide a vehicle for emotional expression, and lead to lower perceived stress and more adaptive emotional, behavioral, and physiological responses (Lazarus & Folkman, 1984; Taylor, 2011; Thoits, 1986; Uchino, 2006).

The matching hypothesis (Cutrona & Russell, 1990) posits that social support is most helpful when it fits an individual's needs and desires. Due to their similar experiences, women with MBC may be in a unique position to provide effective support to one another (Vilhauer, 2009; Wortman & Lehman, 1985). Peer support (i.e., social support provided to individuals with cancer by others who have also experienced cancer; Gray, Fitch, Davis, & Phillips, 1997) may foster universality and altruism, factors theorized as key to therapeutic change in group settings (Yalom, 1995). Universality refers to the sense that one is not alone in a difficult circumstance; in a group of similar others, individuals are hypothesized to gain comfort from learning that their experience is not unique. Helping others (i.e., altruistic behavior) is hypothesized to benefit group members by instilling a sense of purpose, distracting from one's own problems, enhancing perceived self-efficacy, and cultivating positive emotional states (Midlarsky, 1991).

Many women with breast cancer participate in peer support groups (Davison et al., 2000), and randomized controlled trials have demonstrated significant benefits of peer support for psychological functioning and perceived social support (Campbell et al., 2004; Gustafson et al., 2001; Winzelberg et al., 2003). Evidence regarding the efficacy of breast cancer peer support groups to improve outcomes, however, is not entirely consistent (Helgeson, Cohen, Schulz, & Yasko, 2000; Hoey et al., 2008; Salzer et al., 2010; Ussher et al., 2006). Peer support groups may be more effective for those who lack support from their partners (Helgeson et al., 2000).

Moreover, peer discussions, particularly those conducted online and without professional mediation, may be unsupportive, confrontational, and include misinformation (Campbell et al., 2004). Group members may feel misunderstood or uncomfortable sharing their feelings, and distress may increase following the death of a group member (Campbell et al., 2004; Gray et al., 1997). The current study aimed to test the potential benefits of sharing personal websites with other women with MBC enrolled in the study in order to decrease loneliness and facilitate peer support, universality, and altruism. Potentially harmful aspects of peer communication were addressed proactively during the PCO PLUS intervention session in an effort to promote helpful peer interactions.

### **Conceptual Model for the Study**

The conceptual model for the current comparative effectiveness study, depicted in Figure 2-1, is based on theory and research in peer support and adjustment to cancer. Women with MBC participated in a three-hour hands-on workshop to create personal websites to communicate with others and develop a narrative of their experience. Women were randomly assigned to either participate in a one-on-one workshop with research staff and to share their personal websites with family and friends (PCO ONLY condition), or to participate in a group workshop with two to seven other women with MBC and to share their personal websites with family, friends, and the other women attending their workshop (PCO PLUS condition). Women in the PCO PLUS condition were encouraged to communicate with one another via their websites throughout the duration of the study.

Participants in both conditions were expected to evidence improved psychosocial and physical health-related adjustment. Furthermore, based on theory and empirical evidence, we expected that women randomly assigned to the PCO PLUS condition would experience greater

improvements in outcomes than women in the PCO ONLY condition due to increased peer support, decreased loneliness, and enhanced perceived universality and altruism.

**Mediator variables.** Few psychosocial interventions for adults with cancer have examined mechanisms of the interventions' effects (i.e., how the interventions achieved their effects; Moyer et al., 2012; Stanton, Luecken, MacKinnon, & Thompson, 2013). Identifying variables that mediate the effects of PCO PLUS will advance theory and knowledge regarding peer support and adjustment to cancer and inform future psychosocial interventions for women with MBC to enhance efficacy and efficiency (Stanton, Luecken, et al., 2013).

**Peer support.** As described previously, social support is a strong predictor of positive adjustment to cancer (Hoyt & Stanton, 2012; Northouse et al., 2002; Widows et al., 2000). Social support may buffer the negative impact of a serious life stressor on psychological and physical health (Cohen & Wills, 1985). The matching hypothesis suggests that support is most effective when it aligns with the needs and desires of the individual experiencing stress (Cutrona & Russell, 1990). Thus, women with MBC may be well-suited to support one another. Indeed, evidence suggests that peer support from others diagnosed with cancer can be helpful (Campbell et al., 2004; Gustafson et al., 2001; Winzelberg et al., 2003). However, social support has received little empirical attention as a potential mediator of psychosocial interventions for individuals with cancer (Stanton, Luecken, et al., 2013). The PCO PLUS condition was hypothesized to enhance peer support by facilitating communication among women diagnosed with MBC; PCO ONLY was not expected to produce an increase in peer support.

**Decreased loneliness.** Social isolation and loneliness are associated with poor health outcomes in the general population (Hawkey & Cacioppo, 2010) and, more specifically, in cancer patients (Jaremka et al., 2013; Lutgendorf & Sood, 2011; Widows et al., 2000). A meta-

analysis found that psychosocial interventions can reduce loneliness (Masi, Chen, Hawkley, & Cacioppo, 2010). The current study was hypothesized to decrease loneliness for women in both conditions by facilitating communication and support. We predicted that, due to enhanced support from other women with MBC, women in the PCO PLUS condition would evidence a greater decrease in loneliness than women in the PCO ONLY condition.

**Universality.** According to Yalom's (1995) factors of therapeutic change model, universality (i.e., the recognition that one is not alone in his or her experience) is an important mechanism of change in group therapy settings. Universality may be particularly valuable for individuals with cancer because of its potential to reduce feelings of isolation and foster willingness to share personal experiences and express emotions (Singer, 1983). Evidence suggests that cancer patients in support groups identify universality as an important part of their group experience (Magen & Glajchen, 1999; Roberts, Piper, Denny, & Cuddeback, 1997; Vilhauer, 2009; Weinberg, Uken, Schmale, & Adamek, 1995), but investigation of universality as a potential mechanism of change in psychosocial interventions for cancer patients is lacking.

Women with MBC may feel that their experience is unique due to lack of contact with others who have experienced MBC. The current research was designed to enhance perceived universality for women in the PCO PLUS condition by connecting them with other MBC patients whose experiences may be similar to their own. An increase in universality was expected to mediate improved psychosocial and physical adjustment for women in PCO PLUS but not for those in PCO ONLY.

**Altruism.** Whereas the health benefits of receiving social support, love, and compassion are well documented, empirical examination of the potential benefit of helping others is more recent (Post, 2005). Evidence suggests that altruism (i.e., behaviors motivated by concern for the

welfare of another, rather than by anticipation of rewards; Midlarsky & Kahana, 1994) is associated with psychological and physical health (when the helping is not experienced as overly taxing; Post, 2005). Midlarsky (1991) proposed several potential mechanisms for the relationship between altruism and health, including enhanced social integration, sense of purpose, and perceived self-efficacy; distraction from one's own problems; and cultivation of positive emotional states. Altruistic behaviors may also be associated with a dampened physiological stress response (e.g., Field, Hernandez-Reif, Quintino, Schanberg, & Kuhn, 1998), which may confer health benefits over time.

Although the original PCO trial was not designed to enable participants to help other women with breast cancer, 43% of women in the intervention arm of the trial expressed a desire to use their personal websites to support other women diagnosed with breast cancer (Harris et al., 2015). Following a longitudinal study of older adults which demonstrated that helping others, but not receiving help, was associated with increased longevity, Brown and colleagues (2003) posited that “if giving, rather than receiving, promotes longevity, then interventions that are currently designed to help people feel supported may need to be redesigned so that the emphasis is on what people do to help others.” Specific to the group therapy setting, Yalom (1995) proposed that altruism is a key mechanism of change and demonstrated that group members perceive altruism as an important part of the group therapy experience. Experimental research also demonstrates benefits of providing cancer-related peer support. In a randomized controlled trial of cancer survivors treated with hematopoietic stem cell transplant, expressive helping (i.e., helping others prepare for transplant by writing about one's own transplant experiences and providing advice and encouragement) reduced distress and improved physical symptoms among providers of support with moderate to severe survivorship problems (Rini et al., 2014). The

current study aimed to provide a vehicle for women randomly assigned to PCO PLUS to support other women with MBC, which was in turn expected to improve psychosocial and physical health outcomes.

**Predictors of change in intervention outcomes.** In the original PCO trial, several significant mediators of the intervention's effects were identified (Cleary & Stanton, 2015). Change in coping self-efficacy, loneliness, and social support from friends mediated the relationship between PCO and benefit on depressive symptoms. Change in coping self-efficacy mediated the relationship between PCO and enhanced positive mood, and change in social support from friends mediated the effect of the intervention on life appreciation. Due to the lack of a control condition in the current study, factors that are hypothesized to effect change equally in *both* conditions (i.e., support from friends, emotional expression, coping self-efficacy) cannot be examined as mediators. Based on theory and empirical evidence in social support, emotional expression, and self-efficacy as well as results of the original PCO trial, we expected that changes in social support from friends, emotional expression, and coping self-efficacy would predict improvements in adjustment for women in both conditions. We also examined whether observed effects varied by condition assignment.

***Social support.*** The stress-buffering model of social support suggests that perceived support promotes psychological and physical adjustment to a stressor by preventing negative cognitive, emotional, behavioral, and physiological responses (Cohen & Wills, 1985). The current study was designed to enhance support from women's existing social networks for women in both conditions by providing participants with a channel for sharing their experience and soliciting desired support. PCO aimed to facilitate well-matched support, hypothesized to be an important component of effective social support (Cutrona & Russell, 1990). Based on

findings of the original PCO trial (Cleary & Stanton, 2015; Harris et al., 2015), we predicted that women in both conditions would perceive an increase in support from friends, the most frequent visitors to personal websites in the original trial.

***Emotional expression.*** Correlational and experimental research demonstrate a link between cancer-related emotional expression and positive adjustment (e.g., Frattaroli, 2006; Owen et al., 2005; Stanton, Danoff-Burg, et al., 2000; Stanton, Danoff-Burg, Sworowski, et al., 2002). Although self-reported coping through emotional expression was not a significant mediator of PCO's effects in the original trial (Cleary & Stanton, 2015), higher use of positive and negative emotion words on women's websites was associated with better outcomes (Harris et al., 2015). Furthermore, a randomized controlled trial of a coping and communication-enhancing intervention for women with gynecological cancer found that emotional expression mediated the effect of the intervention on depressive symptoms (Manne et al., 2008). Overall, however, emotional expression is understudied as a potential mediator of the effects of psychosocial interventions for cancer patients (Stanton, Luecken, et al., 2013) and research regarding emotional expression and adjustment in the context of advanced cancer is limited (Low et al., 2007). Both PCO conditions were hypothesized to facilitate emotional expression by providing a vehicle (i.e., online journal) for women to write about their cancer experience and related feelings, which was expected to predict improvements in outcomes. Both self-reported and objective (i.e., use of emotion words in women's writing) measures of emotional expression were examined.

***Coping self-efficacy.*** The link between cancer-related coping self-efficacy (i.e., confidence in one's ability to manage the cancer experience) and adjustment is well documented (Arora et al., 2002; Merluzzi, Nairn, Hege, Martinez-Sanchez, & Dunn, 2001; Penedo et al.,

2003), and several psychosocial interventions for cancer patients have demonstrated that increased coping self-efficacy mediates intervention effects on outcomes including depressive symptoms, positive affect, benefit finding, and physical functioning (e.g., Antoni et al., 2006; Hawkins et al., 2010; Penedo et al., 2004; Penedo et al., 2006; Scheier et al., 2005). Coping self-efficacy significantly mediated the effects of the original PCO intervention on depressive symptoms and positive mood (Cleary & Stanton, 2015). In the current study, we expected that creation and maintenance of personal websites would increase perceived ability to cope with stressors related to MBC, which would in turn predict improvements in outcomes.

**Outcome variables.** Dependent variables were selected to examine the effects of the intervention on measures of general and cancer-specific negative and positive psychosocial adjustment as well as physical health-related adjustment. Research regarding positive adjustment to cancer and other stressful life events is limited in comparison to investigation of indicators of negative adjustment (Cohen & Pressman, 2006; Folkman & Moskowitz, 2000; Hoyt & Stanton, 2012), yet many individuals adjust well and even experience personal growth following serious stressors including diagnosis of MBC (Jim & Jacobsen, 2008; Moreno & Stanton, 2013; Stanton, Bower, & Low, 2006). Moreover, despite evidence suggesting that psychosocial interventions can improve physical adjustment to cancer (e.g., Butler et al., 2009; Savard et al., 2006), the original PCO trial (Stanton et al., 2013) did not assess changes in physical health-related outcomes. In addition to evaluating psychological distress, positive adjustment and physical health-related outcomes should be considered in order to assess adjustment to living with MBC comprehensively (Low et al., 2007).

**General psychosocial adjustment.** As discussed previously, rates of depression for women living with MBC are elevated and are associated with poor physical functioning and

adjustment (Caplette-Gingras & Savard, 2008; Greenberg, 2004; Low et al., 2007; Turner et al., 2005). Breast cancer patients who participated in the original PCO trial, and particularly those who were in active oncologic treatment, evidenced significant benefit on depressive symptoms (Stanton et al., 2013). Therefore, depressive symptoms were selected as the primary outcome of interest in the current study. Negative mood was assessed as a secondary outcome. Negative mood is a core feature of depression, and measures of negative mood capture a wider array of affective states (e.g., afraid, ashamed) than symptom-based measures of depression.

Symptoms of anxiety, another important marker of psychological adjustment, are also elevated among women with MBC (Fulton, 1998; Okamura et al., 2005). PCO has the potential to improve symptoms of anxiety by bolstering cancer-related coping self-efficacy (Bandura, 1988) and engaging effective social support (Hipkins, Whitworth, Tarrier, & Jayson, 2004).

Positive mood was selected as a measure of positive psychological adjustment. A growing body of literature has demonstrated a link between positive mood and better physical health, stronger social ties, better health behaviors (e.g., exercise), and lower levels of stress hormones (i.e., cortisol, epinephrine, norepinephrine) in healthy adults (Cohen & Pressman, 2006; Pressman & Cohen, 2005). Increasing positive mood could have important health implications for women diagnosed with MBC. Women with breast cancer who participated in the intervention arm of the original PCO trial evidenced significant benefit on positive, but not negative, mood (Stanton et al., 2013).

***Cancer-specific psychosocial adjustment.*** Cancer-specific psychosocial adjustment was assessed in the current study using measures of cancer-related intrusive thoughts and perceived personal growth (i.e., strengthened relationships, life appreciation). Cancer-related intrusive thoughts negatively influence the trajectory of pain, depressive symptoms, negative affect, and

physical functioning among breast cancer survivors (Dupont, Bower, Stanton, & Ganz, 2014). Evidence suggests that social support, a target of the current research, can buffer the negative consequences of cancer-related intrusive thoughts (Lewis et al., 2001). The original trial of PCO, however, did not significantly reduce cancer-related intrusive thoughts (Stanton et al., 2013).

Strengthened relationships and enhanced life appreciation are important markers of personal growth following a cancer diagnosis (Tedeschi & Calhoun, 1996). Despite facing significant physical and psychosocial challenges, many women with MBC find personal growth in their experience (Low et al., 2007; Moreno & Stanton, 2013). Whereas personal growth in the broader cancer context is generally associated with positive psychosocial adjustment (Algoe & Stanton, 2009; Tomich & Helgeson, 2012), personal growth in the context of metastatic disease is related to both distress (e.g., depressive symptoms, cancer-related intrusive thoughts) and positive adjustment (e.g., positive affect, optimism; Moreno & Stanton, 2013). The original PCO trial had a significant positive impact on life appreciation among women in the intervention arm (Stanton et al., 2013) through increased social support from friends (Cleary & Stanton, 2015), but not on strengthened relationships. Investigation of the current intervention's effects on measures of personal growth among women with MBC is warranted.

***Physical adjustment.*** As discussed above, MBC and its treatment can have a profound negative impact on physical symptoms and functioning (Low et al., 2007; Luoma & Hakamies-Blomqvist, 2004; Osse et al., 2002). Psychosocial interventions for women with MBC have demonstrated improvements in pain (Butler et al., 2009), fatigue, and insomnia (Savard et al., 2006), suggesting that indicators of physical health-related adjustment are amenable to change via psychosocial intervention. PCO may influence measures of physical health (i.e., cancer-related physical symptoms, pain, insomnia, fatigue) and functioning through enhanced social

support and decreased loneliness (Helgeson & Cohen, 1996; Lutgendorf & Sood, 2011), increased emotional expression (Stanton, Danoff-Burg, Sworowski, et al., 2002), and increased cancer-related coping self-efficacy (Scheier et al., 2005).

### **Aims of the Study**

**Aim 1.** The first aim of the current study was to examine the intervention's effects on psychosocial and physical health-related adjustment.

*Hypothesis 1a.* We predicted that women in both the PCO ONLY and PCO PLUS conditions would demonstrate improvements in psychosocial and physical health-related adjustment from baseline to four-month follow-up.

*Hypothesis 1b.* We hypothesized that women in PCO PLUS would demonstrate greater benefits than women in PCO ONLY due to increased peer support, universality, and altruism, and decreased loneliness.

**Aim 2.** The study's second aim was to examine mediators of the effects of PCO PLUS, compared with PCO ONLY, on psychosocial and physical health-related adjustment.

*Hypothesis 2.* We hypothesized that increased social support from other women with MBC, enhanced perceived universality and altruism, and decreased loneliness would mediate the effects of PCO PLUS (compared with PCO ONLY) on outcomes.

**Aim 3.** The third aim of the current study was to examine predictors of improved psychosocial and physical health-related adjustment from baseline to four-month follow-up in PCO ONLY and PCO PLUS, and whether effects of predictors varied by condition assignment.

*Hypothesis 3.* We hypothesized that increases in coping self-efficacy, emotional expression, and social support from friends from baseline to two months would predict improvements in adjustment over the study period in both conditions. In the original PCO trial,

coping self-efficacy, social support from friends, and objectively measured emotional expression (i.e., positive and negative word use on women's websites) were associated with benefits on outcomes (Cleary & Stanton, 2015; Harris et al., 2015). We did not expect the effects of predictors to vary by condition assignment.

**Aim 4.** The fourth aim of the current study was to characterize women's website use, including frequency of use, number of posts to websites, perceived usefulness and satisfaction with websites, and whether website use varied by condition assignment. We also aimed to examine whether demographic and cancer-related variables predicted website use (i.e., website use within one month of the workshop [yes/no], total number of posts over the study period, total word count of posts over the study period).

**Hypothesis 4a.** Consistent with findings from the original PCO trial (Harris et al., 2015), we predicted that women would use their websites most in the first month following the intervention session, with subsequent tapering of use. However, it is possible that weekly email reminders to encourage website use may have bolstered engagement in the current study.

**Hypothesis 4b.** We hypothesized that women in PCO PLUS would evidence greater website use (i.e., frequency, number of posts) and higher perceived website usefulness and satisfaction than women in PCO ONLY.

**Hypothesis 4c.** Advanced cancer stage was the only significant predictor of website use in the original PCO trial (Harris et al., 2015); all participants in the current study had metastatic disease. Thus, examination of demographic and cancer-related variables as predictors of website use was exploratory.

## **Methods**

### **Participants**

Thirty-five women diagnosed with MBC were recruited to participate in the study and 30 completed an intervention session (see Figure 2-2 for CONSORT flow diagram). Of the 30 women who attended an intervention session, 87% ( $n = 26$ ) completed the two-month assessment and 87% ( $n = 26$ ) completed the four-month assessment. The  $n_{\text{effective}}$  technique was used to calculate power to find effects with the current sample size (Snijders & Bosker, 2012). This approach accounts for the repeated measures nature of the study design and effectively determines the equivalent single-level sample corresponding to a multilevel design. First, the design effect was computed [design effect =  $1 + (\text{number of observations per subject} - 1)\rho$ ], where  $\rho$  = the intraclass correlation. In the current study,  $\rho = .64$  for depressive symptoms, the main outcome variable. The current study had three observations per subject (i.e., baseline, two months, four months). Thus, the design effect for the current study was 2.28. Then,  $n_{\text{effective}}$  was computed ( $n_{\text{effective}} = \text{single-level sample size}/\text{design effect}$ ). G\*Power was used to determine the necessary sample size if the study was single-level (Faul, Erdfelder, Lang, & Buchner, 2007). To find large effects (Cohen's  $f = .40$ ; Cohen, 1992) in an ANCOVA model with 80% power, the necessary single-level sample size was  $N = 52$ , which is equal to an  $n_{\text{effective}}$  of 23. To find medium effects (Cohen's  $f = .25$ ) in an ANCOVA model with 80% power, the necessary single-level sample size was  $N = 128$ , or an  $n_{\text{effective}}$  of 56. Thus, with a repeated measures design, it is estimated that the current sample size of 30 is adequately powered to detect large effects in multilevel analyses. A total sample size of 64 women would be needed in order to detect medium effects, assuming 87% retention (56 study completers) at two and four months.

Eligibility criteria included: (1) women at least 18 years of age; (2) first diagnosis of stage IV breast cancer or a recurrent diagnosis of MBC (i.e., spread to distant organs), any interval since diagnosis; (3) ability to engage in self-care activities (i.e., dressing, bathing), (4)

ability to complete the intervention and assessments in English; (5) interest in designing a personal website about the cancer experience, and (6) ability and willingness to attend an in-person workshop located in Los Angeles or Orange County, California. Any medical treatment for breast cancer was allowed. Computer or Internet experience was not required. Participants were required to complete baseline questionnaires within one month of receipt.

Exclusion criteria included: (1) male (because men constitute less than 1% of breast cancer patients, numbers would not be sufficient for reliable analyses) and (2) local (i.e., same breast, surgical scar, chest wall) or regional (i.e., lymph nodes) recurrent disease.

### **Procedure**

University of California, Los Angeles Institutional Review Board approval was obtained prior to the initiation of study recruitment. Participants were recruited through several avenues, including (1) flyers distributed to locations frequented by women with MBC (e.g., oncology clinics, cancer support clinics); (2) flyers and announcements at community events concerning MBC (e.g., Susan G. Komen Los Angeles MBC Conference, Susan G. Komen Race for the Cure, Simms/Mann UCLA Center for Integrative Oncology Insights into Cancer Lecture Series); (3) email listserv announcements (e.g., Simms/Mann UCLA Center for Integrative Oncology monthly newsletter); (4) letters mailed to MBC patients of a local breast oncology practice; and (5) an e-blast posting to Dr. Susan Love Research Foundation Army of Women, an online registry for participation in breast cancer research. Treating physicians were unaware of patients' participation. Women indicated interest in the study by calling or emailing research staff or providing their contact information at events.

Women were screened for eligibility over the phone by research staff following a standard verbal script (see Appendix B). After a cohort of at least eight eligible women was

gathered, women were emailed links to complete informed consent and baseline questionnaires on the Qualtrics website (see Appendix B for informed consent and measures in the Public Domain). After completing baseline questionnaires, participants were randomized. A random allocation sequence was generated by a biostatistician uninvolved in the trial. To ensure even assignment of participants to conditions within each recruitment wave, randomization of consecutive women enrolled in the study was done in blocks of two, with a 1:1 ratio of assignment to PCO ONLY or PCO PLUS.

After randomization, participants were called by research staff to schedule the intervention session (i.e., workshop). Two and four months after the workshop, women were emailed follow-up online questionnaires. The two-month assessment was timed to capture change in potential mediating variables; in the original PCO trial, follow-up at one month was insufficient to capture change in proposed mediators (Cleary & Stanton, 2015). The four-month assessment was timed to capture effects of PCO as well as change in mediators. A shorter four-month follow-up was selected for the current study, compared with the six-month follow-up in the original PCO trial, due to the poorer prognosis of women with MBC. Participants received \$30 in gift cards per assessment they completed, for a potential total of \$90.

**PCO intervention.** Development of the original PCO trial was informed by several phases of research (Stanton et al., 2013). First, semistructured interviews were conducted with eight women with breast cancer who had created personal websites related to the cancer experience. Second, focus groups with seven breast cancer patients who did not have personal websites assessed potential barriers to and preferences for creating cancer-related websites. Third, after development of the website templates, a manual, and the workshop, a pilot intervention session with four breast cancer patients was conducted to obtain feedback.

The original randomized controlled trial of PCO was conducted with 88 women with breast cancer (any stage, any interval since diagnosis). Women were randomly assigned to a waiting-list control condition or to participate in a three-hour workshop for hands-on creation of personal websites to communicate with family and friends. Participants completed baseline questionnaires prior to randomization and follow-up assessments at one and six months.

The current study used the WordPress website and blogging platform (WordPress.com) to develop personal websites for each participant. Website templates were standardized to include the following identical functions: (1) a journal (i.e., blog) that could contain photos; (2) an About Me page; (3) a section for external website links (the researchers provided a list of potential websites [e.g., Breast Cancer Research Foundation]); (4) a My Special Requests page for participants to indicate their preferences for receiving support; (5) a How You Can Help page containing a calendar for participants to indicate actions visitors could undertake (e.g., meal provision, transportation to medical appointments); (6) a Contact Me section, where visitors could contact participants with a private message; (7) instructions for website visitors to subscribe for automatic notification of website updates; (8) an online survey for visitors to complete regarding their experience of the website; and (9) choice of privacy settings (i.e., password protection for website visitor access).

The three-hour intervention sessions were conducted by trained post-baccalaureate research staff members in a private conference room on the UCLA campus or at a breast oncology practice in Orange County. Participants used their own laptops or researcher-provided laptops during the workshop. For participants randomized to the PCO PLUS condition, the intervention was delivered by two research staff members to a group of two to four participants ( $M = 2.8$ ), along with significant others if participants chose to invite them. For participants

randomized to PCO ONLY, the intervention was delivered individually by one research staff member, along with significant others if the participant chose to invite them. Five women in PCO PLUS and four women in PCO ONLY brought a significant other to the workshop (five brought their husbands, three brought a daughter, and one brought a friend).

All workshops involved (1) a description of functions of personal websites (e.g., to manage communication, keep others informed, chronicle the cancer experience) and discussion regarding women's goals for their websites; (2) proactive discussion of common concerns about maintaining a personal website (e.g., perceived pressure to post frequently or convey only positive content); (3) demonstration of all website functions (i.e., journal, About Me page, Contact Me page, My Special Requests page, posting photos and links, How You Can Help calendar, managing subscribers, visitor survey, privacy settings); (4) hands-on creation of personal websites, which involved choosing a template, creating a website title, and posting the first journal entry; and (5) discussion of how to introduce the website to others.

Women were instructed on how to share their websites with family and friends (PCO ONLY condition) or family, friends, and the other women with MBC attending the workshop (PCO PLUS condition). For women in PCO PLUS, the workshop also included instructions for visiting other participants' websites and discussion of recommended ways to support other participants (e.g., providing encouragement, avoiding hurtful language). Following the workshop, women in PCO PLUS were emailed instructions for accessing the websites of the other women who attended their workshop. To promote continued engagement, women in PCO PLUS also received automatic email notifications when other women posted to their websites.

All participants were provided a manual with written and visual instructions for maintaining the websites, which was developed for the original PCO trial and was modified for

use in the current study. Participants were also provided with a phone number and email address to contact research staff for technical support. As scheduled during the intervention session, research staff called participants in both conditions one week later to respond to questions and promote website use. As in the original PCO trial (Stanton et al., 2013), conversations lasted no more than 15 minutes. Additionally, standardized personalized emails were sent to participants each week to encourage website use (see example in Appendix B). Emails to women in PCO PLUS included links to the websites of the other women who attended their workshop.

## **Measures**

Demographic and cancer-related variables were assessed at baseline. Cancer-related variables were also assessed at two- and four-month follow-up. Outcome and mediator variables were assessed at baseline and two and four months. Website use variables were assessed at two and four months (see Appendix B). Fidelity to the intervention session (i.e., adherence to the session's intended delivery) was assessed using a 19-item author-constructed measure (adapted from Stanton et al., 2013; see Appendix B). Intervention sessions were audio-recorded with informed consent from participants. Research staff uninvolved in PCO performance rated eight randomly selected audio recordings of the intervention sessions (four from each condition) on each yes/no item (e.g., “discussed common concerns about using a website and how these can be proactively addressed,” “explained privacy settings”).

**Demographic and cancer-related variables.** At baseline, demographic and cancer-related variables were assessed via self-report. Cancer-related variables were re-assessed at two and four months. Evidence suggests that breast cancer patients' self-report regarding treatment and disease status (i.e., type of treatment, location of recurrence) is very accurate (>90%

agreement between self-report and medical records; Phillips et al., 2005; Stanton, Danoff-Burg, Sworowski, et al., 2002).

Demographic and cancer-related variables included age, race/ethnicity, education, total annual household income, employment status, partner status, date of first breast cancer diagnosis, date of MBC diagnosis, menopausal status prior to first breast cancer diagnosis, de novo metastatic disease (yes/no), number of metastatic sites, and current treatment(s) being received. In addition, number of diagnosed medical comorbidities was assessed at baseline using the Functional Comorbidity Index (Groll, To, Bombardier, & Wright, 2005). Women indicated (yes/no) whether they had been diagnosed with each of 16 medical conditions (e.g., arthritis, high blood pressure, diabetes). Perceived functional status was assessed at baseline with the self-rated Karnofsky Performance Status Scale (KPS; Loprinzi et al., 1994). On a scale ranging from 1 (*normal, no complaints, no symptoms of disease*) to 8 (*severely disabled, require continuous nursing care*), women rated their current functional ability. Research has demonstrated that patient- and physician-rated KPS scores are similar and that patient-rated KPS scores are strong indicators of prognosis for cancer patients (Loprinzi et al., 1994). At two and four months, women reported whether tests had indicated disease progression since study baseline.

**Baseline Internet use.** At baseline, women reported on their frequency of accessing the Internet, number of hours per week spent online, and comfort level using a computer on a scale ranging from 1 (*very uncomfortable*) to 4 (*very comfortable*).

**Objective website use data.** Objective website use data included examination of whether women posted a new journal entry within one month of the workshop (yes/no), total number of journal entries posted during the four-month study period, and total word count of journal entries posted during the study period.

**Website use questionnaire.** A website use questionnaire developed in the original PCO trial (Stanton et al., 2013) was administered at two and four months. At two months, 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. Women 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*). Women also rated the usefulness of various website features (e.g., “writing and publishing posts,” “approving and replying to comments”) on the same scale. In free-response format, women described the most useful consequence of the website.

The website use questionnaire was re-administered at four months with the addition of the following items. Women rated how positive or negative their experience with the website was on scale ranging from 1 (*very negative*) to 7 (*very positive*). In a yes/no format supplemented by free-response, women indicated whether they experienced any challenges with or barriers to website use and whether they were surprised or disappointed by any aspect of using their websites. In a free-response format, women provided general feedback regarding website use.

At four months, women in the PCO PLUS condition indicated how often they had visited other participants’ websites during the past month on a scale ranging from 1 (*every day*) to 4 (*less than once a week*). Women indicated how often they had commented on other participants’ websites, sent private messages via the Contact Me page, and contacted participants outside of the websites. PCO PLUS participants also reported how often they had received communication from other women in the study via comments, private messages, and contact outside of the websites. Women in PCO PLUS indicated the extent to which they felt the other women in the study were (1) similar to them, (2) approachable, and (3) likeable on a scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Lastly, women rated how useful it was to visit the

websites of other women in the study on a scale ranging from 1 (*not at all*) to 5 (*extremely useful*) and provided a brief explanation regarding what was useful, or not useful, about visiting other women's websites.

**Dependent variables.** Assessed at baseline and two and four months, dependent variables included global and cancer-specific psychosocial adjustment as well as physical health-related adjustment.

**Depressive symptoms.** The primary outcome, depressive symptoms, was assessed using the 20-item Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). Participants indicated how they felt or behaved during the past week with regard to each item (e.g., "I was bothered by things that usually don't bother me") on a scale ranging from 0 (*rarely or none of the time; less than 1 day*) to 3 (*most or all of the time; 5-7 days*). The CES-D has demonstrated internal consistency reliability and construct validity with breast cancer patients (Hann, Winter, & Jacobsen, 1999). In the current study, internal consistency reliability was high at all assessments ( $\alpha = .91$  to  $.92$ ).

**Positive and negative mood.** The Positive Affect and Negative Affect subscales from the Positive and Negative Affect Schedule – X (PANAS-X; Watson, Clark, & Tellegen, 1988; Watson & Clark, 1999) were used to assess positive and negative mood states during the past week. Each subscale contains 10 items (e.g., "enthusiastic," "interested" for Positive Affect, "scared," "upset" for Negative Affect), which are rated on a 5-point scale (1 = *very slightly or not at all*, 5 = *extremely*). The PANAS-X has demonstrated internal consistency reliability in prior studies with cancer patients (e.g., Carpenter, Johnson, Wagner, & Andrykowski, 2002). In the current study, internal consistency reliability was high at all assessments for both positive ( $\alpha = .91$  to  $.93$ ) and negative ( $\alpha = .87$  to  $.94$ ) mood.

**Anxiety.** Symptoms of generalized anxiety were assessed using the seven-item Generalized Anxiety Disorder Scale (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006), which has demonstrated internal consistency reliability in cancer patient samples (e.g., Kroenke et al., 2010) and is sensitive to change following psychosocial intervention for cancer patients (e.g., Johns et al., 2015). Participants rated how often they were bothered by each symptom (e.g., “worrying too much about different things”) during the past two weeks on a scale ranging from 0 (*not at all*) to 3 (*nearly every day*). This measure demonstrated excellent internal consistency at all assessment points ( $\alpha = .91$  to  $.95$ ).

**Personal growth.** Perceived personal growth following breast cancer diagnosis was assessed using the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) Appreciation of Life (e.g., “I have a greater appreciation for the value of my own life”) and Relating to Others (e.g., “I more clearly see that I can count on people in times of trouble”) subscales. Items were rated for the degree to which a change has occurred as a result of the cancer experience on a scale ranging from 0 (*I did not experience this change*) to 5 (*I experienced this change to a very great degree*). The PTGI has demonstrated internal consistency reliability and concurrent, discriminant, and construct validity (Tedeschi & Calhoun, 1996) as well as internal consistency reliability in samples of women with breast cancer (e.g., Sears, Stanton, & Danoff-Burg, 2003; Stanton et al., 2013; Tomich & Helgeson, 2012). In the current study, internal consistency reliability was adequate at all assessments for the Appreciation of Life ( $\alpha = .69$  to  $.87$ ) and Relating to Others ( $\alpha = .89$  to  $.93$ ) subscales.

**Cancer-related intrusive thoughts.** The seven-item Intrusion subscale of the Impact of Event Scale – Revised (IES-R; Horowitz, Wilner, & Alvarez, 1979; Weiss, 2007) was used to assess cancer-related intrusive thoughts. Respondents rated how often they had experienced each

item (e.g., “I thought about it when I didn’t mean to”) in relation to cancer during the past week on a scale ranging from 0 (*not at all*) to 4 (*extremely*). This measure is frequently used in breast cancer patient samples and has demonstrated internal consistency reliability (e.g., Cordova, Cunningham, Carlson, & Andrykowski, 2001; Sears et al., 2003; Stanton et al., 2013). In the current study, internal consistency reliability was high at all assessments ( $\alpha = .90$  to  $.93$ ).

***Cancer-related physical symptom bother.*** Physical symptoms related to cancer and its treatment were assessed using the 18-item Breast Cancer Prevention Trial (BCPT) Symptom Scales (Stanton, Bernaards, & Ganz, 2005), with four items added to assess fatigue and sexual problems. Respondents indicated how much they were bothered by each symptom (e.g., hot flashes, nausea) during the past four weeks on a scale ranging from 0 (*not at all*) to 4 (*extremely*). All items were averaged to yield an overall metric of bothersome physical symptoms, with higher scores indicating greater physical symptom bother. The BCPT was developed specifically to assess bother from common cancer and treatment-related side effects and symptoms among women with breast cancer and has demonstrated internal consistency reliability (e.g., Stanton et al., 2005) and discriminant validity (Cella et al., 2008). In the current study, internal consistency reliability was high at all assessments ( $\alpha = .83$  to  $.89$ ).

***Sleep disturbance.*** The four-item Sleep Disturbance scale from the Patient-Reported Outcomes Measurement Information System (PROMIS; Cella et al., 2007; Cella et al., 2010) was used to assess sleep difficulties. Respondents rated their sleep quality during the past week on a scale ranging from 1 (*very poor*) to 5 (*very good*) and sleep disturbance during the past week on a scale ranging from 1 (*not at all*) to 5 (*very much*). Items were summed, with higher scores indicating more sleep disturbance; two items (including sleep quality) were reverse coded. Internal consistency reliability was high at all assessments ( $\alpha = .87$  to  $.91$ ).

**Pain.** Pain was assessed using the PROMIS Pain Interference and Pain Intensity scales (Cella et al., 2007). On the four-item PROMIS Pain Interference scale (Amtmann et al., 2010), respondents rated how much pain interfered with daily activities (e.g., household chores) during the past week on a scale ranging from 1 (*not at all*) to 5 (*very much*). This scale has demonstrated good internal consistency reliability and construct validity in large samples of adults with different types of chronic pain (Revicki et al., 2009). On the three-item PROMIS Pain Intensity scale (Cella et al., 2010), respondents rated the intensity of their current pain, their average level of pain during the past week, and their worst pain during the past week on a scale ranging from 1 (*no pain*) to 5 (*very severe*). Items from each scale were summed; higher scores indicate greater levels of pain. Internal consistency reliability was high at all assessments for both the Pain Interference ( $\alpha = .93$  to  $.97$ ) and the Pain Intensity ( $\alpha = .79$  to  $.89$ ) scales.

**Physical functioning.** General physical functioning was assessed using the four-item PROMIS Physical Function scale (Cella et al., 2007; Cella et al., 2010). Respondents rated their current ability to perform various activities (e.g., run errands, shop) on a scale ranging from 1 (*unable to do*) to 5 (*without any difficulty*). Items were summed, with higher scores reflecting better functioning. Internal consistency reliability was high at all assessments ( $\alpha = .83$  to  $.89$ ).

**Fatigue.** Fatigue was assessed using the four-item PROMIS Fatigue scale (Cella et al., 2007; Cella et al., 2010). Respondents rated their fatigue (e.g., “How run-down did you feel on average?”) during the past seven days on a scale ranging from 1 (*not at all*) to 5 (*very much*). Items were summed; higher scores indicate greater levels of fatigue. Internal consistency reliability in the current study was high at all assessments ( $\alpha = .93$  to  $.97$ ).

#### **Mediator variables.**

**Peer support.** The Sources of Social Support Scale (SSSS; Carver, 2006) was used to assess perceived emotional, instrumental, and informational support from other women with MBC. Women rated how much support they received on 10 items (e.g., “how much do other women with metastatic breast cancer give you reassurance, encouragement, and emotional support concerning your breast cancer?”) ranging from 1 (*not at all*) to 5 (*a lot*). Items were averaged to produce a metric of total MBC-peer support. The SSSS has demonstrated internal consistency reliability in breast cancer patient samples (e.g., Cleary & Stanton, 2015; Kinsinger, Laurenceau, Carver, & Antoni, 2011). In the current study, internal consistency reliability was adequate at all assessments ( $\alpha = .65$  to  $.79$ ).

**Loneliness.** The UCLA Loneliness Scale (Russell, 1996) was used to assess loneliness. Items included, “How often do you feel you have nobody to talk to?” and “How often do you feel completely alone?” and were rated on a scale ranging from 1 (*I never feel this way*) to 4 (*I often feel this way*). Russell (1996) demonstrated the scale’s internal consistency reliability, convergent validity, and construct validity. The original PCO trial demonstrated high internal consistency reliability of the measure in breast cancer patients (Cleary & Stanton, 2015), and internal consistency reliability was high at all assessments in the current study ( $\alpha = .88$  to  $.95$ ).

**Universality.** Universality regarding the MBC experience was assessed using five items adapted from the Universality subscale of Yalom’s 60-item Therapeutic Factors Questionnaire (1995), which was developed for use in group therapy settings. A study of a computer-mediated support group for women with breast cancer demonstrated high internal consistency reliability for an adapted version of the Universality subscale (Weinberg et al., 1995). In the current study, respondents rated their agreement with each item (e.g., “I have learned I am not alone in my

experience with metastatic breast cancer”) on a scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Internal consistency reliability was adequate at all assessments ( $\alpha = .70$  to  $.78$ ).

**Altruism.** Similarly, MBC-related altruism was assessed using four items adapted from the Altruism subscale of Yalom’s 60-item Therapeutic Factors Questionnaire (1995). Weinberg and colleagues (1995) demonstrated high internal consistency reliability for an adapted version of the Altruism subscale in a sample of breast cancer patients. In the current study, respondents rated their agreement with each item (e.g., “I value helping other women with metastatic breast cancer”) on a scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Internal consistency reliability was adequate at all assessments ( $\alpha = .67$  to  $.82$ ).

**Predictors of Change in Outcomes.** Changes in social support from friends, cancer-related emotional expression, and coping self-efficacy from baseline to two months were examined as predictors of change in dependent variables over the four-month study period. Use of positive and negative emotion words on women’s websites was also examined as a predictor of change in outcomes over the study period. Differences in effects as a function of condition assignment were investigated.

**Social support from friends.** The Sources of Social Support Scale (SSSS; Carver, 2006) was used to assess perceived emotional, instrumental, and informational support from women’s friends. Women rated how much support they received on 10 items (e.g., “how much do your friends listen to and try to understand your worries about your breast cancer?”) ranging from 1 (*not at all*) to 5 (*a lot*). Items were averaged to produce a metric of total support from friends. The SSSS has demonstrated high internal consistency reliability in breast cancer patient samples (e.g., Cleary & Stanton, 2015; Kinsinger et al., 2011). In the current study, internal consistency reliability was adequate at all assessments ( $\alpha = .77$  to  $.89$ ).

**Emotional expression.** Self-reported emotional expression regarding cancer during the past four weeks was assessed using the Emotional Expression subscale of the COPE (Carver, Scheier, & Weintraub, 1989; Stanton, Kirk, Cameron, & Danoff-Burg, 2000). Four items (e.g., “I take time to express my emotions”) were rated on a scale ranging from 1 (*I don’t do this at all*) to 4 (*I do this a lot*). Previous research has demonstrated internal consistency reliability of the Emotional Expression subscale of the COPE in breast cancer patient samples (e.g., Stanton, Danoff-Burg, & Huggins, 2002; Stanton et al., 2013). Internal consistency reliability for this subscale was excellent at all assessments ( $\alpha = .92$  to  $.93$ ).

Use of positive emotion words (e.g., “joy”) and negative emotion words (e.g., “angry”) in website content posted during the four-month study period was analyzed with the computerized text analysis program, Linguistic Inquiry and Word Count (LIWC; Pennebaker, Chung, Ireland, Gonzales, & Booth, 2007) as a secondary measure of emotional expression. The LIWC program analyzes text files and computes the percentage of words in various content categories.

**Coping self-efficacy.** Cancer-related coping self-efficacy was assessed with the five-item Coping Confidence subscale and the three-item Getting Needs Met subscale of the Measure of Current Status (MOCS), which was specifically designed to investigate mediational processes in psychosocial interventions for adults with cancer and has demonstrated internal consistency reliability (Antoni et al., 2006; Carver, 2006; Penedo et al., 2004). Respondents rated their perceived ability to respond to challenges associated with cancer (e.g., “It’s easy for me to decide how to cope with whatever problems arise” from the Coping Confidence subscale and “I can clearly express my needs to other people who are important to me” from the Getting Needs Met subscale) on a scale ranging from 1 (*I cannot do this at all*) to 5 (*I can do this extremely well*). Items from each subscale were averaged to yield overall Coping Confidence and Getting Needs

Met scores. Internal consistency reliability was adequate at all assessments for both the Coping Confidence ( $\alpha = .65$  to  $.91$ ) and the Getting Needs Met ( $\alpha = .85$  to  $.91$ ) subscales.

### **Data Analysis**

Analyses included examination of changes in primary and secondary outcomes during the four-month study period, comparative efficacy analyses, mediation analyses of hypothesized mechanisms of PCO PLUS, investigation of predictors of the intervention's effects, and examination of website use variables. First, descriptive statistics were computed for demographic, cancer-related, and Internet use variables and are reported as frequencies and percentages. Descriptive statistics on major variables and correlations between variables were also computed. Cronbach's alpha for each measure at each assessment was calculated.

The randomized groups were compared on all baseline variables using  $\chi^2$  for categorical variables and  $t$  tests for continuous variables. Effect sizes of differences between conditions at baseline were also calculated. Effect sizes provide a measure of the magnitude of an effect, even in the absence of statistical significance, and are generally independent of sample size (Selya, Rose, Dierker, Hedeker, & Mermelstein, 2012). Effect sizes for  $\chi^2$  tests with dichotomous variables were estimated with Phi ( $\phi$ ); for  $\chi^2$  tests with variables with more than two categories, effect sizes were estimated with Cramer's  $V$  (small =  $.1$ , medium =  $.3$ , large =  $.5$  for both measures; Cohen, 1992). Effect sizes for continuous variables were estimated with Cohen's  $d$  (small =  $.2$ , medium =  $.5$ , large =  $.8$ ; Cohen, 1992). Participants retained at four months were compared with those lost to follow-up. Effect sizes of differences by study completion status also were examined. Hedges'  $g$ , an alternative to Cohen's  $d$  that accounts for unbalanced group sizes, was used to estimate effect sizes for continuous variables (small =  $.2$ , medium =  $.5$ , large =  $.8$ ; Hedges, 1981). Treatment fidelity was calculated as the percentage of protocol elements covered

during the intervention sessions, as rated by an independent research staff member uninvolved in PCO performance.

**Aim 1.** Due to the hierarchical nature of the data, with repeated assessments (Level 1) nested within participants (Level 2), multilevel modeling (MLM; Snijders & Bosker, 2012) was used to assess change in outcomes during the study period across conditions and to evaluate the influence of condition assignment (PCO ONLY versus PCO PLUS) on each outcome over time (i.e., baseline, two months, four months). To test random intercept and random linear slope terms, likelihood ratio tests (Hayes, 2006) were conducted. All significant variance and covariance components were retained in subsequent models. Unconditional models without predictors or covariates were estimated to examine the overall trajectory of each outcome over the study period. Then, models examining the effect of condition on each outcome across time were estimated. These models included the following predictors: time, condition, a time x condition interaction, and demographic and cancer-related variables on which any significant baseline imbalance was observed. Effect sizes were estimated with the proportional reduction in residual variance statistic (Peugh, 2010; Raudenbush & Bryk, 2002; Singer & Willett, 2003), which calculates the reduction in Level 1 variance after adding predictors to an empty model (i.e., a model without predictors). All MLM analyses were conducted in R version 3.3.2. No adjustment was made to correct for multiple statistical comparisons.

Intent-to-treat (ITT) analyses, in which participant data are analyzed in their assigned condition regardless of compliance, were conducted in order to maintain the prognostic balance generated by random allocation. However, due to the poor prognosis of this population, we expected some attrition due to significant deterioration in physical condition as well as death. Furthermore, women with MBC often experience a significant increase in reported distress and

pain prior to death (Butler et al., 2003), which may add variance to follow-up assessments that could obscure intervention effects. Therefore, we utilized a modified ITT analysis that excluded women who died prior to four-month follow-up.

**Aim 2.** Next, multilevel mediation analyses were conducted to evaluate hypothesized mediators (i.e., peer support, loneliness, universality, altruism) of the effects of PCO PLUS (versus PCO ONLY) on outcomes. Mediation analyses were conducted within an MLM framework, with the predictor variable (i.e., condition assignment) at Level 2 and the mediator and outcome variables at Level 1 (i.e., 2-1-1 mediation; Krull & MacKinnon, 2001). Models were estimated separately for each mediator. The indirect effect represents the effect of condition assignment on the outcome through the mediator variable. Quasi-Bayesian Monte Carlo simulations were used to produce confidence intervals for the indirect effect (Imai, Keele, & Tingley, 2010). Indirect effects are statistically significant if the confidence interval does not include zero. Even in the absence of significant intervention effects on outcomes, examination of indirect effects through mediators can inform future intervention development (MacKinnon, Lockwood, Hoffman, West, & Sheets, 2002; Stanton, Luecken, et al., 2013).

**Aim 3.** We then evaluated hypothesized predictors of change in outcomes. MLM was used to examine the separate effects of change in social support from friends, emotional expression, and coping self-efficacy from baseline to two months on outcomes over the study period (i.e., baseline, two months, four months). These analyses used data from both groups and included a time x predictor x condition interaction term (and all lower-order terms) in order to examine whether the effects of predictors varied by condition assignment. If the time x predictor x condition term was not significant, it was dropped and the time x predictor term was examined to determine whether change in predictors was significantly related to change in outcomes across

conditions. Predictor variables were centered at the grand mean of each respective variable to reduce multicollinearity.

**Aim 4.** Descriptive statistics were computed for website use variables (i.e., frequency of website use, number of journal posts to websites by month, perceived usefulness of websites) and are reported as frequencies and percentages. The randomized groups were compared on website use variables using  $\chi^2$  for categorical variables and  $t$  tests for continuous variables. To evaluate predictors of three indices of website use (i.e., posting to website within one month of the workshop [yes/no], total number of journal posts, total word count of journal posts) and whether predictors of website use varied by condition assignment,  $\chi^2$  tests, independent-samples  $t$  tests, and regressions were computed. Effect sizes of relationships between predictors and website use also were examined. Effect sizes for  $t$  tests were estimated using Cohen's  $d$ , effect sizes for  $\chi^2$  tests were calculated with  $\phi$  and Cramer's  $V$ , and effect sizes for regressions were calculated with  $R^2$  (small = .02, medium = .13, large = .26; Ellis, 2010).

## Results

### Participant Characteristics

On average, participants were 52.3 years old ( $SD = 7.6$ , range = 39-67 years; Table 2-1). Most were married (63%), college graduates (70%), and non-Hispanic white (70%). A minority of women were Latina (13%), African American (10%), or Asian American (7%). Nearly one-third of women were employed outside the home (30%), 40% were disabled or on medical leave, 17% were retired, 7% were unemployed, and 7% were homemakers. More than one-third had a total yearly household income under \$50,000 (37%); 40% had an income between \$50,000 and \$100,000, and 23% had an income above \$100,000. On average, women had one to two diagnosed medical conditions other than cancer on the Functional Comorbidity Index ( $M = 1.6$ ,

$SD = 1.7$ , range = 0-6; Groll et al., 2005) and characterized their functioning at baseline on the self-report KPS as able to perform “normal activity with effort, some symptoms of disease” ( $M = 2.8$ ,  $SD = 1.0$ , range = 1-5; Loprinzi et al., 1994).

Women were first diagnosed with breast cancer an average of 7.5 years prior to study entry ( $SD = 6.6$ , range = 0-25 years; Table 2-2) and were diagnosed with MBC an average of 2.8 years before study entry ( $SD = 2.8$ , range = 0-10 years). Approximately one-third of women were diagnosed with de novo stage IV breast cancer (30%). At study entry, women reported an average of 1.8 metastatic sites ( $SD = 1.0$ , range = 1-5), most commonly bone (60%), liver (33%), lung (30%), and brain (10%). A minority of women had gone through menopause prior to their first breast cancer diagnosis (17%). Regarding treatment, one-third of women had undergone surgery for treatment of MBC (33%). More than one-third were receiving chemotherapy at study entry (40%), and another 40% had completed chemotherapy for treatment of MBC prior to study entry. A small minority of women were receiving radiation at study entry (7%), and more than one-third of women had completed radiation for treatment of MBC (37%). Over half of women (57%) were receiving hormonal therapy at study entry (e.g., Tamoxifen), and 40% were receiving biologic therapy (e.g., Herceptin) at study entry. More than one-third of women (37%) reported disease progression between study entry and four-month follow-up. To our knowledge, no participants died during the four-month study period.

Internet use variables at baseline are displayed in Table 2-3. At study entry, participants reported that they spent an average of 12.3 hours per week online ( $SD = 9.4$ , range = 0-40 hours) and nearly all accessed the Internet daily (33%) or several times a day (63%). All women indicated that they were somewhat (23%) or very (77%) comfortable using a computer.

The randomized groups did not differ significantly (all  $P > .05$ ) at baseline on any demographic, cancer-related, Internet use, outcome, mediator, or predictor variable. Owing to small cell sizes, categories for the following variables were collapsed as follows in all analyses: race/ethnicity = white vs. other race/ethnicity; employment status = employed vs. not employed (includes unemployed, retired, homemaker) vs. disabled/on medical leave; frequency of accessing Internet = daily or less vs. several times a day; comfort level using a computer = somewhat comfortable vs. very comfortable. The effect sizes of differences between conditions on baseline variables also were examined; all differences with medium or large effect sizes are described below.

There was a marginally significant, medium to large difference between conditions on income ( $X^2(2) = 4.89, p = .09$ , Cramer's  $V = .40$ ). Compared with PCO ONLY participants, PCO PLUS participants were less likely to fall in the highest income category ( $> \$100,000$ ). There was a marginally significant, medium difference between conditions on receipt of biologic treatment ( $X^2(1) = 3.78, p = .07, \phi = .36$ ). PCO PLUS participants were less likely than PCO ONLY participants to be receiving biologic treatment at study baseline. There was a non-significant, medium difference between conditions on time since first breast cancer diagnosis ( $t(28) = 1.45, p = .16$ , Cohen's  $d = .54$ ) such that women in PCO PLUS tended to be diagnosed more recently than women in PCO ONLY. There was also a non-significant, medium difference between conditions on time since MBC diagnosis ( $t(27) = 1.67, p = .11$ , Cohen's  $d = .61$ ) such that PCO ONLY participants tended to be diagnosed with MBC more recently than PCO PLUS participants. There was a non-significant, medium difference between conditions on loneliness, a mediator variable, at study baseline ( $t(28) = 1.65, p = .11$ , Cohen's  $d = .60$ ) such that women in PCO PLUS tended to have higher loneliness ratings than women in PCO ONLY. Effect sizes for

differences between conditions at baseline were smaller than medium for all other variables examined (i.e., age, race/ethnicity, education, marital status, employment status, number of medical comorbidities, self-rated KPS, menopausal status, de novo MBC, number of metastatic sites, surgery for MBC, current chemotherapy, current radiation, current hormonal treatment, duration and frequency of Internet use, comfort using computers, CES-D, PANAS Negative Affect, PANAS Positive Affect, GAD-7, PTGI Life Appreciation, PTGI Relating to Others, IES-R, BCPT, PROMIS Sleep Disturbance, PROMIS Pain Interference, PROMIS Pain Intensity, PROMIS Physical Function, PROMIS Fatigue, SSSS Women with MBC, Universality, Altruism, SSSS Friends, COPE Emotional Expression, MOCS Coping Confidence, MOCS Getting Needs Met). Because the randomized groups did not differ significantly (all  $P > .05$ ) at baseline on any examined variable, no covariates were included in outcome analyses.

Baseline demographic, cancer-related, Internet use, and outcome variables did not differ significantly (all  $P > .05$ ) between participants who completed ( $n = 26$ ; 87%) or did not complete ( $n = 4$ ) the four-month assessment. Effect sizes of differences by study completion status also were examined; all differences with medium and large effect sizes are described below. There was a marginally significant, large difference between study completers and non-completers by time spent online at study baseline ( $t(23) = 1.92, p = .07$ , Hedges'  $g = 1.19$ ) and a non-significant, medium difference by baseline frequency of Internet use ( $X^2(1) = 2.92, p = .13, \phi = .31$ ). Study completers reported spending more hours online per week and accessing the Internet more often than non-completers. There were marginally significant, medium to large differences by ethnicity ( $X^2(1) = 4.45, p = .07, \phi = .39$ ) and education ( $X^2(1) = 4.45, p = .07, \phi = .39$ ). Women who did not identify as white were less likely to complete the four-month follow-up than white women, and women who did not graduate from college were less likely to complete the

study than college graduates. There was a non-significant, medium difference by income ( $X^2(2) = 3.48, p = .18, \phi = .34$ ) such that women with incomes below \$50,000 and above \$100,000 were less likely to complete the study than women with mid-range incomes. There was a medium to large, non-significant difference by number of comorbidities ( $t(26) = 1.09, p = .29, \text{Hedges' } g = .67$ ) such that study completers had fewer comorbid medical conditions compared with non-completers. Medium to large, non-significant differences in study completion emerged by self-rated KPS score ( $t(28) = 1.24, p = .23, \text{Hedges' } g = .66$ ) and number of metastatic sites ( $t(27) = .90, p = .38, \text{Hedges' } g = .55$ ) such that study completers reported poorer functioning and more metastatic sites, on average, compared with non-completers. Effect sizes of differences by study completion status were smaller than medium for all other demographic, cancer-related, and Internet use variables examined (i.e., age, marital status, employment status, menopausal status, de novo MBC, surgery for MBC, current chemotherapy, current radiation, current hormonal treatment, current biologic treatment, comfort using computers).

Regarding outcome variables, there were medium to large, non-significant differences in study completion by PTGI Life Appreciation ( $t(28) = 1.27, p = .22, \text{Hedges' } g = .68$ ), PTGI Relating to Others ( $t(28) = 1.02, p = .32, \text{Hedges' } g = .55$ ), and BCPT ( $t(28) = 1.40, p = .17, \text{Hedges' } g = .68$ ). Study completers reported greater life appreciation and strengthened relationships and lower treatment-related bothersome physical symptoms at baseline compared with women who did not complete the study. There were also medium, non-significant differences in study completion by PROMIS Sleep ( $t(26) = .96, p = .35, \text{Hedges' } g = .58$ ), Pain Interference ( $t(28) = 1.12, p = .27, \text{Hedges' } g = .60$ ), and Fatigue ( $t(28) = .97, p = .34, \text{Hedges' } g = .52$ ). Women who completed the final assessment reported less sleep disturbance, more pain interference, and more fatigue at baseline compared with non-completers. Effect sizes of

differences by study completion status were smaller than medium for all other outcome variables examined (i.e., CES-D, PANAS Negative Affect, PANAS Positive Affect, GAD-7, IES-R, PROMIS Pain Intensity, PROMIS Physical Function).

### **Scores on Dependent Variables**

On average, women reported CES-D scores below the cutoff suggestive of clinical depression (total CES-D score  $\geq 16$ ) at study baseline (see Table 2-4). Over one-third (37%) of women scored above the cutoff, however. Average baseline CES-D scores in the current sample were somewhat higher than those of women in the original PCO trial (Stanton et al., 2013) and a separate sample of 62 women with MBC who took part in a randomized controlled trial for emotionally expressive writing (Low et al., 2010). PANAS Positive and Negative Affect scores were similar to a sample of 558 women who had recently completed primary treatment for early-stage breast cancer (Ganz et al., 2004). On average, GAD-7 scores were elevated compared with women in the general population (Lowe et al., 2008) and similar to a sample of 35 cancer survivors with clinically significant fatigue (Johns et al., 2015). Women in the current study reported scores on PTGI Life Appreciation and Relating to Others comparable to those of women in the original PCO trial (Stanton et al., 2013) and somewhat higher than a separate sample of 100 women with MBC (Mystakidou et al., 2008). On average, women's scores on the Intrusion subscale of the IES-R at study baseline were similar to those of women in the original PCO trial (Stanton et al., 2013) and a sample of 62 MBC patients (Low et al., 2010).

For descriptive statistics regarding dependent variables measuring physical functioning at each assessment, see Table 2-5. Correlations between dependent variables are displayed in Table 2-6. Average baseline BCPT scores in the current sample were higher than those of 560 women who had recently completed treatment for non-metastatic breast cancer (Stanton et al., 2005).

PROMIS measures were calibrated at  $M = 50$  and  $SD = 10$  in a large sample of the general U.S. population (Gershon, Rothrock, Hanrahan, Bass, & Cella, 2010). Scores in the current sample were compared with sub-norms for women in the general U.S. population when available (average T-scores for women: Pain Interference = 51.1, Physical Function = 48.9, Fatigue = 51.1). The average PROMIS Pain Interference score in the current sample was equivalent to a T-score of 58.5, reflecting levels of pain interference substantially higher than women in the general population. The average PROMIS Physical Function score was equivalent to a T-score of 41.8, reflecting substantially poorer functioning compared with women in the general population. The average PROMIS Fatigue score was equivalent to a T-score of 57.0, reflecting greater than average fatigue. The average PROMIS Pain Intensity score was equivalent to a T-score of 49.4 in the general U.S. population, reflecting levels similar to the general population (sub-norms for women were unavailable for this measure). PROMIS Sleep Disturbance scores were calibrated in a chronically ill sample rather than a nationally representative sample; average PROMIS Sleep Disturbance in the current sample, equivalent to a T-score of 52.4, reflects slightly greater than average sleep disturbance compared with chronically ill U.S. adults.

### **Scores on Mediator Variables**

Descriptive statistics for mediator variables at each assessment are displayed in Table 2-7. For correlations among mediators, see Table 2-8. On average, UCLA Loneliness Scale scores at study baseline were similar to those of women in the original PCO trial (Stanton et al., 2013). Measures of altruism, universality, and social support from other women with MBC were adapted for use in the current study and are not directly comparable to scores reported elsewhere (Carver, 2006; Weinberg et al., 1995).

### **Scores on Predictors of Change in Outcomes**

For descriptive statistics on predictor variables at each assessment, see Table 2-9. Correlations among predictors are displayed in Table 2-10. On average, women in the current study reported higher levels of social support from friends than women in the original PCO trial (Cleary & Stanton, 2015). Levels of self-reported emotional expression at study baseline were similar to levels reported by women in the original PCO trial (Cleary & Stanton, 2015) and a separate sample of 92 women who had received treatment for early-stage breast cancer (Stanton, Danoff-Burg, et al., 2000). As a secondary measure of emotional expression, LIWC software (Pennebaker et al., 2007) was used to analyze the use of positive emotion words (e.g., “joy”) and negative emotion words (e.g., “angry”) in website content posted during the four-month study period. On average, 5.1% of total words used in posts were classified as positive emotion words ( $SD = 1.3$ ) and .8% were negative emotion words ( $SD = .7$ ). Compared with the original PCO trial (Harris et al., 2015), average positive emotion word use in the current study was higher and negative emotion word use was lower. MOCS Coping Confidence scores at study baseline were higher than levels reported by women in the original PCO trial (Cleary & Stanton, 2015). MOCS Coping Confidence and Getting Needs Met scores were similar to those reported by a sample of 199 women newly treated for non-metastatic breast cancer (Antoni et al., 2006).

### **Treatment Fidelity**

Eight randomly selected intervention sessions (four from each condition) were evaluated for adherence to the intended treatment by research staff uninvolved in PCO performance. There was 99% fidelity to the workshop protocol across all rated intervention sessions, with no significant difference in fidelity ratings between conditions ( $p > .05$ ).

### **Outcome Analyses (Aim 1)**

Unconditional models without predictors or covariates were estimated to examine the overall trajectory of each outcome over the four-month study period across conditions. There was a significant increase in PTGI Life Appreciation ( $b = .50, p < .05$ ) and a marginally significant decrease in GAD-7 ( $b = -.53, p = .08$ ) over the study period. BCPT scores increased significantly over the study period ( $b = .08, p < .05$ ), indicating an increase in bothersome symptoms. PROMIS Physical Function scores decreased significantly ( $b = -.61, p < .05$ ), indicating worsening physical functioning over time. Other outcome variables (i.e., CES-D, PANAS Negative Affect, PANAS Positive Affect, PTGI Relating to Others, IES-R, PROMIS Sleep Disturbance, PROMIS Pain Interference, PROMIS Pain Intensity, PROMIS Fatigue) did not evidence significant change over the study period (all  $P > .05$ ).

Models examining the effect of condition on outcomes across time included as predictors time, condition, and a time x condition interaction. Because the randomized groups did not differ significantly (all  $P > .05$ ) at baseline on any demographic, cancer-related, Internet use, or outcome measure, no covariates were included in outcome analyses. There was no significant effect of condition on any outcome variable (all  $P > .05$ ). Although the relationship was not statistically significant, there was a 2.7% reduction in residual variance after adding the condition x time term to an empty model with GAD-7 as the outcome ( $b = -.89, p = .14$ ). Generalized anxiety decreased significantly over the study period in the PCO PLUS condition ( $b = -.98, p < .05$ ) and remained constant in the PCO ONLY condition ( $b = -.09, p > .05$ ; see Figure 2-3). Effect size estimates for all other outcomes suggested that the proportional reduction in residual variance that resulted from adding condition to the empty model was negligible (< 1%).

### **Mediation Analyses (Aim 2)**

Mediation analyses were conducted to examine potential mechanisms through which enhanced peer support in PCO PLUS conferred psychosocial and physical health-related benefits. Multilevel mediation analyses examined hypothesized mediators (i.e., MBC-peer support, loneliness, universality, altruism) of the effects of PCO PLUS versus PCO ONLY on outcomes. Models were estimated separately for each mediator. Although there were no significant effects of condition on outcome variables, examination of mediated effects can inform future intervention development (MacKinnon et al., 2002; Stanton, Luecken, et al., 2013). However, mediation analyses did not reveal any significant effects (all  $P > .05$ ).

Multilevel models were then estimated to examine the effect of condition on each hypothesized mediator across the study period. There was a marginally significant effect of condition on loneliness ( $b = -1.60, p = .05$ ; see Figure 2-4), with a trend toward a decrease in loneliness in PCO PLUS ( $b = -.88, p = .13$ ) and no change in loneliness in PCO ONLY ( $b = .75, p = .21$ ). Adding the condition x time term to an empty model with loneliness as the outcome resulted in a 6.4% reduction in residual variance. There were no significant effects of condition on any other mediator variable (all  $P > .05$ ), and effect size estimates suggested that the proportional reduction in residual variance that resulted from adding condition to the empty model was negligible (< 1%). Unconditional models examining the overall trajectories of mediators across conditions revealed a significant increase in altruism ( $b = .74, p < .05$ ) and a marginally significant increase in universality ( $b = .91, p = .05$ ) during the study period. There was no change in MBC-peer support during the study period ( $p > .05$ ).

### **Predictors of Change in Outcomes Analyses (Aim 3)**

Due to the lack of a control condition in the current study, factors that were hypothesized to effect change equally in *both* conditions (i.e., support from friends, emotional expression,

coping self-efficacy) could not be examined as mediators. These factors were associated with change in outcomes in the original PCO trial (Cleary & Stanton, 2015; Harris et al., 2015) and were therefore expected to predict improvements in adjustment for women in both conditions in the current study. Multilevel models examined the separate effects of changes in social support from friends, emotional expression, and coping self-efficacy from baseline to two months on outcomes over the study period (i.e., baseline, two months, four months). We also examined whether observed effects varied by condition assignment.

Change in SSSS Friends score from baseline to two months was a significant predictor of CES-D over the study period ( $b = -7.18, p < .05$ ) such that greater increase in support from friends was related to a steeper decline in depressive symptoms (see Figure 2-5; effects shown at  $\pm 1 SD$  change in SSSS Friends score). Change in support from friends was also a significant predictor of both PANAS Negative Affect ( $b = -7.05, p < .05$ ; Figure 2-5) and PANAS Positive Affect ( $b = 7.31, p < .001$ ; Figure 2-5) over the study period. Greater increase in support was related to a steeper decrease in negative affect and a steeper increase in positive affect. Change in support from friends was a significant predictor of PROMIS Fatigue over the study period ( $b = -3.47, p < .01$ ; Figure 2-5) such that greater increase in support was related to a steeper decline in fatigue during the study. These effects did not vary by condition (all  $P > .05$ ).

There was a significant effect of change in support from friends on IES-R over time, and the effect was moderated by condition ( $b = 7.12, p < .05$ ; Figure 2-6; effects shown at  $\pm 1 SD$  change in SSSS Friends score). Greater increase in support was related to a steeper decline in intrusive thoughts in PCO ONLY ( $b = -6.87, p < .01$ ); there was no significant relationship between change in support and intrusive thoughts in PCO PLUS ( $p > .05$ ). Change in support from friends was also a significant predictor of PROMIS Pain Interference over the study period,

and condition moderated the effect ( $b = 7.36, p < .01$ ; Figure 2-6). Greater increase in support was related to a steeper decline in pain interference in PCO ONLY ( $b = -6.43, p < .01$ ); there was no significant relationship in PCO PLUS ( $p > .05$ ). Additionally, there was a significant effect of change in support from friends on physical functioning over the study period, and the effect was moderated by condition ( $b = -4.02, p < .05$ ; Figure 2-6). Greater increase in support from friends was marginally related to greater improvement in physical functioning in PCO ONLY ( $b = 2.09, p = .06$ ); there was no significant relationship in PCO PLUS ( $p > .05$ ).

There was a marginally significant effect of change in COPE Emotional Expression on IES-R over time ( $b = 1.87, p = .06$ ; Figure 2-7; effects shown at  $\pm 1 SD$  change in COPE Emotional Expression score) such that greater increase in emotional expression was related to a steeper increase in cancer-related intrusive thoughts over the study period. The effect did not vary by condition ( $p > .05$ ). Change in emotional expression significantly predicted PROMIS Pain Interference ( $b = -4.68, p < .05$ ) and PROMIS Pain Intensity ( $b = -2.84, p < .01$ ) over the study period, and the effects varied by condition (Figure 2-8; effects shown at  $\pm 1 SD$  change in COPE Emotional Expression score). In PCO ONLY, greater increase in emotional expression was marginally related to a steeper increase in pain interference ( $b = 2.74, p = .06$ ). In PCO PLUS, greater increase in emotional expression was marginally related to a steeper decline in pain interference ( $b = -1.94, p = .09$ ). Similarly, greater increase in emotional expression was significantly related to a steeper increase in pain intensity in PCO ONLY ( $b = 1.80, p < .05$ ) and marginally related to a steeper decrease in pain intensity in PCO PLUS ( $b = -1.04, p = .07$ ).

Women's positive and negative emotion word use on their websites during the four-month study period was examined as a secondary measure of emotional expression. There was a marginally significant relationship between positive emotion word use and PTGI Relating to

Others, and the effect was moderated by condition ( $b = -1.52, p = .09$ ; Figure 2-9; effects show positive emotion word use at  $\pm 1 SD$  from mean). In PCO PLUS, higher positive emotion word use was marginally related to a steeper decrease in relating to others over the study period ( $b = -1.11, p = .08$ ); no significant relationship emerged in PCO ONLY ( $p > .05$ ). There was a significant relationship between positive emotion word use and PROMIS Pain Intensity, and the relationship varied by condition ( $b = .93, p < .01$ ; Figure 2-9). In PCO ONLY, higher positive emotion word use was related to a steeper decrease in pain intensity over the study period ( $b = -.66, p < .01$ ); there was no significant relationship in PCO PLUS ( $p > .05$ ).

Marginally significant relationships emerged between negative emotion word use and PANAS Positive Affect ( $b = 1.85, p = .06$ ; Figure 2-10; effects show negative emotion word use at  $\pm 1 SD$  from mean) and PTGI Life Appreciation ( $b = .65, p = .05$ ; Figure 2-10) over the study period such that higher negative emotion word use was related to steeper increases in positive affect and life appreciation over the study period. The effects were not moderated by condition (all  $P > .05$ ). There was a significant relationship between negative emotion word use and PROMIS Pain Intensity, and the relationship varied by condition ( $b = -1.49, p < .05$ ; Figure 2-11; effects show negative emotion word use at  $\pm 1 SD$  from mean). In PCO ONLY, higher negative emotion word use was related to a steeper increase in pain intensity over the study period ( $b = .89, p < .05$ ); there was no significant relationship in PCO PLUS ( $p > .05$ ). A marginally significant relationship between negative emotion word use and PROMIS Fatigue emerged, and condition moderated the effect ( $b = 2.20, p = .06$ ; Figure 2-11). In PCO ONLY, higher negative emotion word use was related to a steeper decrease in fatigue over the study period ( $b = -1.51, p < .05$ ); there was no significant relationship in PCO PLUS ( $p > .05$ ).

There was a marginally significant effect of change in MOCS Coping Confidence on PTGI Life Appreciation ( $b = .17, p = .08$ ; Figure 2-12; effects shown at +/- 1 *SD* change in MOCS Coping Confidence score) such that greater increase in coping confidence was related to a steeper increase in life appreciation over the study period. The effect was not moderated by condition ( $p > .05$ ). There were significant relationships between change in coping confidence and CES-D ( $b = 1.97, p < .05$ ; Figure 2-13), PROMIS Physical Function ( $b = -.69, p < .01$ ; Figure 2-13), and PROMIS Fatigue ( $b = .91, p < .05$ ; Figure 2-14) scores over time, and a marginally significant relationship between change in coping confidence and PANAS Positive Affect ( $b = -1.29, p = .05$ ; Figure 2-14). These relationships were moderated by condition (all  $P < .05$ ). In PCO ONLY, greater increase in coping confidence was related to a steeper decline in depressive symptoms ( $b = -1.98, p < .05$ ), improvement in physical functioning ( $b = .69, p < .01$ ), decline in fatigue ( $b = .62, p < .01$ ), and increase in positive affect ( $b = 1.36, p < .05$ ); no significant relationships emerged in PCO PLUS. No other significant relationships between predictors and outcomes emerged (all  $P > .05$ ).

#### **Website Use Analyses (Aim 4)**

**Website use.** Objective website data indicated that two-thirds (67%) of women posted a journal entry within one month after attending a workshop, and 77% posted during the four-month study period. On average, women posted 6.7 entries ( $SD = 18.2$ , range = 0-102) to their websites during the first month after attending a workshop, 2.4 entries ( $SD = 3.4$ , range = 0-13) during the second month, 1.3 entries ( $SD = 2.0$ , range = 0-9) during the third month, and 1.2 entries ( $SD = 1.6$ , range = 0-7) during the fourth month. In total, women posted an average of 11.6 entries ( $SD = 23.3$ , range = 0-129) to their websites during the four months after attending a

workshop. No significant difference between conditions was observed with regard to total number of journal entries posted ( $p > .05$ ).

At two months, women reported spending an average of 1.4 hours ( $SD = 1.7$ , range = 0-6.3) on their websites during the previous month. Nearly half of women (46%) reported that they logged in to their websites once per week or more during the previous month (15% logged in once per week, 27% logged in a few times each week, and 4% logged in every day), and about half (54%) reported logging in to their websites less than once per week during the previous month. At four months, women reported that they had spent an average of 2.2 hours ( $SD = 2.4$ , range = 0-8.3) on their websites during the previous month. More than half of women (60%) reported that they logged in to their websites once per week or more during the previous month (40% logged in once per week and 20% logged in a few times per week), and 40% reported logging in to their websites less than once per week. There were no significant differences between conditions with regard to time spent using the websites or frequency of logging in at two or four months (all  $P > .05$ ).

Four months after the workshop, women reported that they had invited an average of 27 individuals to view their websites ( $SD = 33.9$ , range = 0-130), with no significant difference between conditions ( $p > .05$ ). More than half of women reported that they had invited friends and family via email (57%) or in person (57%). Approximately one-fourth of women invited others through Facebook (23%), and a smaller proportion invited others over the phone (17%) or by text (17%).

**Perceived website usefulness.** At two months (see Table 2-11), women reported that their websites were “very useful” on average in terms of giving them a place to express emotions, telling the story of their experience, keeping others informed about how they were

doing, and reducing the need to repeat information over and over (53% rated each of these items “very useful” or “extremely useful”). Women reported that their websites were “a little useful” on average in terms of getting help from others (47% rated this item “not at all useful” or “a little useful”) and letting others know what would be helpful for them (40% rated this item “not at all useful” or “a little useful”). Although website usefulness ratings were slightly lower at four months for all items, no significant differences between ratings at two and four months were observed (all  $P > .05$ ). The randomized groups did not differ significantly (all  $P > .05$ ) at two or four months on any website usefulness item.

At two months (see Table 2-12), women reported that the following website features were “very useful” on average: About Me page (65% rated this item “very useful” or “extremely useful”), writing and publishing posts, adding photos, and the ability for friends and family to comment on posts (62% rated each of these three items “very useful” or “extremely useful”). Women rated the How You Can Help calendar as “a little useful” on average (58% rated this item “not at all useful” or “a little useful”). Women reported that the About Me and Useful Links pages were significantly more useful at two months than at four months ( $p < .01$  and  $p < .05$ , respectively). Women also indicated that approving and replying to comments was significantly more useful at two months than at four months ( $p < .05$ ). The randomized groups did not differ significantly (all  $P > .05$ ) at two or four months on any item regarding website features.

At four months, women reported that their experience using their websites was positive on average ( $M = 6.0$ ,  $SD = 1.1$ ); ratings did not differ significantly between randomized groups ( $p > .05$ ). One-third (33%) of women reported experiencing barriers to website use. Most women ( $n = 7$ ) who reported barriers commented that they lacked time to contribute to their websites due to other obligations (e.g., travel) or health issues (e.g., treatment side effects). Two women noted

that they preferred other methods to communicate with family and friends, and one woman reported that her website subscribers had difficulty accessing her website. Approximately one-fourth (27%) of women reported challenges with using their websites. Most women ( $n = 5$ ) who experienced challenges reported technical difficulties with logging in to their websites or forgetting their passwords. Two women reported initial challenges with using their websites that resolved, and one woman reported lack of comfort with using her website. Approximately one-quarter of women (27%) reported disappointment with their website experience due to lack of response from family and friends ( $n = 3$ ), difficulty with website features ( $n = 3$ ), or lack of time ( $n = 2$ ). One-fifth (20%) of women reported that they were surprised about some aspect of their experience with their websites. Three women were surprised that they did not post to their websites as frequently as they had intended. Two women received more responses and support from family and friends than expected.

Women in the PCO PLUS condition responded to additional questions regarding interactions with other women in the study. At four months, most PCO PLUS participants reported that they had visited the websites of other women in the study less than once a week during the past month (64%); some visited others' websites once a week (21%) or a few times a week (7%). Most women had commented on other women's websites less than once a week (64%), and about one-fourth (21%) had commented once a week. All respondents indicated that they had sent private messages to other women in the study less than once a week. The majority of women had contacted other participants outside of their websites less than once a week (79%); one woman had contacted others once a week. Regarding how often they had been contacted by other participants, most women in PCO PLUS reported that others had written comments on their websites less than once a week (79%); one woman received comments once a week. All

respondents indicated that they had received private messages less than once a week. Nearly all women reported that other participants had contacted them outside of their websites less than once a week (79%); one woman had been contacted a few times a week. PCO PLUS participants indicated that, on average, they “agreed slightly” that other women in the study were similar to them ( $M = 4.6, SD = 1.8$ ) and approachable ( $M = 4.9, SD = 1.6$ ), and “agreed” that other women in the study were likeable ( $M = 5.8, SD = 1.2$ ). Women reported that visiting other participants’ websites was moderately useful ( $M = 2.5, SD = 1.1$ ).

**Predictors of website use.** Baseline demographic, cancer-related, and Internet use variables were examined as predictors of website use (i.e., posting at least one journal entry during the study period [yes/no], total number of posts). Due to the high correlation between total number of posts and total word count of posts ( $r = .96$ ), total word count was not examined separately in analyses. Effect sizes also were examined; all medium and large effects are reported below.

Time since first breast cancer diagnosis was a marginally significant predictor of posting at least one journal entry during the study period ( $t(28) = 1.87, p = .07$ ) such that women who posted were diagnosed more recently than women who did not post. The effect size of this relationship was large (Cohen’s  $d = .77$ ). Time spent online at study baseline was a non-significant, moderate predictor of posting at least once during the study period ( $t(23) = .87, p = .39$ ; Cohen’s  $d = .54$ ) such that women who spent more time online were more likely to post than women who spent less time online. No other baseline demographic (i.e., age, marital status, race/ethnicity, education, income, employment, number of medical comorbidities), cancer-related (i.e., time since MBC diagnosis, number of metastatic sites, KPS score, de novo MBC diagnosis, current treatment), or Internet use (i.e., frequency of Internet use, comfort level with

computers) variables were significantly related to website use (all  $P > .05$ ) and all other effect sizes were smaller than medium.

## **Discussion**

### **Comparative Effectiveness of PCO PLUS versus PCO ONLY**

There was no significant effect of condition on the primary outcome variable, depressive symptoms, in the current study. In addition, there were no significant effects of condition on most secondary outcomes examined (i.e., positive and negative affect, personal growth, cancer-related intrusive thoughts, sleep disturbance, pain, physical symptoms and functioning, fatigue). Differences by condition emerged on two secondary outcomes: generalized anxiety and loneliness. Anxiety decreased significantly during the four-month study period among women in PCO PLUS; no change was observed for women in PCO ONLY. Similarly, a marginally significant decrease in loneliness across conditions was driven by a trend toward decreasing loneliness in PCO PLUS.

Consistent with previous research (Fulton, 1998; Okamura et al., 2005), symptoms of generalized anxiety in the current sample of women with MBC were elevated compared with general population norms (Lowe et al., 2008). Women with MBC commonly experience anxiety related to making treatment-related decisions, loss of independence and functional ability, changes in life roles, mortality, and the impact of the cancer on loved ones (Low et al., 2007; Turner et al., 2005). In addition, many women with MBC experience social isolation due to physical symptoms, functional limitations, and burdensome treatment schedules (Low et al., 2007). Loneliness and isolation are associated with poor health outcomes both in the general population (Hawkley & Cacioppo, 2010) and in cancer patients (Jaremka et al, 2013; Lutgendorf & Sood, 2011; Widows et al., 2000).

Peer support in PCO PLUS may have improved anxiety and loneliness by bolstering women's confidence in their ability to cope with the challenges of MBC and fostering universality (i.e., the sense that one is not alone in a difficult circumstance) and altruism. Findings could also be due to the group intervention session providing participants the opportunity to compare themselves to others experiencing MBC. Social comparison theory and empirical evidence suggest that individuals experiencing serious stressors, including cancer, seek affiliation and information from others perceived as more fortunate (i.e., upward comparison) and compare themselves favorably to less fortunate others (i.e., downward comparison) in order to motivate self-improvement and enhance self-esteem (Stanton, Danoff-Burg, Cameron, Snider, & Kirk, 1999; Suls & Wheeler, 2012; Taylor & Lobel, 1989).

Contrary to hypotheses, there were no significant effects of condition on most outcomes. There are several possible explanations for the observed lack of differences by condition. First, the sample size of the current study lacked statistical power to detect small or medium effects. In the original PCO trial, intervention effects were moderate to large (Stanton et al., 2013). Other psychosocial interventions for adults with cancer have found small to medium treatment effects on emotional distress, anxiety, and quality of life and moderate to large effects on depression (Faller et al., 2013; Naaman, Radwan, Fergusson, & Johnson, 2009). Second, the current trial compared two active treatment arms and did not include a control group. Given that psychosocial adjustment was expected to improve in both conditions, hypothesized differences in improvements between PCO PLUS and PCO ONLY are likely more difficult to detect.

Third, it is possible that the addition of peer support in PCO PLUS did not add benefit beyond the standard PCO intervention on the majority of measured outcomes. Perhaps the dose of peer support was not sufficient to confer benefits, as evidenced by infrequent interaction

between women in PCO PLUS via personal websites, email, or other means of communication. Well-matched support is hypothesized to be an important component of effective social support (Cutrona & Russell, 1990), and it is possible that the peer support in PCO PLUS was not well-matched if women did not feel similar to, or understood by, others in the study. Women in PCO PLUS reported that they “agreed slightly” that other women in the study were approachable and similar to them. One woman commented that she had difficulty relating to other women in the study because she felt her situation was “unique and like no one is out there like [her].”

It is also possible that women in the current study did not perceive a need for peer support. Research indicates that relatively few MBC patients participate in support groups, suggesting that many are either unable to access opportunities for peer support or prefer to seek support from their existing social networks (Mayer & Grober, 2006). Women with MBC may seek support from peers at critical times during the trajectory of illness (e.g., when making treatment-related decisions, experiencing difficult side effects or disease progression, or feeling distressed; Mayer & Grober, 2006). Women may not have wanted to learn about others’ experiences, particularly if they described disease progression, declining health, or other problems. However, a majority of women in a survey of 618 women with MBC indicated that learning about other women’s experiences was helpful (Mayer & Grober, 2006), and women in the current study reported that visiting other participants’ websites was moderately useful. More research is needed to better understand women’s preferences for peer support during the experience of MBC in order to facilitate well-matched support.

### **Changes in Outcomes and Mediators Across Conditions**

Life appreciation and MBC-related altruism increased significantly during the study period across conditions, and there was a marginally significant increase in MBC-related

universality. These findings are consistent with the hypothesis that women in both conditions would benefit from the intervention on measures of cancer-specific psychosocial adjustment. Results regarding life appreciation, an important marker of personal growth following a cancer diagnosis (Tedeschi & Calhoun, 1996), replicate findings from the original PCO trial (Stanton et al., 2013). Women in PCO PLUS were expected to evidence increases in altruism and universality due to enhanced MBC-peer support; increases for women in PCO ONLY on these measures were not anticipated. The observed increases in MBC-related altruism and universality in both conditions suggest that creating a narrative of the cancer experience and sharing with family and friends – perhaps even in the absence of communicating with other MBC patients – can help women feel more connected with others undergoing a similar experience. Interestingly, PCO did not confer benefits on other measures of cancer-specific psychosocial adjustment (i.e., intrusive thoughts, strengthened relationships) in either the current trial or the original PCO trial (Stanton et al., 2013).

Due to the lack of a control group in the current study, improvements in psychosocial adjustment across conditions cannot be definitively attributed to the intervention itself. Changes may be due to the passing of time or another factor. Generally, however, psychosocial functioning in advanced cancer is expected to decline over time as the disease progresses and physical symptoms worsen (Butler et al., 2003; Hwang, Chang, Fairclough, Cogswell, & Kasimis, 2003; Mayer, 2011; Mayer & Grober, 2013). Over one-third (37%) of women in the current study reported disease progression during the four-month study period, and, on average, women reported an increase in bothersome cancer-related physical symptoms and worsening physical functioning. Thus, overall improvement on several measures of cancer-specific psychosocial adjustment despite worsening physical condition is notable.

In addition to conferring psychosocial benefits, PCO was expected to improve physical health-related functioning for women in both conditions through decreased loneliness and increased social support, emotional expression, and coping self-efficacy (Helgeson & Cohen, 1996; Lutgendorf & Sood, 2011; Scheier et al., 2005; Stanton, Danoff-Burg, Sworowski, et al., 2002). Indeed, previous psychosocial interventions for women with MBC have demonstrated improvements in pain, fatigue, and insomnia (Butler et al., 2009; Savard et al., 2006). Without a control group, the lack of change on some measures of physical functioning (i.e., sleep disturbance, pain, fatigue) and declines on other measures (i.e., physical function, cancer-related physical symptoms) in the current study are difficult to interpret, particularly given the expectation of worsening physical condition over time in this population (Butler et al., 2003; Cheville et al., 2008; Mayer, 2011; Mayer & Grober, 2013; Reed & Corner, 2013).

### **Mediators of the Effects of PCO PLUS on Outcomes**

MBC-peer support, loneliness, and MBC-related universality and altruism were examined as mediators of the effects of PCO PLUS (versus PCO ONLY) on outcomes to identify *how* peer support in PCO PLUS may have conferred benefits. Despite the lack of significant effects of condition on most outcomes, examination of mediated effects can inform development of future interventions (MacKinnon et al., 2002; Stanton, Luecken, et al., 2013). Although benefits on loneliness, universality, and altruism were observed in the current study, no significant mediated effects of PCO PLUS on outcomes emerged. Universality and altruism increased in both conditions, suggesting that peer support in PCO PLUS was not the mechanism of change in these constructs. There was a trend toward a decrease in loneliness in PCO PLUS, but it did not mediate the condition's effects on outcomes.

### **Predictors of Change in Outcomes**

Variables examined as mediators in the original PCO trial (i.e., social support from friends, emotional expression, coping self-efficacy; Cleary & Stanton, 2015) were examined as predictors of change in outcomes in the current study. Because these factors were expected to effect change equally in *both* conditions, they could not be examined as mediators. Instead, change in each variable from baseline to two months was used to predict change in outcomes over the four-month study period. Findings may inform potential targets for future interventions.

An increase in support from friends from baseline to two months was related to reduced depressive symptoms, negative affect, and fatigue and increased positive affect across conditions. Findings are consistent with research suggesting that social support is strongly associated with adjustment to MBC (Northouse et al., 2002; Widows et al., 2000). In the original PCO trial, increase in support from friends mediated the relationship between PCO and change in depressive symptoms, negative affect, and life appreciation (Cleary & Stanton, 2015). MBC patients often face social isolation (Low et al., 2007; Luoma & Hakamies-Blomqvist, 2004; Mayer & Grober, 2013), highlighting the importance of interventions to facilitate communication and support between women and their social network. To our knowledge, PCO is the first intervention designed to increase social support from friends among women with breast cancer.

Both self-reported cancer-related emotional expression and objectively measured positive and negative emotion word use on women's websites were used to assess emotional expression as a predictor of change in outcomes. Compared with the original PCO trial (Harris et al., 2015), women's use of positive emotion words in the current study was higher and use of negative emotion words was lower. However, average self-reported emotional expression was similar and depressive symptoms were higher in the current study compared with the original PCO trial (Stanton et al., 2013). Thus, the high positive and low negative emotion word use observed in the

current study may not accurately reflect women's emotional states. Writing for an audience may influence how women choose to express emotions. Indeed, research suggests that some women with MBC perceive social pressure to be positive and may hesitate to express negative emotions in order to protect loved ones (Low et al., 2007).

An increase in self-reported emotional expression from baseline to two months was related to a marginally significant increase in cancer-related intrusive thoughts across conditions. In contrast, greater negative emotion word use on websites was related to marginally significant increases in positive affect and life appreciation in both conditions. Although research generally demonstrates a positive influence of cancer-related emotional expression on psychosocial adjustment (e.g., Frattaroli, 2006; Owen et al., 2005; Stanton, Danoff-Burg, et al., 2000), evidence regarding emotional expression and adjustment in MBC is mixed (Low et al., 2010; Stanton & Low, 2012a; Mosher et al., 2012). Consistent with current findings, negative emotion word use in the original PCO trial was related to an improvement in depressive symptoms over the study period (Harris et al., 2015). Findings suggest that examination of more nuanced relationships between emotional expression and adjustment in MBC is necessary, and that self-reported and objective measures of emotional expression may offer different lenses through which to investigate this construct.

Increased self-reported emotional expression from baseline to two months was related to decreases in pain interference and pain intensity in PCO PLUS and increases in pain in PCO ONLY. In addition, greater use of positive emotion words on websites was related to a decrease in pain intensity in PCO ONLY, and greater use of negative emotion words was related to an increase in pain intensity in PCO ONLY. These findings are consistent with research suggesting that the social context in which cancer-related emotional disclosure occurs may modify its

effects (Stanton & Low, 2012b). Individuals are more likely to benefit from emotional expression regarding cancer when they perceive that their social network is receptive to such expression than when they feel constrained by close others in terms of emotional expression (Hoyt, 2009; Lepore, Ragan, & Jones, 2000; Stanton, 2011). As discussed previously, family and friends may feel uncomfortable with women's disclosure of negative emotions, and women with MBC may avoid sharing emotions and fears if they do not feel understood (Low et al., 2007). Women may feel better supported and understood by other MBC patients (Mayer & Grober, 2006; Vilhauer, 2009). In the current study, women in PCO PLUS may have perceived their audience as more receptive to emotional expression than women in PCO ONLY, suggesting that needs for support were well-matched by MBC-peer support in PCO PLUS. Interestingly, however, higher positive emotion word use was marginally related to a decrease in relating to others in PCO PLUS. It is possible that women who expressed a high level of positive emotions had difficulty relating to peers if their positivity was not matched. In contrast with results regarding pain described above, higher negative emotion word use was related to a decrease in fatigue in PCO ONLY. More research is needed to better understand the influence of social receptivity on the utility of emotional expression in MBC.

An increase in coping confidence was related to enhanced life appreciation in both conditions. Previous interventions have demonstrated that increased coping self-efficacy (e.g., confidence in one's ability to relax, reframe thoughts, use social support effectively) among cancer patients mediated the relationship between the intervention and outcomes (Antoni et al., 2006; Hawkins et al., 2010; Manne et al., 2008; Penedo et al., 2004, Penedo et al., 2006; Scheier et al., 2005). In the original PCO trial, an increase in coping confidence mediated the relationship between PCO and benefits on psychosocial outcomes (Cleary & Stanton, 2015).

Interesting differences by condition emerged for support from friends and coping confidence as predictors of change in outcomes. An increase in support from friends was related to improvements in pain interference, cancer-related intrusive thoughts, and physical functioning in PCO ONLY; no significant relationships were observed in PCO PLUS. Similarly, an increase in coping confidence was related to improvements in depressive symptoms, positive affect, physical functioning, and fatigue in PCO ONLY, but not in PCO PLUS. MBC-peer support may have buffered relationships between these predictors and outcomes in PCO PLUS such that changes in support from friends and coping confidence had less influence on adjustment due to the addition of peer support. This interpretation is purely speculative and other explanations require study.

#### **Use and Perceived Usefulness of Websites**

Women indicated that using their websites was a positive experience and found the websites most useful for giving them a place to express emotions, telling the story of their experience, keeping others informed about how they were doing, and reducing the need to repeat information. One woman commented that the most useful aspect of her website was “not having to talk about my cancer to everyone all the time. The website has helped me keep everyone updated.” In addition, women’s engagement with their websites after attending the intervention session was high. Over three-quarters of women (77%) posted at least one journal entry during the study period; on average, women posted 12 entries total. Interestingly, women’s website use increased over time. Women spent an average of 1.4 hours per month using their websites at two months and 2.2 hours per month at four months. At two months, 46% logged into their websites once per week or more, and at four months, 60% logged in once per week or more.

Many Internet-based interventions evidence relatively modest engagement (Christensen & Mackinnon, 2006; Eysenbach, 2005). Indeed, in the original PCO trial, website use tapered after the first month post-intervention (Harris et al., 2015). Factors that may have bolstered engagement in the current trial include discussion of women's goals for their websites during the intervention session (Greaves et al., 2011) and weekly emails encouraging website use. High engagement in the current study may also suggest that women with MBC perceive a greater need for, or have more time to use, websites compared with women diagnosed with early-stage disease in the original PCO trial (Harris et al., 2015).

Contrary to hypotheses, the addition of MBC-peer support in PCO PLUS did not enhance engagement or perceived website usefulness. No significant differences were observed between conditions with regard to number of journal entries posted, frequency of logging in, time spent using websites, or number of individuals women invited to view their websites. As described previously, communication between women in PCO PLUS during the study was infrequent; it appears that most women used their websites to connect with their existing social networks.

Women invited an average of 27 individuals to view their websites, typically via email or in person; one-quarter invited others through Facebook. Women reported that writing journal entries, receiving comments, and the ability for family and friends to receive automatic notifications regarding new posts were the most useful features of the websites. One woman wrote that the most useful aspect of her website was "getting feedback via email or comments on blogs... It feels good to have [my] feelings validated." Despite women's apparent interest in sharing their websites with family and friends, items evaluating website usefulness in terms of seeking support (e.g., getting help from others, letting others know what would be helpful, How You Can Help calendar) generally received low ratings. These items also received low ratings in

the original PCO trial (Harris et al., 2015), suggesting that future interventions could include more explicit features promoting interaction between participants and website visitors to bolster social support. Alternatively, results may suggest that women find their websites helpful for keeping others informed but prefer not to ask for help directly.

Despite women's high level of engagement with their websites, some indicated that they experienced barriers to website use including technical difficulties (e.g., trouble logging in, forgetting passwords) and lacking time to contribute to their websites due to other obligations (e.g., travel) and health issues (e.g., treatment side effects). Future interventions could reduce barriers by recruiting a friend or family member to assist with website use or facilitating website use on mobile devices, which patients may find more accessible while waiting for medical appointments or traveling.

Predictors of website use were examined to identify subsets of women who were highly engaged in the intervention. Compared with women who did not post a journal entry after attending the workshop, women who posted were diagnosed with cancer more recently. Perhaps women diagnosed more recently perceived a greater need for support and/or to create a narrative of their experience. Although women reported daily Internet use at study baseline and felt comfortable using computers, those who spent more time online at baseline were somewhat more likely to post than women who spent less time online. This finding highlights the need for future Internet-based interventions to facilitate engagement for less computer-savvy individuals.

### **Sample Characteristics**

Women in the current study reported higher levels of depressive symptoms at baseline compared with women in the original PCO trial (Stanton et al., 2013) and a sample of MBC patients who participated in an expressive writing trial (Low et al., 2010). In addition,

generalized anxiety was elevated compared with norms for women in the general population (Lowe et al., 2008). Women also reported substantially poorer physical functioning and higher levels of pain interference and fatigue compared to women in the general population, and greater sleep disturbance compared with norms for chronically ill adults (Gershon et al., 2010). These findings are consistent with evidence that MBC patients experience significant psychological distress and physical symptoms (Caplette-Gingras & Savard, 2008; Low et al., 2007).

Examination of differences between women who completed the four-month follow-up assessment and those who did not can inform generalizability of findings and potential areas to address in future studies to enhance retention (although retention in the current trial was high; 87%). No statistically significant differences between study completers and non-completers were observed; however, effect size estimates indicated medium to large differences by study completion status on the following characteristics. Although Internet use was high overall, women who did not complete the study used the Internet less at baseline than study completers. Women who used the Internet less may have found their websites less useful and/or accessible. As described above, intervention researchers should aim to enhance engagement among individuals with low computer literacy to broaden the reach of Internet-based interventions. Participants who did not identify as white were less likely to complete the study than white women, and women who did not graduate from college were less likely to complete the study than college graduates. Interestingly, women with low (<\$50,000) and high (>\$100,000) incomes were less likely to complete the study than women with mid-range incomes (\$50,000-\$100,000). These findings highlight the need to engage and retain diverse women with MBC in research to ensure generalizability of findings to all MBC patients.

Perhaps suggesting less perceived need for personal websites, women who did not complete the study reported better physical functioning, fewer metastatic sites, and lower levels of pain interference and fatigue compared with study completers. However, non-completers also reported more comorbid physical conditions, higher levels of bothersome physical symptoms, greater sleep disturbance, and less personal growth at baseline than study completers, suggesting that these aspects of functioning may have prevented continued engagement in PCO.

Characteristics associated with study retention should be examined in future research in order to identify potential targets for enhancing retention in interventions for MBC patients.

### **Study Limitations**

Limitations of the current study warrant discussion. As discussed previously, the lack of control condition limits conclusions regarding the cause of observed changes in outcomes across both conditions. In addition, because outcomes were hypothesized to improve in both conditions (with greater improvements in PCO PLUS), differences between the two conditions may have been too small to detect. Indeed, the current sample size was sufficient to detect only large effects. Analyses did not include multiple-test adjustment. The sample included predominately well-educated, computer literate, non-Hispanic white women. Results may not generalize to men, other cancer diagnoses, disadvantaged groups, or those with low computer literacy. Women in the sample were younger ( $M = 52$  years old) than the average age of women diagnosed with breast cancer ( $M = 61$  years old; ACS, 2016) and a large sample of women with MBC ( $M = 63$  years old; Lobbezoo et al., 2015). The current study used only self-report, rather than objective, measures of psychosocial and physical health-related adjustment. Furthermore, the four-month follow-up period in the current study is relatively short. A four-month follow-up was selected

due to the poor prognosis of women with MBC; however, examining longer-term adjustment in this population is important as survival improves (Dawood et al., 2008; Shigematsu et al., 2011).

### **Future Research**

Continued research could examine potential cultural variation of PCO intervention effects in a more diverse sample; sustainability of effects beyond four months; effects on objective, in addition to self-reported, measures of adjustment (e.g., cancer-related medical appointments); and potential benefits of PCO for men and women with other advanced cancers and life-limiting illnesses. Future trials of PCO could also test whether online delivery of the intervention session confers benefits comparable to an in-person session, which could enable wider dissemination of the intervention.

Findings highlight a need for future Internet-based interventions to reduce barriers to engagement for advanced cancer patients, perhaps by engaging a loved one or providing additional support for those who feel less comfortable using computers. Continued research regarding peer support in cancer is needed to determine patients' preferences for support. Our findings suggest that interventions may need to incorporate additional strategies to encourage continued communication between patients in order to facilitate more effective peer support.

### **Conclusions**

The current trial of PCO for women with MBC represents a brief psychosocial intervention to help women create personal websites during a three-hour hands-on workshop. Due to slow accrual in the current trial, the interim analyses reported in this dissertation were conducted in order to examine intervention effects on primary and secondary outcomes. Given the lack of significant improvement in the primary outcome, depressive symptoms, at two- or four-month follow-up, the trial will close after the current recruitment wave. Improvements in

some secondary cancer-specific psychosocial outcomes were observed across conditions (i.e., life appreciation, altruism, universality) despite worsening physical symptoms and functioning. The addition of the presence of and potential support from other women with MBC led to a significant reduction in anxiety and a trend toward a reduction in loneliness. Results replicate findings from the original PCO trial suggesting benefits of PCO for women with MBC (Harris et al., 2015; Stanton et al., 2013) and contribute to the small body of literature on the benefits of peer support in cancer (Campbell et al., 2004; Gustafson et al., 2001; Winzelberg et al., 2003).

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Table 2-1. Demographic Characteristics of Participants at Baseline

|                                  | All<br>Participants<br>( <i>N</i> = 30)    | PCO ONLY<br>Participants<br>( <i>n</i> = 16) | PCO PLUS<br>Participants<br>( <i>n</i> = 14) |
|----------------------------------|--|--|--|
| Characteristic                   | No. (%) /<br><i>M</i> ( <i>SD</i> ), Range | No. (%) /<br><i>M</i> ( <i>SD</i> ), Range   | No. (%) /<br><i>M</i> ( <i>SD</i> ), Range   |
| Age, years                       | 52.3 (7.6), 39-67                          | 50.9 (7.9), 39-66                            | 54.0 (7.4), 40-67                            |
| Race/ethnicity                   |  |  |  |
| Non-Hispanic white               | 21 (70.0)                                  | 11 (68.8)                                    | 10 (71.4)                                    |
| African American                 | 3 (10.0)                                   | 1 (6.3)                                      | 2 (14.3)                                     |
| Asian American                   | 2 (6.7)                                    | 2 (12.5)                                     | 0 (0.0)                                      |
| Latina                           | 4 (13.3)                                   | 2 (12.5)                                     | 2 (14.3)                                     |
| American Indian                  | 0 (0.0)                                    | 0 (0.0)                                      | 0 (0.0)                                      |
| College graduate                 | 21 (70.0)                                  | 12 (75.0)                                    | 9 (64.3)                                     |
| Married/living as married        | 19 (63.3)                                  | 9 (56.3)                                     | 10 (71.4)                                    |
| Total yearly household income    |  |  |  |
| < \$50,000                       | 11 (36.7)                                  | 6 (37.5)                                     | 5 (35.7)                                     |
| \$50,000 to \$100,000            | 12 (40.0)                                  | 4 (25.0)                                     | 8 (57.1)                                     |
| > \$100,000                      | 7 (23.3)                                   | 6 (37.5)                                     | 1 (7.1)                                      |
| Employment status                |  |  |  |
| Employed                         | 9 (30.0)                                   | 5 (31.3)                                     | 4 (28.6)                                     |
| Unemployed                       | 2 (6.7)                                    | 2 (12.5)                                     | 0 (0.0)                                      |
| Retired                          | 5 (16.7)                                   | 2 (12.5)                                     | 3 (21.4)                                     |
| Homemaker                        | 2 (6.7)                                    | 0 (0.0)                                      | 2 (14.3)                                     |
| Disabled/on medical leave        | 12 (40.0)                                  | 7 (43.8)                                     | 5 (35.7)                                     |
| Number of medical comorbidities  | 1.6 (1.7), 0-6                             | 1.7 (2.1), 0-6                               | 1.6 (1.3), 0-4                               |
| Self-rated Karnofsky functioning | 2.8 (1.0), 1-5                             | 2.7 (1.0), 1-5                               | 2.9 (0.9), 1-5                               |

*Note.* The randomized groups did not differ significantly (all  $P > .05$ ) at baseline on any demographic variable. There was a marginally significant difference between conditions on income ( $p = .09$ ). Owing to small cell sizes, categories for the following variables were collapsed as follows in all analyses: race/ethnicity = white vs. other race/ethnicity, employment status = employed vs. not employed (includes unemployed, retired, homemaker) vs. disabled/on medical leave.

Table 2-2. Cancer-Related Variables

|  | All<br>Participants<br>( <i>N</i> = 30)    | PCO ONLY<br>Participants<br>( <i>n</i> = 16) | PCO PLUS<br>Participants<br>( <i>n</i> = 14) |
|--|--|--|--|
| Variable   | No. (%) /<br><i>M</i> ( <i>SD</i> ), Range | No. (%) /<br><i>M</i> ( <i>SD</i> ), Range   | No. (%) /<br><i>M</i> ( <i>SD</i> ), Range   |
| Time since first breast cancer diagnosis, years      | 7.5 (6.6), 0-25                            | 9.1 (7.9), 0-25                              | 5.7 (4.1), 0-13                              |
| Time since metastatic breast cancer diagnosis, years | 2.8 (2.8), 0-10                            | 1.9 (2.1), 0-6                               | 3.6 (3.3), 0-10                              |
| De novo metastatic disease                           | 9 (30.0)                                   | 5 (31.3)                                     | 4 (28.6)                                     |
| Menopause prior to first breast cancer diagnosis     | 5 (16.7)                                   | 2 (12.5)                                     | 3 (21.4)                                     |
| Number of metastatic sites                           | 1.8 (1.0), 1-5                             | 1.9 (1.0), 1-5                               | 1.8 (1.0), 1-4                               |
| Treatment for metastatic breast cancer               |  |  |  |
| Surgery  |  |  |  |
| Prior to baseline                                    | 10 (33.3)                                  | 6 (37.5)                                     | 4 (28.6)                                     |
| Between baseline and 2 months                        | 2 (6.7)                                    | 2 (15.4)                                     | 0 (0.0)                                      |
| Between 2 months and 4 months                        | 0 (0.0)                                    | 0 (0.0)                                      | 0 (0.0)                                      |
| Chemotherapy   |  |  |  |
| Completed prior to baseline                          | 12 (40.0)                                  | 5 (31.3)                                     | 7 (50.0)                                     |
| Current at baseline                                  | 12 (40.0)                                  | 7 (43.8)                                     | 5 (35.7)                                     |
| Current at 2 months                                  | 9 (30.0)                                   | 5 (31.3)                                     | 4 (28.6)                                     |
| Current at 4 months                                  | 13 (43.3)                                  | 9 (56.3)                                     | 4 (28.6)                                     |
| Radiation  |  |  |  |
| Completed prior to baseline                          | 11 (36.7)                                  | 5 (31.3)                                     | 6 (42.9)                                     |
| Current at baseline                                  | 2 (6.7)                                    | 1 (6.3)                                      | 1 (7.1)                                      |
| Current at 2 months                                  | 1 (3.3)                                    | 1 (6.3)                                      | 0 (0.0)                                      |
| Current at 4 months                                  | 0 (0.0)                                    | 0 (0.0)                                      | 0 (0.0)                                      |
| Biologic therapy (e.g., Herceptin)                   |  |  |  |
| Current at baseline                                  | 12 (40.0)                                  | 9 (56.3)                                     | 3 (21.4)                                     |
| Current at 2 months                                  | 12 (40.0)                                  | 8 (50.0)                                     | 4 (28.6)                                     |
| Current at 4 months                                  | 9 (30.0)                                   | 5 (31.3)                                     | 4 (28.6)                                     |
| Hormonal therapy (e.g., Tamoxifen)                   |  |  |  |
| Current at baseline                                  | 17 (56.7)                                  | 10 (62.5)                                    | 7 (50.0)                                     |
| Current at 2 months                                  | 15 (50.0)                                  | 8 (50.0)                                     | 7 (50.0)                                     |
| Current at 4 months                                  | 14 (46.7)                                  | 7 (43.8)                                     | 7 (50.0)                                     |
| Disease progression                                  |  |  |  |
| Baseline to 2 months                                 | 7 (23.3)                                   | 4 (25.0)                                     | 3 (21.4)                                     |
| Baseline to 4 months                                 | 11 (36.7)                                  | 8 (50.0)                                     | 3 (21.4)                                     |

*Note.* The randomized groups did not differ significantly (all  $P > .05$ ) at baseline on any cancer-related variable. There was a marginally significant difference between conditions at baseline on receipt of biologic therapy ( $p = .07$ ). At 2 and 4 months,  $N = 26$  ( $n = 13$  in PCO ONLY,  $n = 13$  in PCO PLUS).

Table 2-3. Internet Use Variables at Baseline

|                                 | All<br>Participants<br>( <i>N</i> = 30)    | PCO ONLY<br>Participants<br>( <i>n</i> = 16) | PCO PLUS<br>Participants<br>( <i>n</i> = 14) |
|---------------------------------|--|--|--|
| Variable                        | No. (%) /<br><i>M</i> ( <i>SD</i> ), Range | No. (%) /<br><i>M</i> ( <i>SD</i> ), Range   | No. (%) /<br><i>M</i> ( <i>SD</i> ), Range   |
| Hours per week spent online     | 12.3 (9.4), 0-40                           | 12.7 (9.4), 0-30                             | 11.8 (9.8), 1-40                             |
| Frequency of accessing Internet |  |  |  |
| Never                           | 0 (0.0)                                    | 0 (0.0)                                      | 0 (0.0)                                      |
| Less than once a month          | 0 (0.0)                                    | 0 (0.0)                                      | 0 (0.0)                                      |
| Once a month                    | 0 (0.0)                                    | 0 (0.0)                                      | 0 (0.0)                                      |
| 2-3 times a month               | 1 (3.3)                                    | 0 (0.0)                                      | 1 (7.1)                                      |
| Once a week                     | 0 (0.0)                                    | 0 (0.0)                                      | 0 (0.0)                                      |
| 2-3 times a week                | 0 (0.0)                                    | 0 (0.0)                                      | 0 (0.0)                                      |
| Daily                           | 10 (33.3)                                  | 5 (31.3)                                     | 5 (35.7)                                     |
| Several times a day             | 19 (63.3)                                  | 11 (68.8)                                    | 8 (57.1)                                     |
| Comfort level using computer    |  |  |  |
| Very uncomfortable              | 0 (0.0)                                    | 0 (0.0)                                      | 0 (0.0)                                      |
| Somewhat uncomfortable          | 0 (0.0)                                    | 0 (0.0)                                      | 0 (0.0)                                      |
| Somewhat comfortable            | 7 (23.3)                                   | 4 (25.0)                                     | 3 (21.4)                                     |
| Very comfortable                | 23 (76.7)                                  | 12 (75.0)                                    | 11 (78.6)                                    |

*Note.* The randomized groups did not differ significantly (all  $P > .05$ ) at baseline on any Internet use variable. Owing to small cell sizes, categories for the following variables were collapsed as follows in all analyses: frequency of accessing Internet = daily or less vs. several times a day, comfort level using a computer = somewhat comfortable vs. very comfortable.

Table 2-4. Dependent Variables – Psychosocial Functioning

| Variable                       | All Participants<br>( <i>N</i> = 30) |       | PCO ONLY<br>Participants<br>( <i>n</i> = 16) |       | PCO PLUS<br>Participants<br>( <i>n</i> = 14) |       |
|--------------------------------|--------------------------------------|-------|--|-------|--|-------|
|                                | <i>M</i> ( <i>SD</i> )               | Range | <i>M</i> ( <i>SD</i> )                       | Range | <i>M</i> ( <i>SD</i> )                       | Range |
| <b>CES-D</b>                   |                                      |       |  |       |  |       |
| Baseline                       | 14.3 (10.6)                          | 0-45  | 14.5 (10.7)                                  | 0-37  | 14.0 (11.0)                                  | 1-45  |
| 2 months                       | 15.4 (11.1)                          | 3-40  | 14.9 (11.0)                                  | 3-35  | 15.8 (11.7)                                  | 4-40  |
| 4 months                       | 15.4 (10.0)                          | 0-38  | 17.1 (10.5)                                  | 0-35  | 13.8 (9.6)                                   | 2-38  |
| <b>PANAS Negative Affect</b>   |                                      |       |  |       |  |       |
| Baseline                       | 17.6 (6.5)                           | 10-36 | 18.4 (7.5)                                   | 10-36 | 16.8 (5.2)                                   | 11-27 |
| 2 months                       | 17.1 (7.0)                           | 10-40 | 17.7 (9.5)                                   | 10-40 | 16.5 (3.6)                                   | 12-22 |
| 4 months                       | 16.5 (6.6)                           | 10-35 | 17.8 (8.6)                                   | 10-35 | 15.2 (3.7)                                   | 10-22 |
| <b>PANAS Positive Affect</b>   |                                      |       |  |       |  |       |
| Baseline                       | 34.5 (7.9)                           | 10-46 | 32.8 (10.0)                                  | 16-46 | 36.5 (4.0)                                   | 31-41 |
| 2 months                       | 33.5 (7.3)                           | 21-47 | 33.4 (8.5)                                   | 21-46 | 33.6 (6.3)                                   | 25-47 |
| 4 months                       | 32.5 (8.0)                           | 15-46 | 30.2 (8.9)                                   | 15-46 | 34.9 (6.3)                                   | 26-46 |
| <b>GAD-7</b>                   |                                      |       |  |       |  |       |
| Baseline                       | 5.8 (5.1)                            | 0-21  | 6.0 (6.3)                                    | 0-21  | 5.5 (3.3)                                    | 2-14  |
| 2 months                       | 4.6 (4.6)                            | 0-19  | 4.4 (5.6)                                    | 0-19  | 4.8 (3.5)                                    | 0-12  |
| 4 months                       | 4.4 (5.3)                            | 0-20  | 5.5 (7.0)                                    | 0-20  | 3.4 (3.0)                                    | 0-10  |
| <b>PTGI Life Appreciation</b>  |                                      |       |  |       |  |       |
| Baseline                       | 11.7 (2.9)                           | 5-15  | 11.1 (2.8)                                   | 5-15  | 12.3 (2.9)                                   | 7-15  |
| 2 months                       | 12.3 (2.2)                           | 7-15  | 12.2 (2.6)                                   | 7-15  | 12.4 (1.8)                                   | 10-15 |
| 4 months                       | 12.8 (2.3)                           | 5-15  | 12.8 (2.9)                                   | 5-15  | 12.8 (1.8)                                   | 9-15  |
| <b>PTGI Relating to Others</b> |                                      |       |  |       |  |       |
| Baseline                       | 23.2 (7.8)                           | 6-35  | 22.5 (8.2)                                   | 6-35  | 24.0 (7.6)                                   | 10-35 |
| 2 months                       | 24.3 (7.5)                           | 7-35  | 26.3 (7.7)                                   | 7-35  | 22.2 (6.9)                                   | 9-32  |
| 4 months                       | 25.3 (7.3)                           | 7-35  | 24.9 (7.9)                                   | 7-35  | 25.7 (7.0)                                   | 7-32  |
| <b>IES-R Intrusion</b>         |                                      |       |  |       |  |       |
| Baseline                       | 8.4 (5.5)                            | 0-20  | 8.9 (5.6)                                    | 2-20  | 7.8 (5.5)                                    | 0-19  |
| 2 months                       | 6.8 (5.0)                            | 0-18  | 7.1 (5.3)                                    | 0-18  | 6.5 (5.0)                                    | 0-13  |
| 4 months                       | 7.6 (5.2)                            | 0-21  | 8.5 (4.9)                                    | 3-19  | 6.7 (5.6)                                    | 0-21  |

*Note.* The randomized groups did not differ significantly (all  $P > .05$ ) at baseline on any dependent variable. At 2 and 4 months,  $N = 26$  ( $n = 13$  in PCO ONLY,  $n = 13$  in PCO PLUS). CES-D = Center for Epidemiologic Studies Depression Scale; PANAS = Positive and Negative Affect Schedule; GAD-7 = Generalized Anxiety Disorder Scale; PTGI = Posttraumatic Growth Inventory; IES-R = Impact of Event Scale – Revised.

Table 2-5. Dependent Variables – Physical Functioning

| Variable                        | All Participants<br>( <i>N</i> = 30) |         | PCO ONLY<br>Participants<br>( <i>n</i> = 16) |         | PCO PLUS<br>Participants<br>( <i>n</i> = 14) |         |
|---------------------------------|--------------------------------------|---------|--|---------|--|---------|
|                                 | <i>M</i> ( <i>SD</i> )               | Range   | <i>M</i> ( <i>SD</i> )                       | Range   | <i>M</i> ( <i>SD</i> )                       | Range   |
| <b>BCPT</b>                     |                                      |         |  |         |  |         |
| Baseline                        | 1.3 (0.5)                            | 0.4-2.6 | 1.2 (0.4)                                    | 0.6-1.8 | 1.3 (0.7)                                    | 0.4-2.6 |
| 2 months                        | 1.3 (0.6)                            | 0.2-2.7 | 1.2 (0.4)                                    | 0.2-1.7 | 1.4 (0.7)                                    | 0.3-2.7 |
| 4 months                        | 1.4 (0.7)                            | 0.3-2.8 | 1.3 (0.6)                                    | 0.3-2.6 | 1.4 (0.7)                                    | 0.5-2.8 |
| <b>PROMIS Sleep Disturbance</b> |                                      |         |  |         |  |         |
| Baseline                        | 10.8 (4.3)                           | 4-20    | 11.0 (4.2)                                   | 4-19    | 10.5 (4.6)                                   | 5-20    |
| 2 months                        | 10.7 (3.7)                           | 4-18    | 10.0 (3.3)                                   | 5-15    | 11.4 (4.1)                                   | 4-18    |
| 4 months                        | 11.2 (4.4)                           | 4-20    | 12.2 (4.7)                                   | 4-19    | 10.3 (4.2)                                   | 4-20    |
| <b>PROMIS Pain Interference</b> |                                      |         |  |         |  |         |
| Baseline                        | 9.9 (3.7)                            | 4-19    | 9.8 (4.2)                                    | 4-19    | 10.1 (3.2)                                   | 4-15    |
| 2 months                        | 9.2 (3.5)                            | 4-19    | 7.6 (2.7)                                    | 4-12    | 10.6 (3.7)                                   | 6-19    |
| 4 months                        | 10.0 (5.0)                           | 4-20    | 10.2 (5.6)                                   | 4-20    | 9.8 (4.7)                                    | 4-20    |
| <b>PROMIS Pain Intensity</b>    |                                      |         |  |         |  |         |
| Baseline                        | 7.9 (2.1)                            | 3-12    | 8.1 (2.3)                                    | 5-12    | 7.5 (2.0)                                    | 3-10    |
| 2 months                        | 7.3 (2.0)                            | 3-12    | 6.5 (2.0)                                    | 3-10    | 8.0 (1.7)                                    | 6-12    |
| 4 months                        | 7.4 (2.3)                            | 3-11    | 7.1 (2.6)                                    | 3-11    | 7.8 (2.0)                                    | 5-11    |
| <b>PROMIS Physical Function</b> |                                      |         |  |         |  |         |
| Baseline                        | 15.7 (3.2)                           | 8-20    | 16.1 (3.5)                                   | 8-20    | 15.2 (2.8)                                   | 9-19    |
| 2 months                        | 16.0 (3.2)                           | 10-20   | 16.8 (3.0)                                   | 10-20   | 15.2 (3.2)                                   | 10-19   |
| 4 months                        | 14.5 (3.6)                           | 7-19    | 14.5 (3.9)                                   | 8-19    | 14.6 (3.5)                                   | 7-19    |
| <b>PROMIS Fatigue</b>           |                                      |         |  |         |  |         |
| Baseline                        | 11.9 (4.1)                           | 5-20    | 11.6 (4.3)                                   | 5-20    | 12.2 (4.1)                                   | 7-20    |
| 2 months                        | 11.7 (4.5)                           | 4-20    | 11.2 (4.2)                                   | 4-16    | 12.3 (5.0)                                   | 7-20    |
| 4 months                        | 12.0 (4.3)                           | 4-20    | 11.8 (4.9)                                   | 4-20    | 12.2 (3.6)                                   | 7-19    |

*Note.* The randomized groups did not differ significantly (all  $P > .05$ ) at baseline on any dependent variable. At 2 and 4 months,  $N = 26$  ( $n = 13$  in PCO ONLY,  $n = 13$  in PCO PLUS). BCPT = Breast Cancer Prevention Trial Symptom Scales; PROMIS = Patient-Reported Outcomes Measurement Information System.

Table 2-6. Correlations Among Dependent Variables at Baseline ( $N = 30$ )

| Measure                         | 2         | 3          | 4         | 5    | 6        | 7         | 8    | 9         | 10   | 11        | 12        | 13         |
|---------------------------------|-----------|------------|-----------|------|----------|-----------|------|-----------|------|-----------|-----------|------------|
| 1. CES-D                        | .67<br>** | -.60<br>** | .67<br>** | -.13 | -.08     | .68<br>** | .35  | .36       | .28  | -.09      | -.09      | .48<br>**  |
| 2. PANAS<br>Negative Affect     | --        | -.24       | .80<br>** | .16  | .04      | .56<br>** | .04  | .02       | .01  | .05       | .31       | .04        |
| 3. PANAS<br>Positive Affect     |           | --         | -.16      | .27  | .13      | -.34      | -.07 | -.31      | -.22 | .24       | .25       | -.56<br>** |
| 4. GAD-7                        |           |            | --        | -.04 | .15      | .63<br>** | .13  | .26       | .24  | .24       | .05       | .09        |
| 5. PTGI Life<br>Appreciation    |           |            |           | --   | .40<br>* | -.07      | -.04 | -.30      | .10  | .04       | .21       | -.26       |
| 6. PTGI Relating<br>to Others   |           |            |           |      | --       | -.08      | -.05 | -.25      | -.03 | -.09      | -.04      | -.33       |
| 7. IES-R Intrusion              |           |            |           |      |          | --        | .11  | .50<br>** | .31  | .18       | .08       | .27        |
| 8. BCPT                         |           |            |           |      |          |           | --   | .13       | .23  | .18       | -.31      | .20        |
| 9. PROMIS Sleep<br>Disturbance  |           |            |           |      |          |           |      | --        | .30  | -.02      | -.28      | .40<br>*   |
| 10. PROMIS Pain<br>Interference |           |            |           |      |          |           |      |           | --   | .59<br>** | -.42<br>* | .41<br>*   |
| 11. PROMIS Pain<br>Intensity    |           |            |           |      |          |           |      |           |      | --        | -.19      | -.05       |
| 12. PROMIS<br>Physical Function |           |            |           |      |          |           |      |           |      |           | --        | -.48<br>** |
| 13. PROMIS<br>Fatigue           |           |            |           |      |          |           |      |           |      |           |           | --         |

*Note.* CES-D = Center for Epidemiologic Studies Depression Scale; PANAS = Positive and Negative Affect Schedule; GAD-7 = Generalized Anxiety Disorder Scale; PTGI = Posttraumatic Growth Inventory; IES-R = Impact of Event Scale – Revised; BCPT = Breast Cancer Prevention Trial Symptom Scales; PROMIS = Patient-Reported Outcomes Measurement Information System.

\* $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

Table 2-7. Mediator Variables

| Variable                     | All Participants<br>( <i>N</i> = 30) |         | PCO ONLY<br>Participants<br>( <i>n</i> = 16) |         | PCO PLUS<br>Participants<br>( <i>n</i> = 14) |         |
|------------------------------|--------------------------------------|---------|--|---------|--|---------|
|                              | <i>M</i> ( <i>SD</i> )               | Range   | <i>M</i> ( <i>SD</i> )                       | Range   | <i>M</i> ( <i>SD</i> )                       | Range   |
| <b>SSSS Women with MBC*</b>  |                                      |         |  |         |  |         |
| Baseline                     | 3.8 (0.5)                            | 2.6-4.6 | 3.7 (0.5)                                    | 2.6-4.6 | 3.9 (0.6)                                    | 3.0-4.6 |
| 2 months                     | 3.7 (0.4)                            | 2.9-4.4 | 3.8 (0.5)                                    | 2.9-4.4 | 3.7 (0.4)                                    | 2.9-4.3 |
| 4 months                     | 3.6 (0.6)                            | 2.6-4.6 | 3.7 (0.5)                                    | 3.1-4.3 | 3.5 (0.7)                                    | 2.6-4.6 |
| <b>UCLA Loneliness Scale</b> |                                      |         |  |         |  |         |
| Baseline                     | 19.4 (5.8)                           | 10-37   | 17.8 (4.9)                                   | 10-25   | 21.2 (6.5)                                   | 13-37   |
| 2 months                     | 20.0 (7.3)                           | 10-39   | 18.7 (6.0)                                   | 10-29   | 21.3 (8.5)                                   | 12-39   |
| 4 months                     | 19.0 (8.0)                           | 10-39   | 17.9 (7.7)                                   | 10-37   | 20.0 (8.4)                                   | 10-39   |
| <b>Universality</b>          |                                      |         |  |         |  |         |
| Baseline                     | 26.5 (5.4)                           | 16-35   | 26.1 (4.9)                                   | 16-32   | 27.1 (6.1)                                   | 18-35   |
| 2 months                     | 27.2 (4.8)                           | 15-33   | 27.1 (4.7)                                   | 17-31   | 27.3 (5.1)                                   | 15-33   |
| 4 months                     | 28.3 (3.7)                           | 20-34   | 28.2 (3.8)                                   | 20-34   | 28.4 (3.7)                                   | 20-32   |
| <b>Altruism</b>              |                                      |         |  |         |  |         |
| Baseline                     | 22.3 (4.7)                           | 10-28   | 21.7 (4.4)                                   | 12-28   | 23.0 (5.1)                                   | 10-28   |
| 2 months                     | 22.7 (4.4)                           | 9-28    | 22.4 (4.8)                                   | 9-28    | 23.0 (4.1)                                   | 14-28   |
| 4 months                     | 24.1 (2.9)                           | 19-28   | 23.8 (3.0)                                   | 19-28   | 24.4 (2.8)                                   | 19-28   |

*Note.* The randomized groups did not differ significantly (all  $P > .05$ ) at baseline on any mediator variable. SSSS = Sources of Social Support Scale. At 2 and 4 months,  $N = 26$  ( $n = 13$  in PCO ONLY,  $n = 13$  in PCO PLUS).

\*Descriptive statistics do not include women who reported that they did not know any other women with MBC (8 women at baseline: 3 in PCO ONLY and 5 in PCO PLUS; 8 women at 2 months: 5 in PCO ONLY and 3 in PCO PLUS; 4 women at 4 months: 4 in PCO ONLY and 0 in PCO PLUS).

Table 2-8. Correlations Among Mediator Variables at Baseline ( $N = 30$ )

| Measure                  | 2    | 3    | 4         |
|--------------------------|------|------|-----------|
| 1. SSSS Women with MBC   | -.31 | .23  | .22       |
| 2. UCLA Loneliness Scale | --   | -.07 | .15       |
| 3. Universality          |      | --   | .53<br>** |
| 4. Altruism              |      |      | --        |

*Note.* SSSS = Sources of Social Support Scale.

\* $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

Table 2-9. Predictors of Change in Outcomes

| Variable                         | All Participants<br>( <i>N</i> = 30) |         | PCO ONLY<br>Participants<br>( <i>n</i> = 16) |         | PCO PLUS<br>Participants<br>( <i>n</i> = 14) |         |
|----------------------------------|--------------------------------------|---------|--|---------|--|---------|
|                                  | <i>M</i> ( <i>SD</i> )               | Range   | <i>M</i> ( <i>SD</i> )                       | Range   | <i>M</i> ( <i>SD</i> )                       | Range   |
| <b>SSSS Friends</b>              |                                      |         |  |         |  |         |
| Baseline                         | 3.8 (0.7)                            | 1.6-4.8 | 3.8 (0.6)                                    | 2.0-4.7 | 3.7 (0.9)                                    | 1.6-4.8 |
| 2 months                         | 3.7 (0.6)                            | 2.1-4.5 | 3.8 (0.4)                                    | 3.0-4.3 | 3.5 (0.7)                                    | 2.1-4.5 |
| 4 months                         | 3.6 (0.5)                            | 2.6-4.4 | 3.7 (0.5)                                    | 2.7-4.3 | 3.5 (0.6)                                    | 2.6-4.4 |
| <b>COPE Emotional Expression</b> |                                      |         |  |         |  |         |
| Baseline                         | 2.7 (0.8)                            | 1.0-4.0 | 2.7 (0.8)                                    | 1.0-3.8 | 2.7 (0.9)                                    | 1.3-4.0 |
| 2 months                         | 2.7 (0.8)                            | 1.0-4.0 | 2.7 (0.8)                                    | 1.0-3.8 | 2.7 (0.9)                                    | 1.8-4.0 |
| 4 months                         | 2.8 (0.8)                            | 1.3-4.0 | 2.7 (0.7)                                    | 1.3-3.8 | 2.8 (0.8)                                    | 2.0-4.0 |
| <b>LIWC Positive Emotion</b>     | 5.1 (1.3)                            | 3.1-7.3 | 5.5 (1.3)                                    | 3.5-7.3 | 4.7 (1.3)                                    | 3.1-7.3 |
| <b>LIWC Negative Emotion</b>     | 0.8 (0.7)                            | 0.0-2.3 | 0.8 (0.8)                                    | 0.0-2.3 | 0.8 (0.6)                                    | 0.0-1.6 |
| <b>MOCS Coping Confidence</b>    |                                      |         |  |         |  |         |
| Baseline                         | 3.6 (0.5)                            | 2.0-4.4 | 3.6 (0.3)                                    | 2.8-4.0 | 3.6 (0.6)                                    | 2.0-4.4 |
| 2 months                         | 3.5 (0.6)                            | 1.8-4.6 | 3.5 (0.5)                                    | 2.4-4.0 | 3.4 (0.7)                                    | 1.8-4.6 |
| 4 months                         | 3.7 (0.8)                            | 2.0-4.8 | 3.8 (0.7)                                    | 2.2-4.8 | 3.6 (0.9)                                    | 2.0-4.8 |
| <b>MOCS Getting Needs Met</b>    |                                      |         |  |         |  |         |
| Baseline                         | 3.2 (0.9)                            | 1.7-5.0 | 3.3 (0.9)                                    | 1.7-5.0 | 3.1 (0.9)                                    | 2.0-4.7 |
| 2 months                         | 3.2 (1.0)                            | 1.0-5.0 | 3.3 (0.8)                                    | 1.7-4.7 | 3.1 (1.1)                                    | 1.0-5.0 |
| 4 months                         | 3.3 (1.0)                            | 1.3-5.0 | 3.3 (1.0)                                    | 1.3-5.0 | 3.2 (0.9)                                    | 2.0-5.0 |

*Note.* The randomized groups did not differ significantly (all  $P > .05$ ) at baseline on any predictor of change in outcomes. At 2 and 4 months,  $N = 26$  ( $n = 13$  in PCO ONLY,  $n = 13$  in PCO PLUS). SSSS = Sources of Social Support Scale; LIWC = Linguistic Inquiry and Word Count; MOCS = Measure of Current Status.

Table 2-10. Correlations Among Predictor Variables at Baseline ( $N = 30$ )

| Measure                      | 2         | 3   | 4          | 5    | 6         |
|------------------------------|-----------|-----|------------|------|-----------|
| 1. SSSS Friends              | .50<br>** | .11 | -.20       | .34  | .58<br>** |
| 2. COPE Emotional Expression | --        | .36 | -.27       | .07  | .59<br>** |
| 3. LIWC Positive Emotion     |           | --  | -.67<br>** | .03  | .28       |
| 4. LIWC Negative Emotion     |           |     | --         | -.11 | -.26      |
| 5. MOCS Coping Confidence    |           |     |            | --   | .25       |
| 6. MOCS Getting Needs Met    |           |     |            |      | --        |

*Note.* SSSS = Sources of Social Support Scale; LIWC = Linguistic Inquiry and Word Count; MOCS = Measure of Current Status.

\* $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

Table 2-11. Website Usefulness at Two- and Four-Month Follow-up

|   | All<br>Participants<br>( <i>N</i> = 26) | PCO ONLY<br>Participants<br>( <i>n</i> = 13) | PCO PLUS<br>Participants<br>( <i>n</i> = 13) |
|---|---|--|--|
| Items   | <i>M</i> ( <i>SD</i> )                  | <i>M</i> ( <i>SD</i> )                       | <i>M</i> ( <i>SD</i> )                       |
| 1. Allowing you to tell the story of your experience                      |   |  |  |
| 2 months  | 3.6 (1.1)                               | 3.5 (1.3)                                    | 3.7 (0.9)                                    |
| 4 months  | 3.5 (1.1)                               | 3.7 (1.1)                                    | 3.4 (1.2)                                    |
| 2. Reducing your having to repeat information over and over               |   |  |  |
| 2 months  | 3.5 (1.2)                               | 3.5 (1.6)                                    | 3.5 (0.8)                                    |
| 4 months  | 3.4 (1.5)                               | 3.8 (1.3)                                    | 2.9 (1.5)                                    |
| 3. Making you feel connected to family and friends                        |   |  |  |
| 2 months  | 3.3 (1.2)                               | 3.3 (1.4)                                    | 3.3 (1.2)                                    |
| 4 months  | 3.1 (1.4)                               | 3.3 (1.4)                                    | 2.9 (1.4)                                    |
| 4. Keeping others informed about how you're doing                         |   |  |  |
| 2 months  | 3.6 (1.2)                               | 3.6 (1.4)                                    | 3.5 (1.1)                                    |
| 4 months  | 3.4 (1.3)                               | 3.8 (1.1)                                    | 3.0 (1.4)                                    |
| 5. Helping you feel cared for by others                                   |   |  |  |
| 2 months  | 3.0 (1.4)                               | 3.2 (1.5)                                    | 2.8 (1.1)                                    |
| 4 months  | 2.8 (1.2)                               | 2.9 (1.2)                                    | 2.6 (1.3)                                    |
| 6. Letting others know what would be helpful to you                       |   |  |  |
| 2 months  | 2.4 (1.0)                               | 2.5 (0.9)                                    | 2.3 (1.1)                                    |
| 4 months  | 2.2 (1.0)                               | 2.3 (1.1)                                    | 2.2 (0.9)                                    |
| 7. Allowing you to help the people who care about you                     |   |  |  |
| 2 months  | 2.8 (1.1)                               | 2.9 (1.2)                                    | 2.8 (1.1)                                    |
| 4 months  | 2.5 (1.1)                               | 2.6 (1.0)                                    | 2.4 (1.3)                                    |
| 8. Reducing the amount of time you spend on the phone/talking with others |   |  |  |
| 2 months  | 2.9 (1.5)                               | 3.1 (1.4)                                    | 2.7 (1.5)                                    |
| 4 months  | 2.7 (1.2)                               | 3.1 (1.1)                                    | 2.4 (1.3)                                    |
| 9. Giving you a place to express your emotions                            |   |  |  |
| 2 months  | 3.7 (1.2)                               | 3.6 (1.2)                                    | 3.9 (1.3)                                    |
| 4 months  | 3.5 (1.4)                               | 3.6 (1.2)                                    | 3.5 (1.6)                                    |
| 10. Getting help from others  |   |  |  |
| 2 months  | 2.3 (1.1)                               | 2.5 (1.2)                                    | 2.1 (1.0)                                    |
| 4 months  | 2.2 (1.2)                               | 2.3 (1.4)                                    | 2.0 (1.2)                                    |

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

*Note.* The randomized groups did not differ significantly (all  $P > .05$ ) on any website usefulness item at 2 or 4 months.

Table 2-12. Usefulness of Website Features at Two- and Four-Month Follow-up

|   | All<br>Participants<br>( <i>N</i> = 26) | PCO ONLY<br>Participants<br>( <i>n</i> = 13) | PCO PLUS<br>Participants<br>( <i>n</i> = 13) |
|---|---|--|--|
| Items   | <i>M</i> ( <i>SD</i> )                  | <i>M</i> ( <i>SD</i> )                       | <i>M</i> ( <i>SD</i> )                       |
| 1. Writing and publishing posts                                 |   |  |  |
| 2 months  | 3.8 (1.1)                               | 3.6 (1.2)                                    | 4.1 (0.9)                                    |
| 4 months  | 3.8 (1.2)                               | 3.9 (1.2)                                    | 3.7 (1.2)                                    |
| 2. Adding photos  |   |  |  |
| 2 months  | 3.7 (1.2)                               | 3.3 (1.3)                                    | 4.1 (0.9)                                    |
| 4 months  | 3.2 (1.3)                               | 2.9 (1.2)                                    | 3.5 (1.3)                                    |
| 3. About Me page  |   |  |  |
| 2 months  | 3.8 (1.1)                               | 3.5 (1.3)                                    | 4.1 (0.9)                                    |
| 4 months  | 3.1 (1.2)                               | 2.8 (1.3)                                    | 3.3 (1.1)                                    |
| 4. My Special Requests page                                     |   |  |  |
| 2 months  | 2.7 (1.3)                               | 2.7 (1.4)                                    | 2.7 (1.2)                                    |
| 4 months  | 2.4 (1.1)                               | 2.3 (1.3)                                    | 2.5 (1.0)                                    |
| 5. Useful Links page  |   |  |  |
| 2 months  | 3.0 (1.0)                               | 2.9 (1.2)                                    | 3.2 (0.8)                                    |
| 4 months  | 2.5 (1.0)                               | 2.3 (1.0)                                    | 2.8 (1.1)                                    |
| 6. Contact Me page  |   |  |  |
| 2 months  | 3.1 (1.2)                               | 3.3 (1.3)                                    | 3.0 (1.0)                                    |
| 4 months  | 2.7 (1.0)                               | 2.4 (0.9)                                    | 2.9 (1.0)                                    |
| 7. How You Can Help calendar                                    |   |  |  |
| 2 months  | 2.4 (1.2)                               | 2.3 (1.2)                                    | 2.5 (1.2)                                    |
| 4 months  | 2.1 (1.0)                               | 2.0 (0.9)                                    | 2.3 (1.1)                                    |
| 8. Ability for friends and family to comment on your posts      |   |  |  |
| 2 months  | 3.7 (1.1)                               | 3.8 (1.3)                                    | 3.5 (0.9)                                    |
| 4 months  | 3.5 (1.3)                               | 3.8 (1.2)                                    | 3.3 (1.3)                                    |
| 9. Approving and replying to comments                           |   |  |  |
| 2 months  | 3.6 (1.1)                               | 3.7 (1.2)                                    | 3.5 (1.0)                                    |
| 4 months  | 3.2 (1.4)                               | 3.2 (1.3)                                    | 3.2 (1.5)                                    |
| 10. Ability for friends and family to subscribe to your website |   |  |  |
| 2 months  | 3.6 (1.1)                               | 3.6 (1.3)                                    | 3.6 (1.0)                                    |
| 4 months  | 3.5 (1.3)                               | 3.7 (1.1)                                    | 3.3 (1.4)                                    |
| 11. Emailing subscribers directly from your website             |   |  |  |
| 2 months  | 3.0 (1.2)                               | 2.8 (1.3)                                    | 3.2 (1.0)                                    |
| 4 months  | 2.7 (1.3)                               | 2.4 (1.2)                                    | 2.9 (1.4)                                    |

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

*Note.* The randomized groups did not differ significantly (all  $P > .05$ ) on any usefulness of website features item at 2 or 4 months.

Figure 2-1. Conceptual Model for the Study

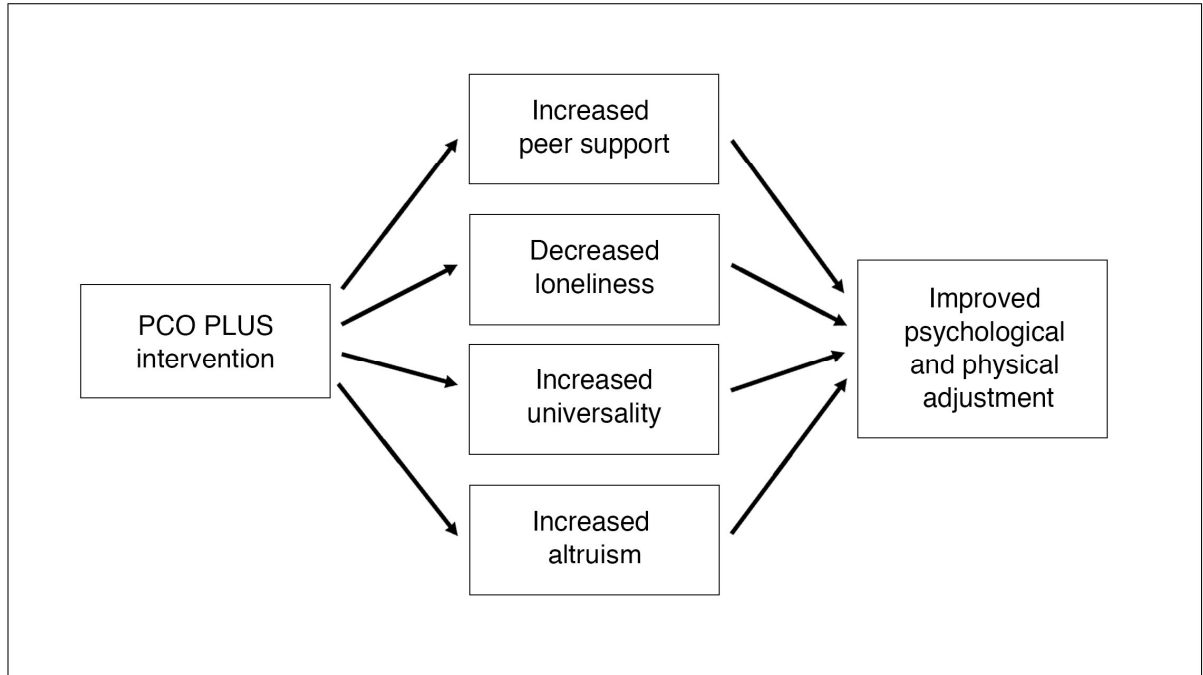


Figure 2-2. Accrual and Retention

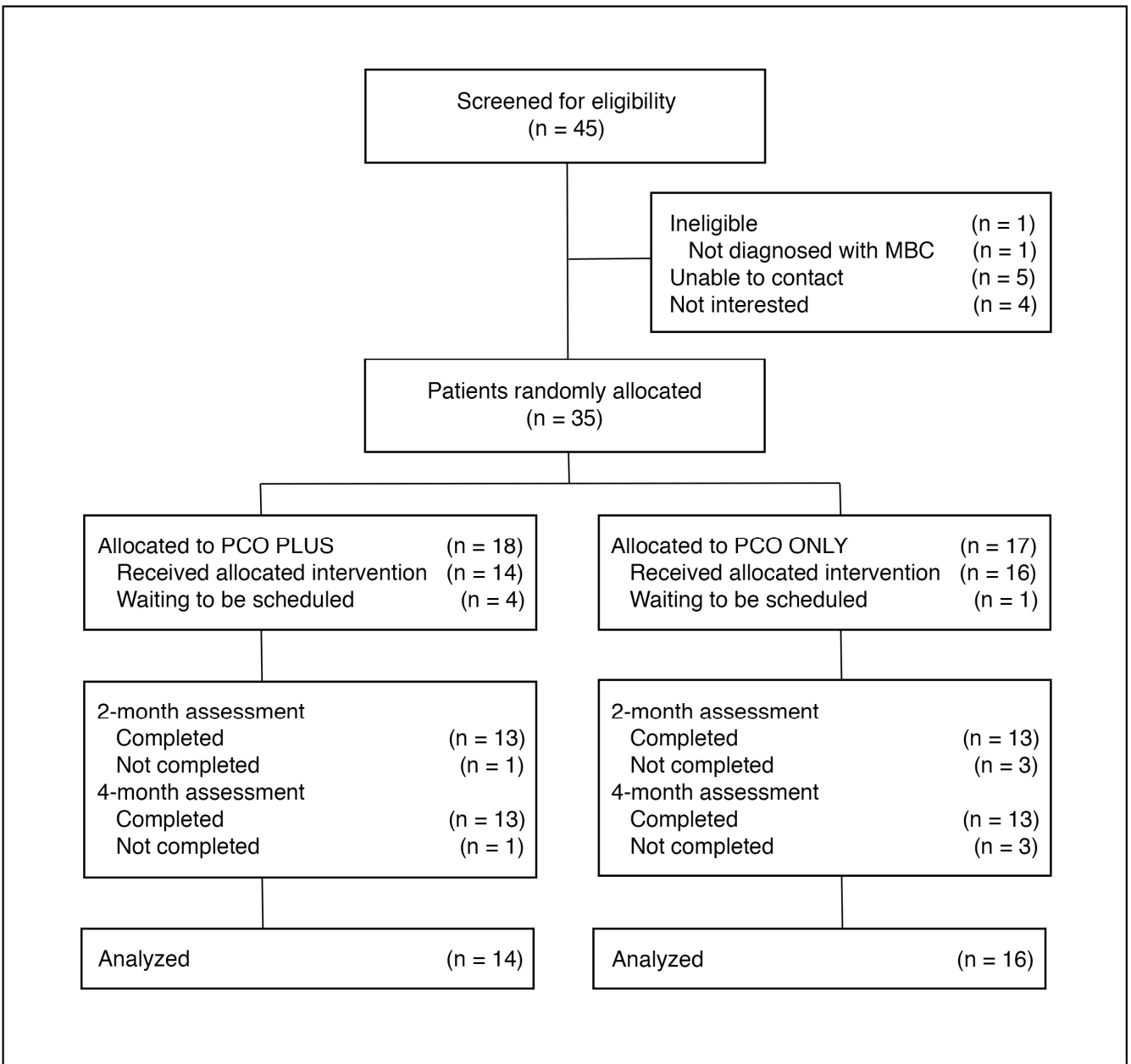
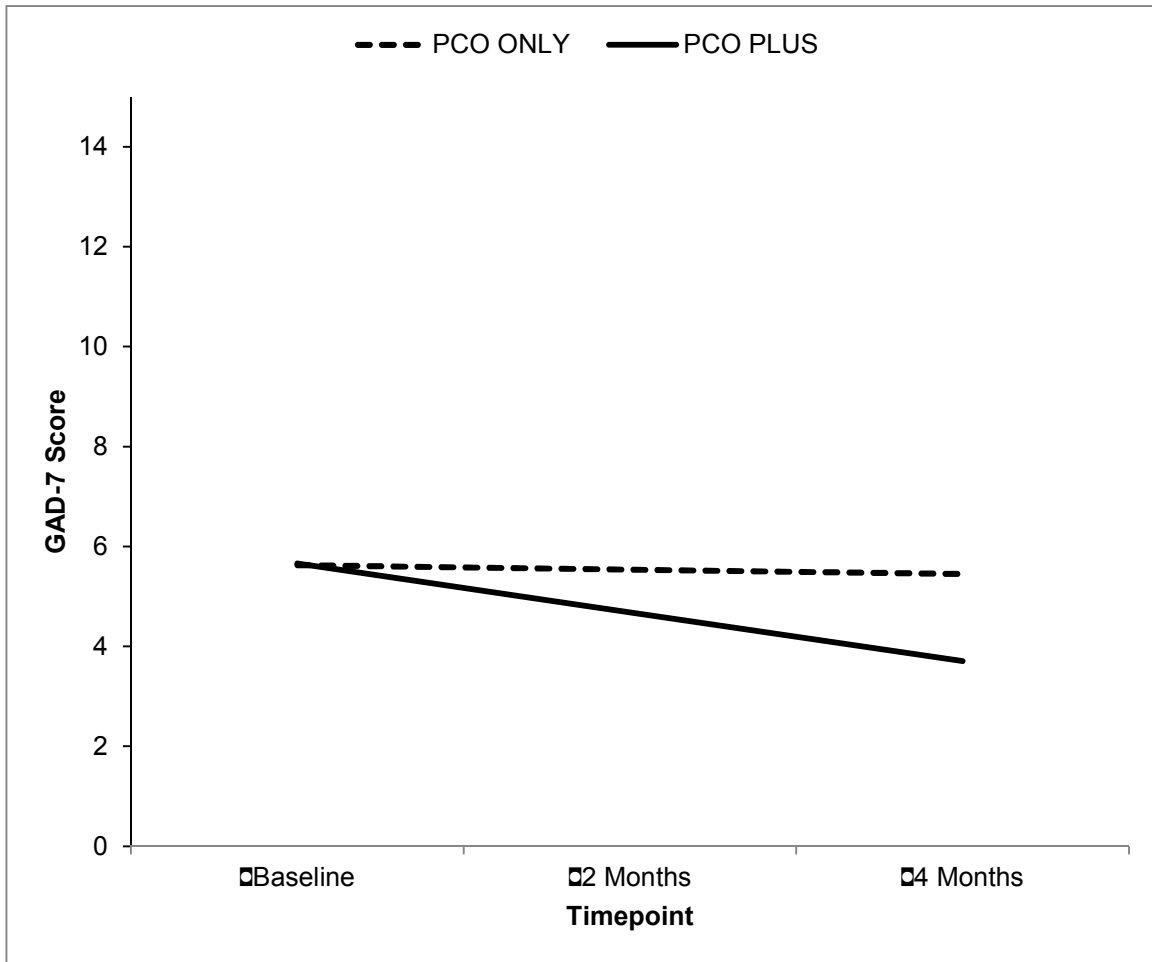


Figure 2-3. Effect of Condition on GAD-7 Score Over Study Period



*Note.* GAD-7 = Generalized Anxiety Disorder Scale.

Figure 2-4. Effect of Condition on UCLA Loneliness Scale Score Over Study Period

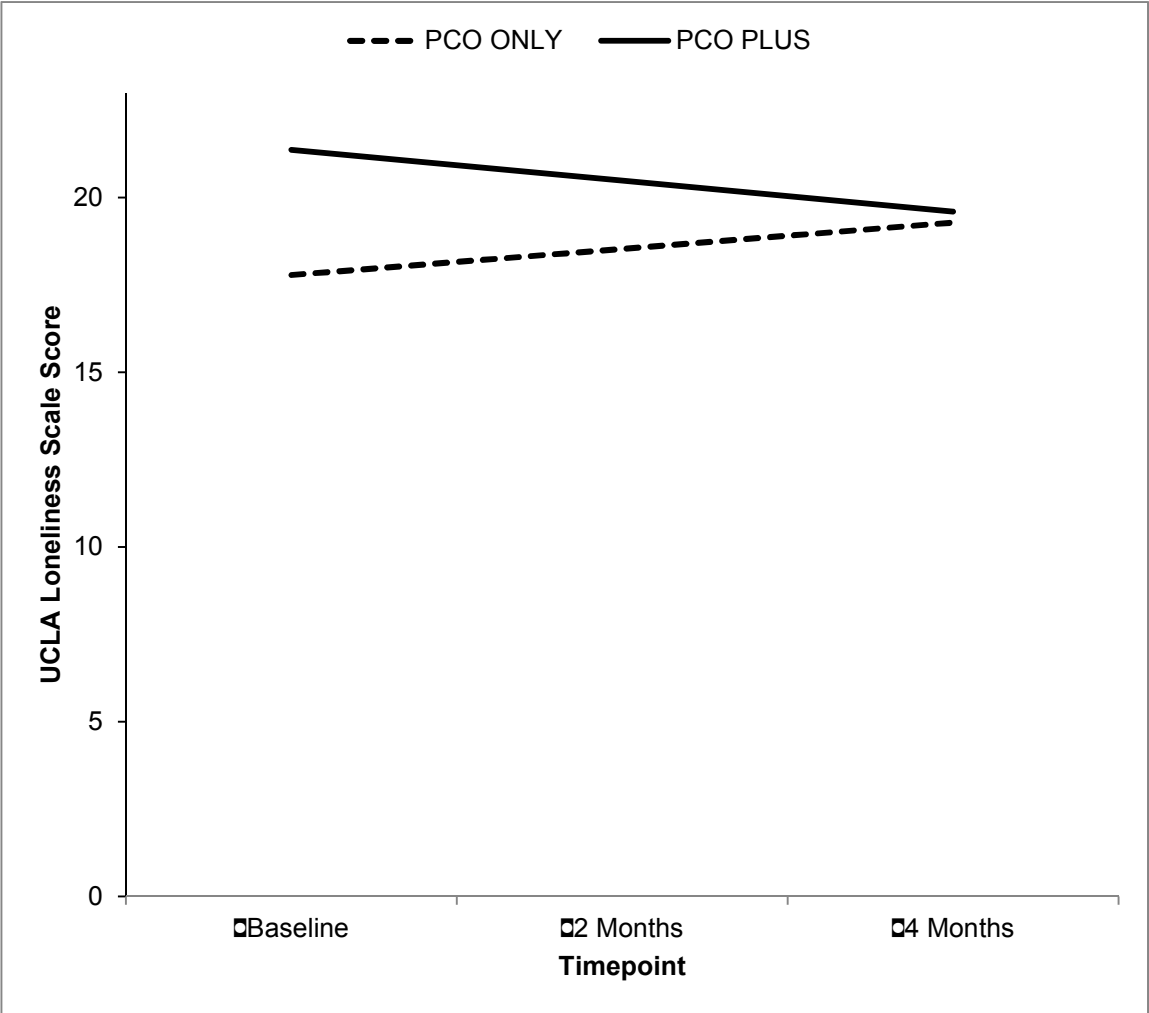
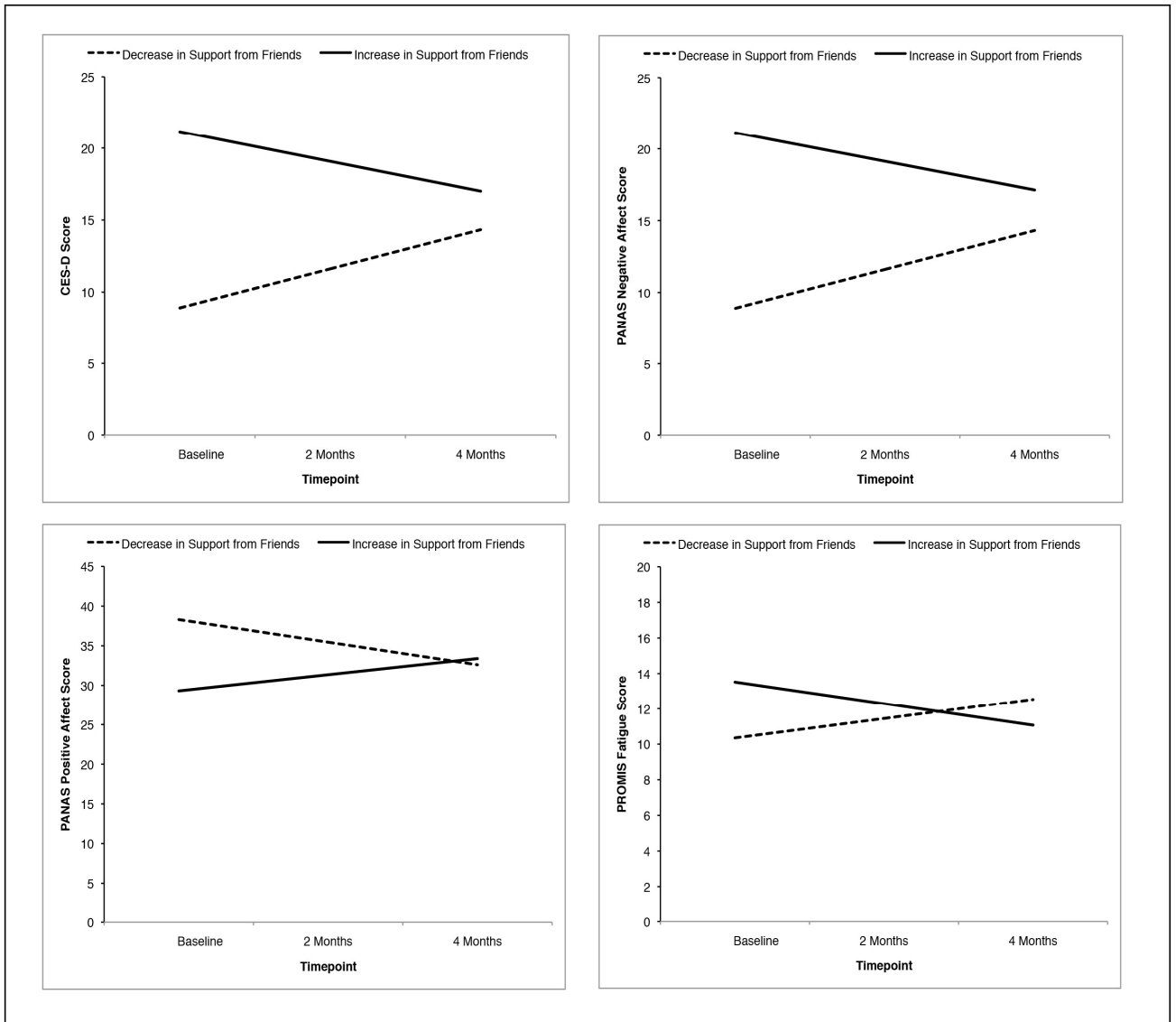
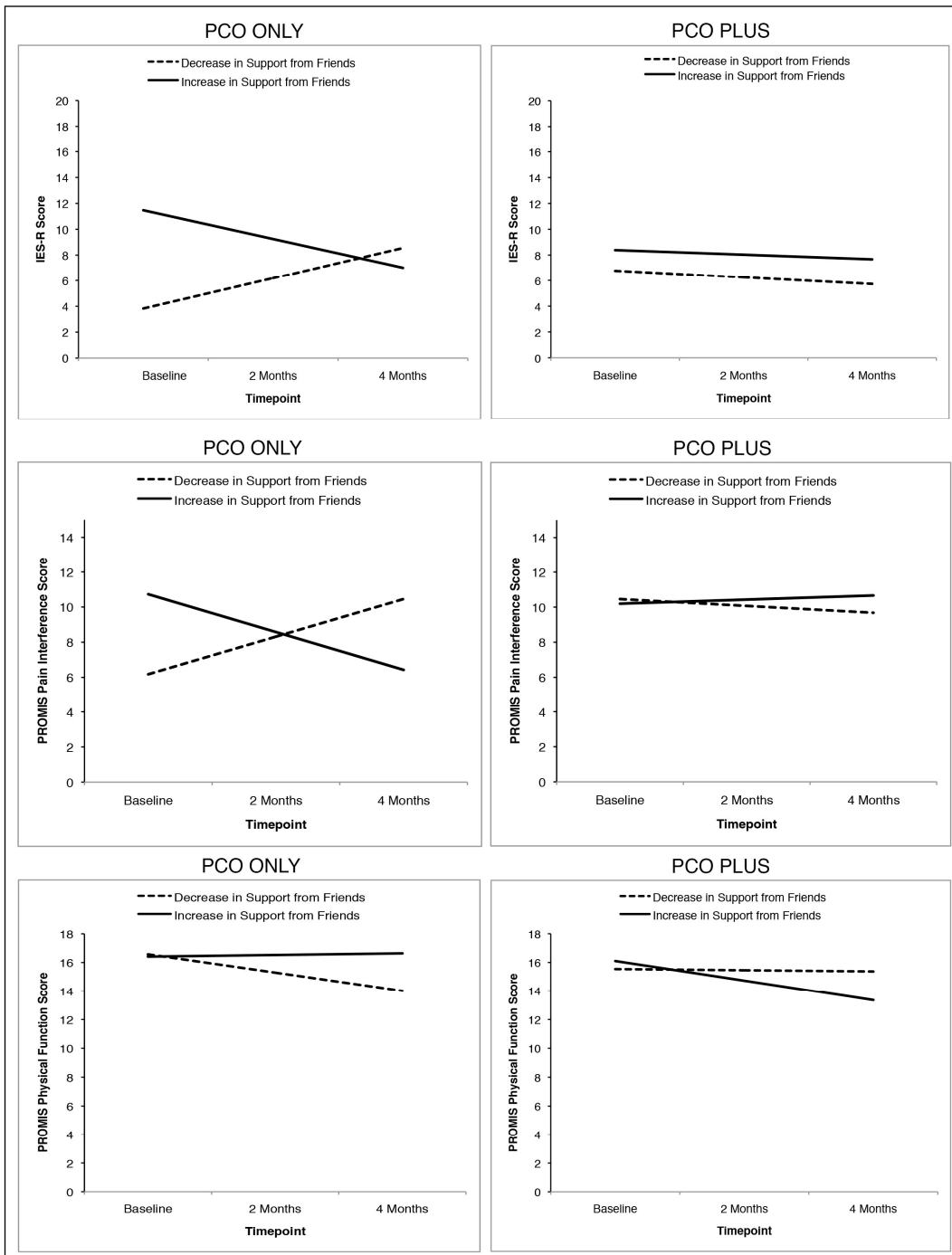


Figure 2-5. Relationship between Change in SSSS Friends Score from Study Baseline to Two Months and Outcomes Over Study Period



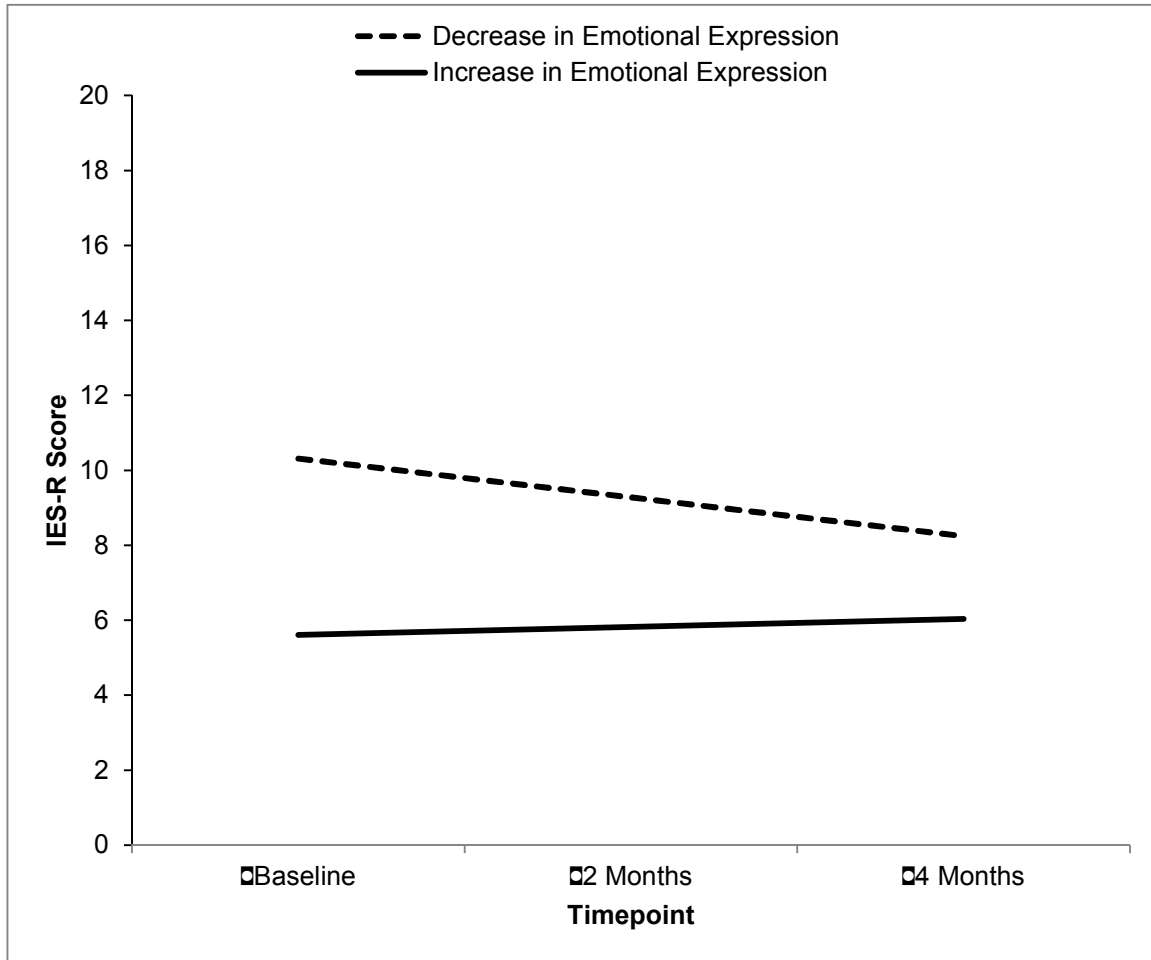
*Note.* Decrease in support from friends = 1 *SD* decrease; increase in support from friends = 1 *SD* increase. SSSS = Sources of Social Support Scale; CES-D = Center for Epidemiologic Studies Depression Scale; PANAS = Positive and Negative Affect Schedule; PROMIS = Patient-Reported Outcomes Measurement Information System.

Figure 2-6. Relationship between Change in SSSS Friends Score from Study Baseline to Two Months and Outcomes Over Study Period, By Condition



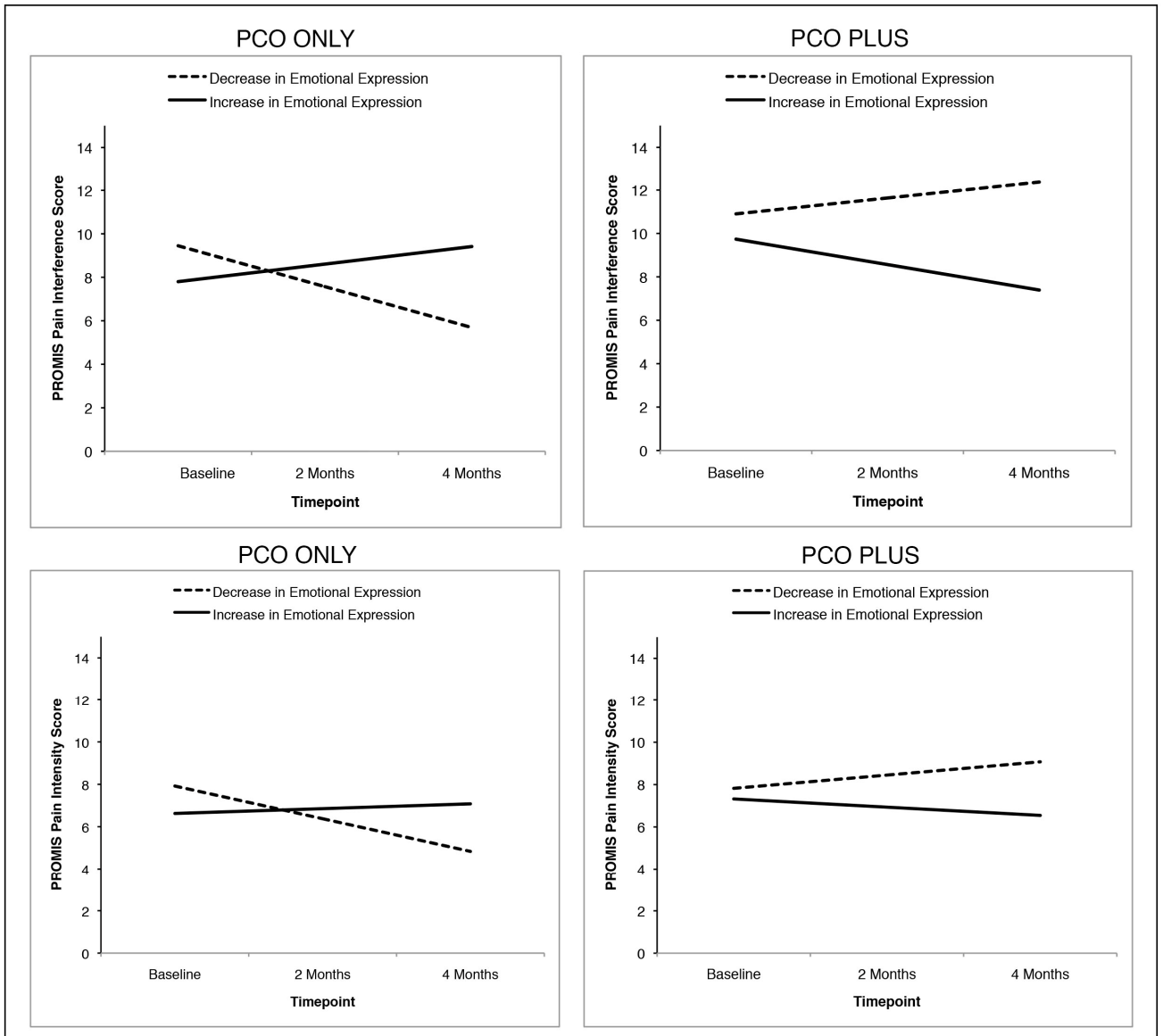
Note. Decrease in support from friends = 1 SD decrease; increase in support from friends = 1 SD increase. SSSS = Sources of Social Support Scale; IES-R = Impact of Event Scale – Revised; PROMIS = Patient-Reported Outcomes Measurement Information System.

Figure 2-7. Relationship between Change in COPE Emotional Expression Score from Study Baseline to Two Months and IES-R Score Over Study Period



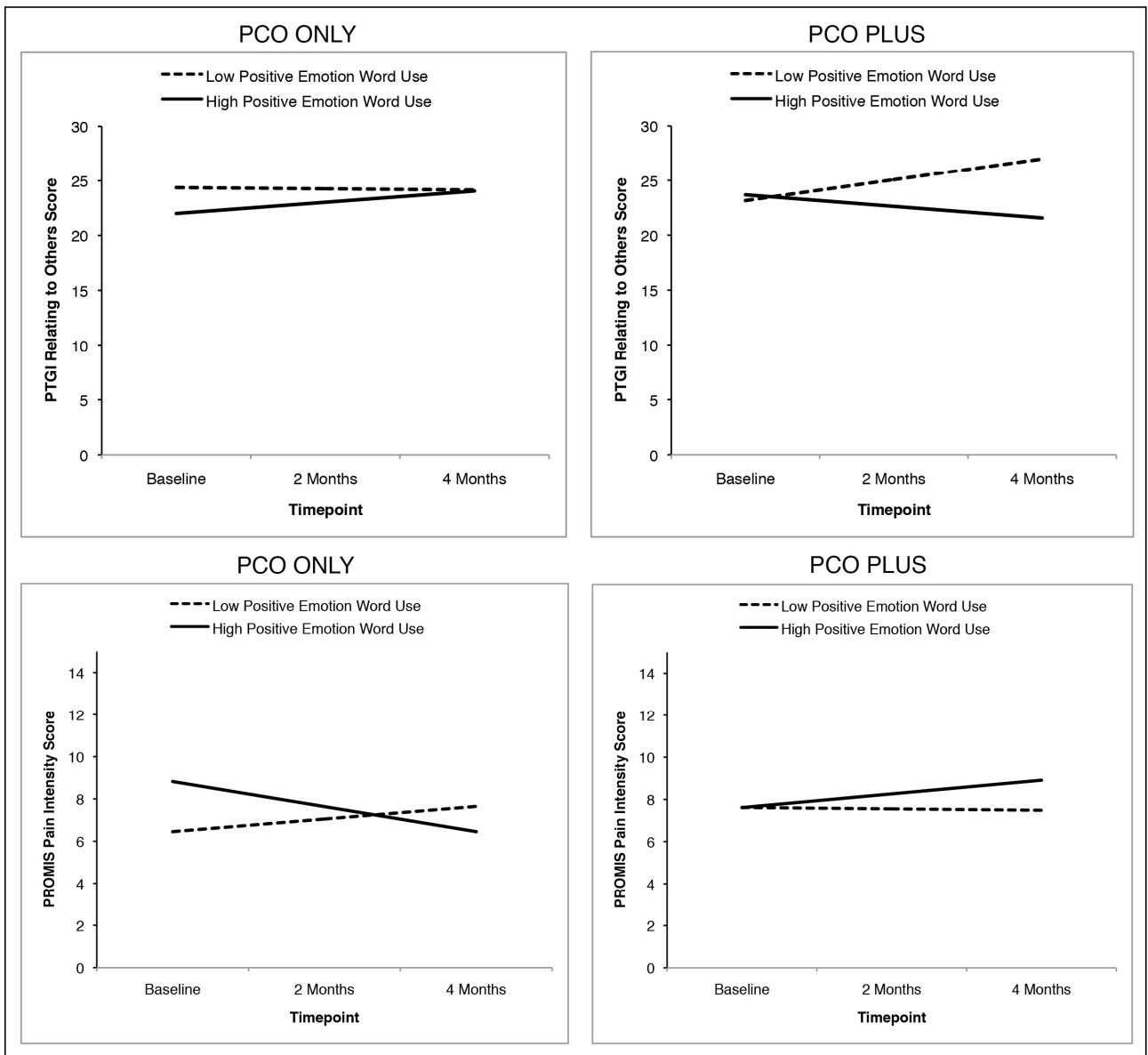
Note. Decrease in emotional expression = 1 *SD* decrease; increase in emotional expression = 1 *SD* increase. IES-R = Impact of Event Scale – Revised.

Figure 2-8. Relationship between Change in COPE Emotional Expression Score from Study Baseline to Two Months and Outcomes Over Study Period, By Condition



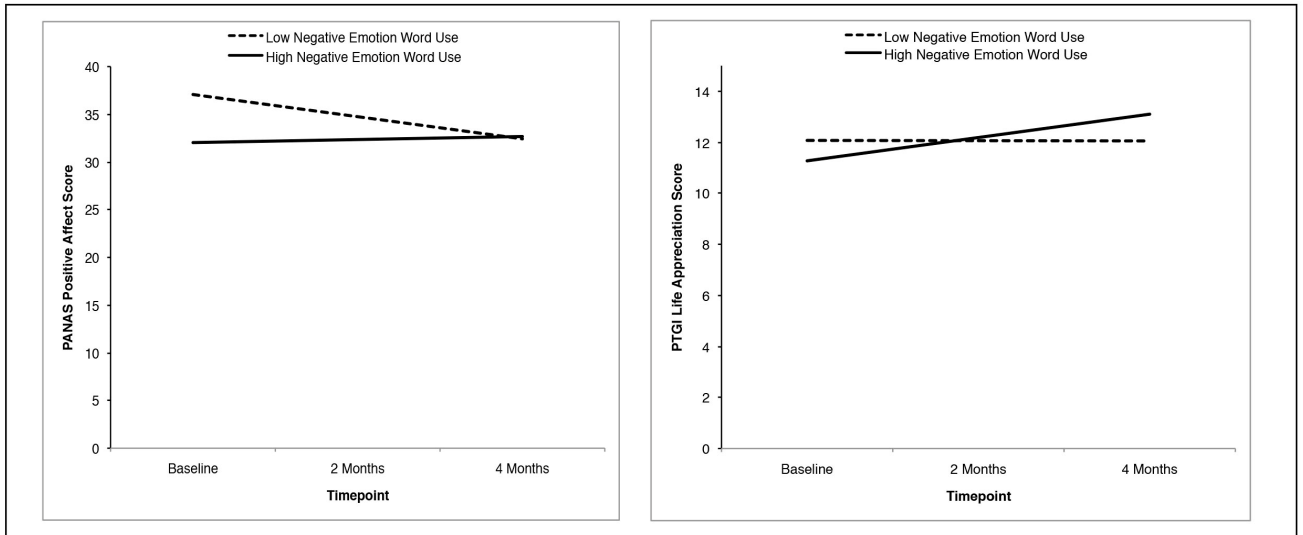
Note. Decrease in emotional expression = 1 SD decrease; increase in emotional expression = 1 SD increase. PROMIS = Patient-Reported Outcomes Measurement Information System.

Figure 2-9. Relationship between LIWC Positive Emotion Word Use and Outcomes Over Study Period, By Condition



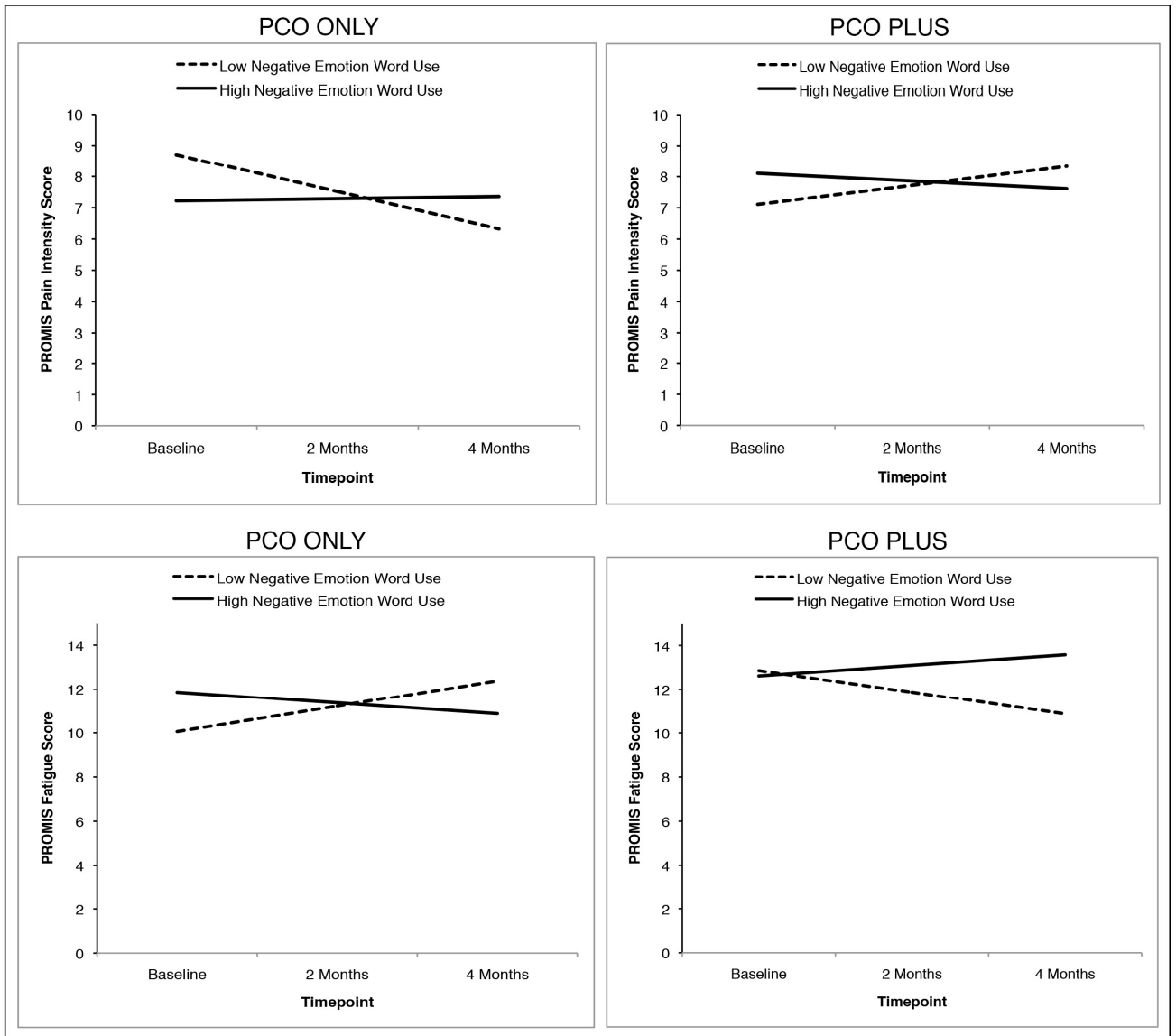
Note. Low positive emotion word use = positive emotion word use at 1 SD below mean; high positive emotion word use = positive emotion word use at 1 SD above mean. LIWC = Linguistic Inquiry and Word Count; PTGI = Posttraumatic Growth Inventory; PROMIS = Patient-Reported Outcomes Measurement Information System.

Figure 2-10. Relationship between LIWC Negative Emotion Word Use and Outcomes Over Study Period



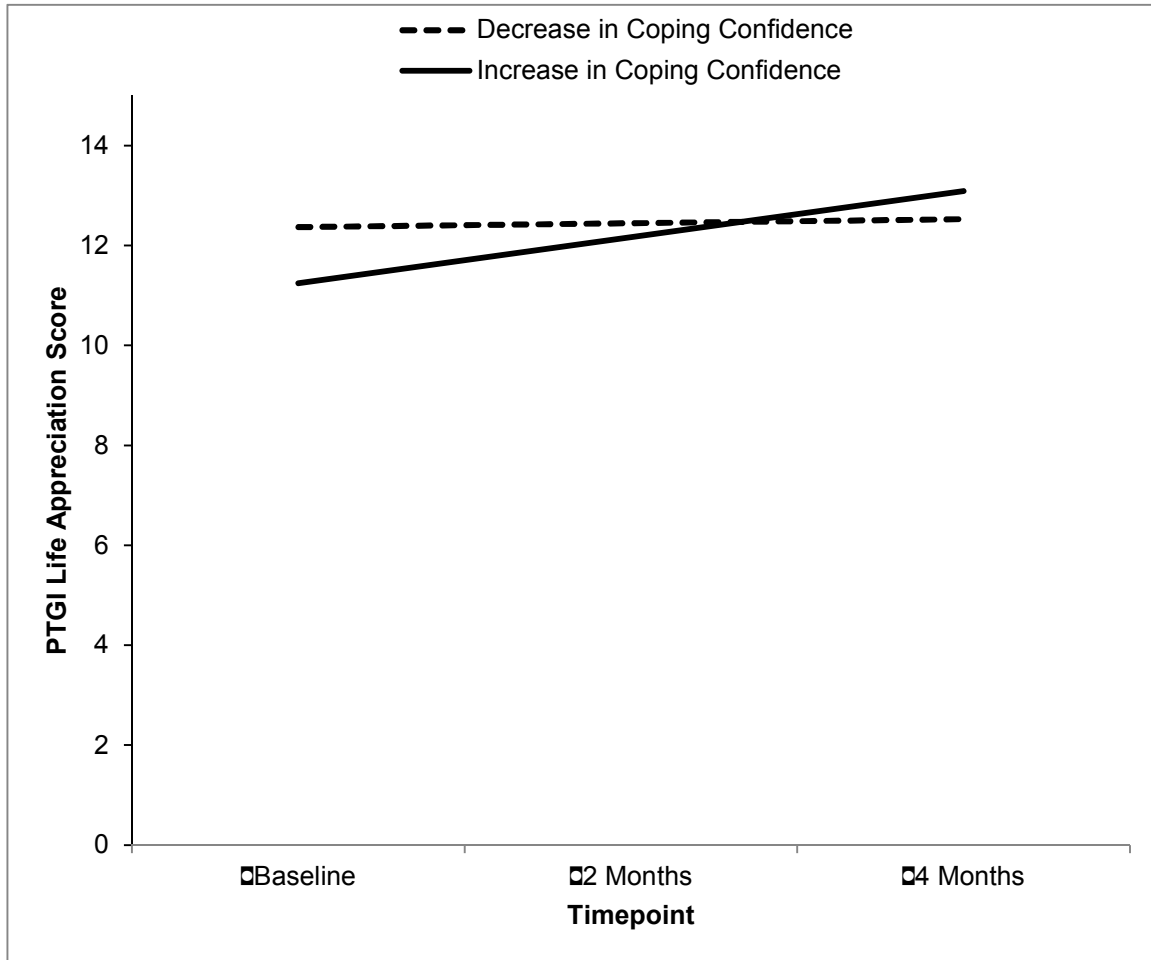
*Note.* Low negative emotion word use = negative emotion word use at 1 *SD* below mean; high negative emotion word use = negative emotion word use at 1 *SD* above mean. LIWC = Linguistic Inquiry and Word Count; PANAS = Positive and Negative Affect Schedule; PTGI = Posttraumatic Growth Inventory.

Figure 2-11. Relationship between LIWC Negative Emotion Word Use and Outcomes Over Study Period, By Condition



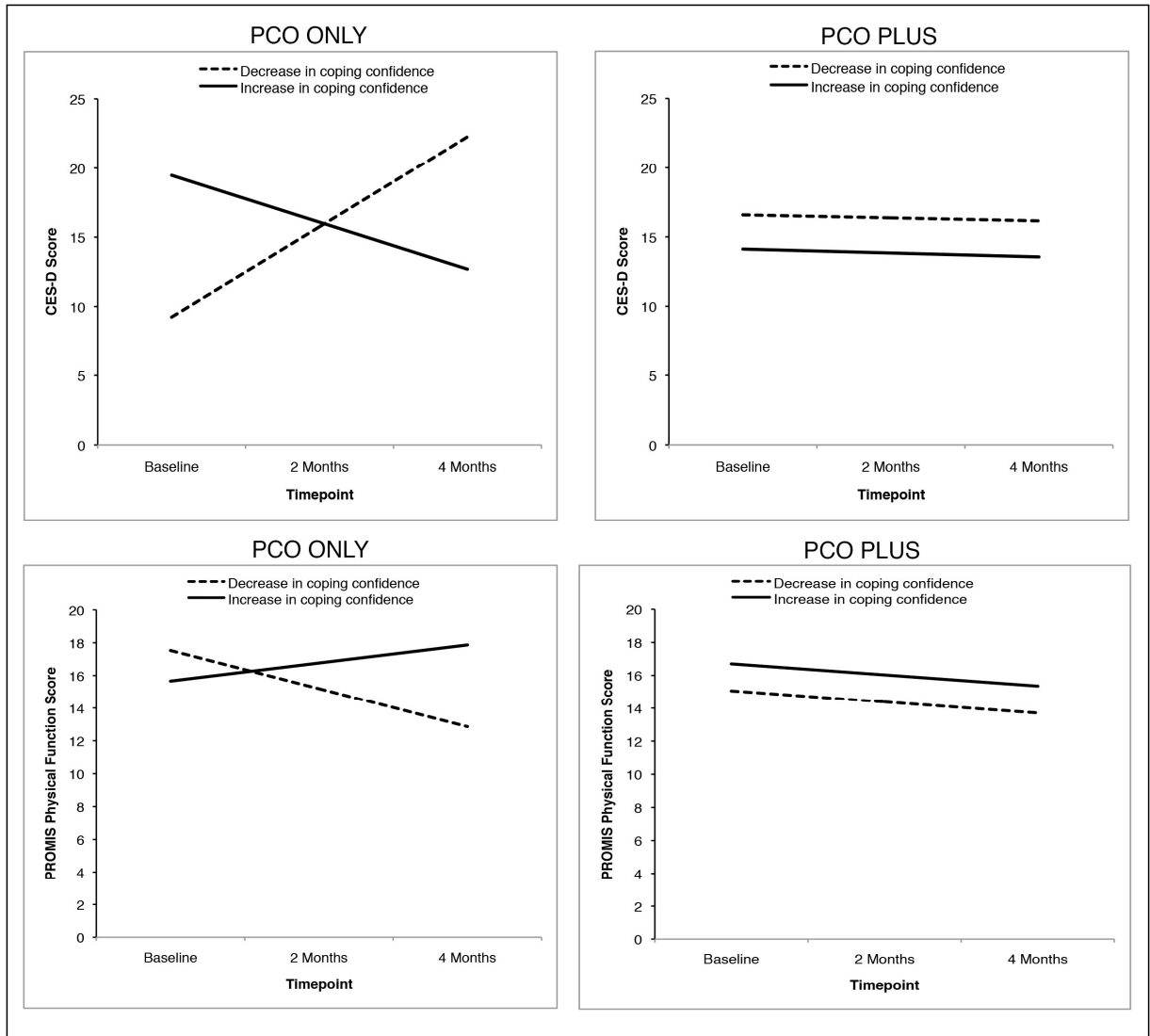
*Note.* Low negative emotion word use = negative emotion word use at 1 *SD* below mean; high negative emotion word use = negative emotion word use at 1 *SD* above mean. LIWC = Linguistic Inquiry and Word Count; PROMIS = Patient-Reported Outcomes Measurement Information System.

Figure 2-12. Relationship between Change in MOCS Coping Confidence Score from Study Baseline to Two Months and PTGI Life Appreciation Score Over Study Period



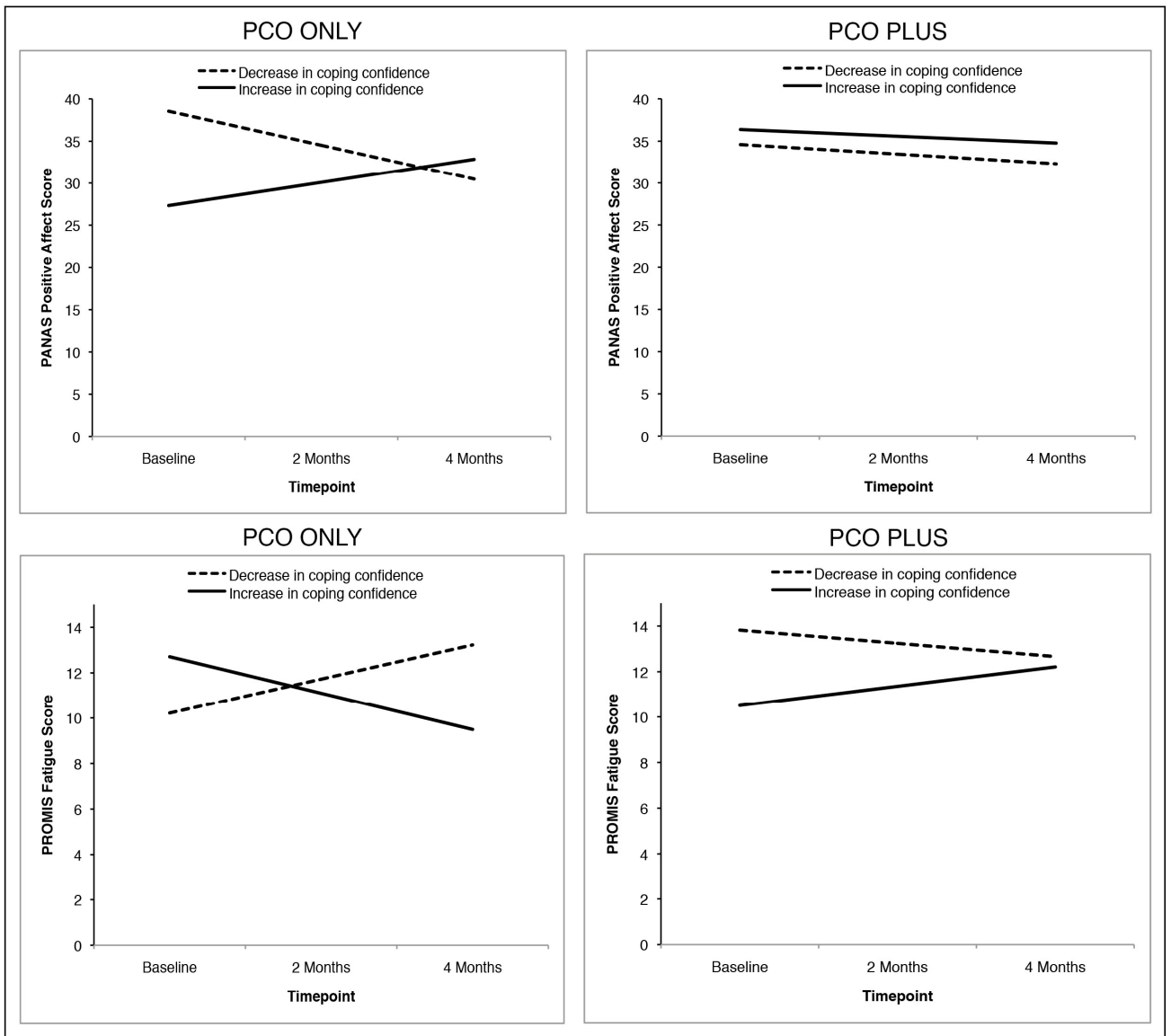
Note. Decrease in coping confidence = 1 *SD* decrease; increase in coping confidence = 1 *SD* increase. MOCS = Measure of Current Status; PTGI = Posttraumatic Growth Inventory.

Figure 2-13. Relationship between Change in MOCS Coping Confidence Score from Study Baseline to Two Months and Outcomes Over Study Period, By Condition



Note. Decrease in coping confidence = 1 SD decrease; increase in coping confidence = 1 SD increase. MOCS = Measure of Current Status; CES-D = Center for Epidemiologic Studies Depression Scale; PROMIS = Patient-Reported Outcomes Measurement Information System.

Figure 2-14. Relationship between Change in MOCS Coping Confidence Score from Study Baseline to Two Months and Outcomes Over Study Period, By Condition



*Note.* Decrease in coping confidence = 1 *SD* decrease; increase in coping confidence = 1 *SD* increase. MOCS = Measure of Current Status; PANAS = Positive and Negative Affect Schedule; PROMIS = Patient-Reported Outcomes Measurement Information System.

## **General Discussion**

### **Strengths of the Current Research**

Project Connect Online (PCO) represents a brief psychosocial intervention for breast cancer patients with high potential for dissemination. PCO was designed to facilitate social support and emotional expression, which extensive literature suggests are beneficial for psychosocial and physical adjustment in cancer (e.g., Frattaroli, 2006; Helgeson & Cohen, 1996; Nosarti, Roberts, Crayford, McKenzie, & David, 2002; Pinquart & Duberstein, 2010; Stanton, 2011). Although personal websites are widely used by individuals with cancer to manage communication and support, to our knowledge PCO is the only randomized controlled trial to evaluate the potential benefits of personal website use among women diagnosed with breast cancer. Furthermore, few psychosocial interventions have targeted women with metastatic breast cancer (MBC) specifically despite the striking psychosocial and physical burden of living with metastatic disease (Low, Beran, & Stanton, 2007; Mayer & Grober, 2006). Psychosocial interventions for cancer patients typically require multiple in-person sessions extending over weeks or months. With its brief intervention format, PCO was designed to overcome common barriers (e.g., physical limitations, intensive treatment schedules) to participating in traditional psychosocial interventions.

### **Comparison of the Original PCO Trial and the Current PCO Trial for MBC**

Women's reactions to website use were positive in both the original PCO trial for women diagnosed with breast cancer (any stage, any time since diagnosis; Stanton, Thompson, Crespi, Link, & Waisman, 2013) and Study 2 of the current research, a comparative effectiveness trial of PCO for women with MBC. In the original PCO trial, women with advanced cancer were more likely than women with early-stage disease to use their websites (Harris, Cleary, & Stanton,

2015); in the current PCO trial for women with MBC, women's engagement with their websites was high overall and increased over the four-month study period. Taken together, findings suggest that women with MBC perceive a need to share their experience with and garner support from others and/or that they have time to do so.

In the original PCO trial, women currently undergoing treatment, most of whom had MBC, were most likely to benefit from the intervention (Stanton et al., 2013). The current trial replicated these findings by demonstrating improvements in psychosocial functioning for women with MBC. Women's physical functioning and cancer-related symptoms worsened over the study period, however. Without a control group, these findings are difficult to interpret due to the expected decline in physical condition over time in this population (Butler et al., 2003; Chevillat, Troxel, Basford, & Kornblith; Mayer, 2011; Mayer & Grober, 2013; Reed & Corner, 2013).

The original PCO trial demonstrated that improvements in perceived support from friends, coping confidence, and loneliness mediated the effects of PCO on changes in depressive symptoms, positive affect, and life appreciation (Cleary & Stanton, 2015). Although self-reported emotional expression did not mediate the intervention's effects, higher use of positive and negative emotion words on women's websites was related to improvements in positive affect and depressive symptoms (Harris et al., 2015). In the current PCO trial for MBC, increases in perceived social support from friends and coping confidence were related to improvements in several outcomes (i.e., depressive symptoms, positive and negative affect, life appreciation, fatigue). Results regarding the relationship between emotional expression and adjustment were mixed. Whereas an increase in self-reported emotional expression was related to increased intrusive thoughts, high negative emotion word use was related to increased positive affect and life appreciation. Results also suggested that the addition of peer support in PCO PLUS

influenced the relationships between support from friends, emotional expression, and coping confidence and some outcomes.

### **Implications and Conclusions**

Findings of the current research inform theory regarding social support and emotional expression in cancer and point to potential targets for future interventions. Consistent with the matching hypothesis, which posits that social support is most effective when perceived as appropriate to the challenges presented by the stressor (Cohen & McKay, 1984; Cutrona & Russell, 1990), the current results suggest that the timing of interventions promoting social support is important. Women undergoing current medical treatment for breast cancer and/or those with MBC may perceive a greater need for tangible and emotional support than women who have completed cancer treatment or those with early-stage disease. In addition, findings highlight a need for continuing research examining how and when women with MBC prefer to receive support from other MBC patients. Again, well-matched support may be key: women may desire support from women they perceive as similar to themselves at specific times during the trajectory of illness (e.g., when making treatment-related decisions, experiencing bothersome symptoms, or feeling isolated).

PCO is also grounded in functionalist theories of emotion, which propose that emotions can promote health and well-being in response to stressors (Keltner & Gross, 1999; Levenson, 1994). In part, emotions are theorized to benefit health by recruiting social support. Our results suggest that women's perception of their social network's receptivity to emotional disclosure may be an important moderator of the relationship between emotional expression and adjustment. Some close others may constrain women's emotional expression by communicating discomfort with emotional disclosure, avoiding difficult conversations, or exerting pressure to

remain positive and optimistic (Low et al., 2007). Furthermore, women with MBC may avoid sharing negative emotions in an effort to protect family and friends from their fears and distress. Women may perceive others with MBC as more receptive to emotional disclosure regarding cancer (Ussher, Kirsten, Butow, & Sandoval, 2006; Wortman & Lehman, 1985). More research is needed to examine the influence of social context on the benefits of emotional expression in advanced cancer.

PCO is a promising brief intervention to promote positive adjustment for women with breast cancer. Results of the current research highlight the benefits of evaluating psychosocial interventions through multiple lenses, including mechanisms of effects, predictors of intervention engagement, and participants' perceived usefulness of the intervention. Identifying which elements of interventions are most impactful and how they confer benefit will inform underlying theory and contribute to more efficient and effective psychosocial treatments for individuals with cancer and other serious illnesses.

## Appendix A: Study 1 Materials

### *Demographics and cancer-related variables*

Years of education (e.g., high school = 12 years) \_\_\_\_\_ years      Age \_\_\_\_\_

Ethnic group \_\_\_\_\_ Approximate total yearly family income \_\_\_\_\_

Current or former occupation \_\_\_\_\_

Current employment status: \_\_\_\_\_ employed at least 30 hours/week  
\_\_\_\_\_ employed fewer than 30 hours/week      \_\_\_\_\_ not employed

Are you: \_\_\_\_\_ married/living as married      If yes, number of years \_\_\_\_\_ years  
\_\_\_\_\_ single      \_\_\_\_\_ divorced/separated      \_\_\_\_\_ widowed

When were you first diagnosed with breast cancer (month and year)? \_\_\_\_\_

What is the stage of your breast cancer?    0    1    2    3    4    Don't know

If you have metastatic breast cancer (i.e., cancer that has spread to other organs, such as liver, lung, bone, brain), when was your diagnosis of metastatic cancer (month and year)? \_\_\_\_\_

To what parts of your body has the cancer spread? \_\_\_\_\_

When was your surgery for breast cancer (month and year)? \_\_\_\_\_

What surgery did you have?    \_\_\_\_\_ mastectomy    \_\_\_\_\_ lumpectomy    \_\_\_\_\_ both

Are you having chemotherapy?      Yes, now      Yes, completed      Yes, planned      No

If yes, when did or will you start chemotherapy (month and year)? \_\_\_\_\_

If yes, when did or will the chemotherapy end (month and year)? \_\_\_\_\_

Are you having radiation therapy?    Yes, now      Yes, completed      Yes, planned      No

If yes, when did or will you start radiation (month and year)? \_\_\_\_\_

If yes, when did or will the radiation end (month and year)? \_\_\_\_\_

Are you currently having Herceptin or any other biological agent?      Yes    No

Are you currently taking Tamoxifen or any other hormonal treatment?      Yes    No

*Website use questionnaire*

The questions below address your experience in using your personal webpage in Project Connect. Please refer to your experience **in the past four weeks**.

How much total time did you spend on your webpage (e.g., writing in your journal, posting photos, responding to visitors)? \_\_\_\_\_ hours

How often did you check your webpage? (circle one)

Every day      A few times a week      Once a week      Less than once a week

Using the scale below, please rate how useful your webpage is with regard to:

- 1 = Not at all useful
- 2 = A little useful
- 3 = Moderately useful
- 4 = Very useful
- 5 = Extremely useful

- \_\_\_\_ 1. Allowing you to tell the story of your experience
- \_\_\_\_ 2. Reducing your having to repeat information over and over
- \_\_\_\_ 3. Making you feel connected to family and friends
- \_\_\_\_ 4. Keeping others informed about how you're doing
- \_\_\_\_ 5. Helping you feel cared for by others
- \_\_\_\_ 6. Lettings others know what would be helpful to you
- \_\_\_\_ 7. Allowing you to help the people who care about you
- \_\_\_\_ 8. Reducing the amount of time you spend on the phone/talking with others
- \_\_\_\_ 9. Giving you a place to express your emotions
- \_\_\_\_ 10. Getting the help you need

Please indicate how positive or negative your experience has been with your personal website thus far:

|               |                 |                   |         |                   |                 |               |
|---------------|-----------------|-------------------|---------|-------------------|-----------------|---------------|
| 1             | 2               | 3                 | 4       | 5                 | 6               | 7             |
| Very negative | Fairly negative | A little negative | Neutral | A little positive | Fairly positive | Very positive |

Have you had any technical difficulties working with your website?      Yes      No  
If yes, please describe:

Has anything prevented you from using your website as you had hoped?      Yes      No  
If yes, please describe:

Did you feel disappointed with anything about your experience with your webpage?      Yes      No  
If yes, please explain:

Did anything surprise you about your experience with your webpage?      Yes      No  
If yes, please explain:

What was the most useful consequence of your webpage?

Do you have any recommendations or anything else you'd like to tell us about your experience with Project Connect?

### *Visitor questionnaire*

Dr. Annette Stanton at UCLA and Dr. James Waisman at the Breastlink Medical Group are conducting a study (Project Connect) to understand the effects of creation and use of personal web pages on women's well-being during their experience of breast cancer. As a visitor to this webpage, you can provide valuable information by taking part in this study.

Your participation will involve completing questions online, which will take about five minutes of your time. Taking part in the study is strictly voluntary and should cause no risks to you. Results of the research might be helpful to women with breast cancer and the people who care about them. Only the researchers, and not the author of this web page, will have access to your responses. We will not ask for your name and will not gather your IP address (the address of your computer). You can feel free not to respond to any question, or you can withdraw at any time simply by exiting the survey. If you have any questions about this study, please contact Dr. Annette Stanton or Elizabeth Thompson (project coordinator) at 310-825-9189 or [stanton.study@ucla.edu](mailto:stanton.study@ucla.edu). If you have any questions about your rights as a research participant, you may contact the UCLA Office for Protection of Research Subjects at 310-825-8714.

If you have participated in this study previously by completing this survey, please do not do so again. If you do not want to participate, simply exit this page. If you agree to take part in this study by completing this survey, please click here.

I agree

1. Have you visited this web page before?    Yes    No
2. If yes, please estimate how many times you have visited this web page: \_\_\_\_\_ times
3. Do you know the owner personally?        Yes    No
4. What is your sex?    Female            Male
5. What is your relationship to the author of the web page?

I am the author's spouse/partner

I am her sister or brother

I am her son or daughter

I am her mother or father

I am a relative

I am a friend

I am a co-worker

I am an acquaintance

I am another woman with breast cancer (no relationship with web page author)

Other

On the following scale, please rate how useful the web page was in each of the following:

1 = Not at all useful

2 = Somewhat useful

3 = Moderately useful

4 = Very useful  
5 = Extremely useful

- 1. Providing an update on the author's health
- 2. Providing an update on how the author is doing emotionally
- 3. Giving me ideas about how I can help the author
- 4. Providing information about breast cancer
- 5. Helping me feel close to the author
- 6. Giving me ideas about how I want to live my life

On the following scale, how likely are you to do the following actions?

1 = Not likely at all  
2 = Somewhat likely  
3 = Moderately likely  
4 = Very likely  
5 = Extremely likely

- 1. Write an email/post to the author
- 2. Contact the author in another way (e.g., phone, card)
- 3. Offer help to the author
- 4. Visit this web page again

If there is anything else you'd like to tell us about your experience with this web page, we will appreciate your comments.

*Center for Epidemiologic Studies Depression Scale (CES-D)*

From: Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401.

Using the scale below, indicate the number which best describes how often you felt or behaved this way DURING THE PAST WEEK.

- 1 = Rarely or none of the time (less than 1 day)
- 2 = Some or a little of the time (1-2 days)
- 3 = Occasionally or a moderate amount of time (3-4 days)
- 4 = Most or all of the time (5-7 days)

DURING THE PAST WEEK

- \_\_\_ 1. I was bothered by things that usually don't bother me.
- \_\_\_ 2. I did not feel like eating: my appetite was poor.
- \_\_\_ 3. I felt I could not shake off the blues, even with help from family or friends.
- \_\_\_ 4. I felt that I was just as good as other people.
- \_\_\_ 5. I had trouble keeping my mind on what I was doing.
- \_\_\_ 6. I felt depressed.
- \_\_\_ 7. I felt that everything I did was an effort.
- \_\_\_ 8. I felt hopeful about the future.
- \_\_\_ 9. I thought my life had been a failure.
- \_\_\_ 10. I felt fearful.
- \_\_\_ 11. My sleep was restless.
- \_\_\_ 12. I was happy.
- \_\_\_ 13. I talked less than usual.
- \_\_\_ 14. I felt lonely.
- \_\_\_ 15. People were unfriendly.
- \_\_\_ 16. I enjoyed life
- \_\_\_ 17. I had crying spells.
- \_\_\_ 18. I felt sad.
- \_\_\_ 19. I felt that people disliked me.
- \_\_\_ 20. I could not get "going."

## Appendix B: Study 2 Materials

### *Screening script*

#### CONSENT SCRIPT TO SCREEN FOR RESEARCH

Thank you for talking with me [Dr. Stanton, research assistant] about the Project Connect study for women with breast cancer. I need to ask you a few questions in order to determine whether you may be eligible for the research, but I'd like to tell you a little bit about the research first.

We are interested in testing Project Connect, a program to help breast cancer patients design personal websites. If you participate, you would be assigned randomly to a session to develop a personal website. You also would complete three sets of questionnaires over the next four months.

In this screening, your participation is completely voluntary, and you do not have to answer any questions you do not wish to answer. You will not benefit from the screening. If you do not participate in the study, your answers will be destroyed. If you do participate, your answers will be kept with your other research data. No one will know the answers except for the research team.

Would you like to continue with the screening, which will take about 30 seconds? *(If no, thank the person and end the session. If yes:)*

1. Are you at least 18 years old?
2. Have you had a diagnosis of metastatic breast cancer?
3. I'd like to find out a little bit about how you're doing.
  - A. Are you currently working? *(If yes, skip to question 4. If no, continue.)*
  - B. Are you able to drive a car? *(If yes, skip to question 4. If no, continue.)*
  - C. Are you able to walk for at least 10 minutes? *(If yes, skip to question 4. If no, continue.)*
  - D. Are you able to dress and bathe yourself without assistance? *(If yes, skip to question 4. If no to one or both of these questions, say, "Thanks so much for answering these questions. I'm sorry to hear about some of the difficulties you're having. We feel that the study would not be a good fit for you at this time. Thanks again for your time."*
4. Would you feel comfortable completing the Project Connect session and questionnaires in English?
5. Are you interested in designing a personal website about your cancer experience?
6. Are you able and willing to attend a 3-hour workshop, held at UCLA or in Orange County, to set up your personal website? Do you have a preference of location?

*(If not eligible)* You are not eligible to participate in Project Connect. *(Explain why and exit.)*

*(If eligible)* Great. You are eligible to participate. Next, I'll be sending you an email with a link that includes an informed consent form. You'll need to complete this online before you're officially in the study. I'd like to go over the basics of the consent form with you now. *(Go over consent form.)*

Closer to your scheduled workshop date, you will also receive a link to an online questionnaire to complete at home which should take about 45 minutes. After you complete it, you will receive a \$30 gift card.

Do you have any questions about the screening or the research? *(Address questions and ensure understanding.)*

Now I'll ask a few more questions that will help us in conducting the Project Connect session.

How comfortable are you using a computer?

Do you have access to a computer at home, work, or both locations?

In the past six months, have you had a personal website on which you have communicated about your experience with breast cancer?

Would you like to bring your own laptop to the workshop? *(If YES, does it have wireless Internet access? If NO, then she will need to use one of our laptops.)*

Are you interested in having your partner, family member or friend attend the training workshop with you?

Do you have a preference for attending a workshop on a weekday, evening, or weekend?

We currently have three upcoming training workshop dates scheduled. Please indicate whether or not you are available for any of these dates. *(Provide dates.)*

May I please have your contact information? *(Gather email/address/phone information.)*

I am going to give you a couple of telephone numbers to call if you have any questions later. Do you have a pen? If you have questions about the research, you may call me – again, my name is \_\_\_\_\_ – or Dr. Stanton or her assistant at 310-825-9189 or 825-3105.

If you have questions about your rights as a research subject, please call the UCLA Office for Protection of Research Subjects at 310-825-5344. Thank you again for your willingness to answer our questions.

## **CONSENT TO PARTICIPATE IN RESEARCH**

### **Project Connect: Enhancing Connections During Metastatic Breast Cancer**

You are being asked to participate in the “Project Connect: Enhancing Connections During Metastatic Breast Cancer” research study conducted by Annette Stanton, Ph.D., in the Department of Psychology and the Division of Cancer Prevention and Control Research, University of California, Los Angeles (UCLA), Dr. Patricia Ganz, M.D., Director of the Cancer Prevention and Control Research, Jonsson Comprehensive Cancer Center, UCLA, and Lauren Harris, M.A., in the Department of Psychology at UCLA. You have been asked to participate in this study because of your interest in developing a personal website to chronicle your experience with breast cancer and communicate with your social network. Participation in this research is voluntary, and refusal to participate will not affect your health care or your relationship with your doctor. This study is not part of your medical treatment.

- **PURPOSE OF THE STUDY**

The purpose of this study is to test the feasibility and usefulness of Project Connect, a program for teaching women to design personal websites to chronicle their experience with metastatic breast cancer and communicate with others.

- **PROCEDURES**

If you volunteer to participate, you will complete a set of baseline questionnaires, which will ask you about topics such as your mood, physical health, and sense of social support. Then, you will attend a Project Connect session and be randomly assigned (like the flip of a coin) to either share your website with family and friends of your choosing plus other women participating in the study, or to share your website only with family and friends of your choosing.

After you complete the baseline questionnaires, we will call you to schedule a time for your Project Connect session to create a personal website, which will be conducted by Dr. Stanton and/or her assistant. The session will last approximately three hours. You may bring a friend or family member with you to help you create your website. No knowledge of programming language or technical details is required. In order to ensure that the session is conducted as intended, the session will be audiotaped. However, it will be coded solely to evaluate the conduct of the session by the leaders; what you say or do during the session will not be coded. Visitors to your website may choose if they would like to complete a short survey about their experience visiting your website. Responses from the survey will not be shared with you. Two months and four months after you join the study, you will receive another email with a link to a set of questionnaires to complete. These questionnaires will also ask you about your mood, physical health, and social support.

- **POTENTIAL RISKS AND DISCOMFORTS**

We foresee no potential risks of participation. You do not need to answer any questions that you do not wish to answer on the questionnaires.

- **ANTICIPATED BENEFITS TO SUBJECTS**

It is possible that you will benefit from creation of a personal website regarding your cancer experience, but we cannot guarantee any benefit.

- **ANTICIPATED BENEFITS TO SOCIETY**

The information gained from this study may benefit society by providing an intervention that bolsters communication and well-being in breast cancer survivors and their loved ones.

- **PAYMENT FOR PARTICIPATION**

You will be offered \$30 for completing each of the three sets of online questionnaires whether or not you answer all the questions, for a potential total of \$90.

- **PRIVACY AND CONFIDENTIALITY**

If you would like, your website can be password-protected, such that access can be granted only to individuals you select. However, granting access to the research team is a requirement of the research, as part of assessing the usefulness of Project Connect. Additionally, if you are randomly assigned to share your website with other study participants, you will be required to do so. The only people who will know that you are a research participant are members of the research team and potentially other participants in the study. If you give your permission to share your website for future research on Project Connect or for educational purposes, other research participants involved in future studies of Project Connect and other involved parties (e.g., scientific conference participants) will be able to view it. We also will ask visitors to your website to complete a brief survey solely for research purposes; you will not have access to any of their responses. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

When the results of the research are published, no information will be included that would reveal your identity. Your confidentiality will be maintained by using only an identification number on all questionnaire and website data. All information will be kept in locked file cabinets and password-protected computers, and only Dr. Stanton and her assistants will have access to these data.

- **PARTICIPATION AND WITHDRAWAL**

Your participation in this study is VOLUNTARY. If you choose not to participate, it will not affect your relationship with UCLA, your medical providers, or your right to health care or other services to which you are otherwise entitled. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without prejudice to your future medical care. You may decline to answer any question and still remain in the study.

- **IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact:

Annette Stanton, Ph.D.  
UCLA Department of Psychology  
1285 Franz Hall, Box 951563

Patricia Ganz, M.D.  
A2-125 CHS  
Box 956900

Los Angeles, CA 90095-1563  
(310) 825-3105; (310) 825-9189

Los Angeles, CA 90095-6900  
(310) 206-1404

• **RIGHTS OF RESEARCH SUBJECTS**

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research subject, you may contact the Office for Protection of Research Subjects, UCLA, Box 951694, Los Angeles, CA, 90095-1694, (310) 825-8714.

• **REQUEST TO SHARE YOUR WEBSITE**

In order to promote future development of and education about Project Connect, we request your permission to share your website with other research participants in future studies of Project Connect and other interested parties (e.g., scientific conference participants). This is completely voluntary. Please indicate by clicking the appropriate box below whether or not you consent to sharing your website with future research participants in Project Connect.

- I consent to share my website with other research participants in future studies of Project Connect and for educational purposes.
- I decline to share my website with other research participants in future studies of Project Connect and for educational purposes.

• **INFORMATION ABOUT THIS RESEARCH**

Please indicate by clicking the appropriate box below what type of information you want to receive. It is your responsibility to let the investigator know if your address and/or telephone number changes. The contact information is in this informed consent form under “Identification of Investigators.”

- I would like to receive general information about what the study found.
- I do not want any information about the study.

• **SIGNATURE OF RESEARCH SUBJECT**

I have read (or someone has read to me) the information provided above. I have been given an opportunity to ask questions and all of my questions have been answered to my satisfaction. I have been given a copy of this form.

BY CLICKING THE BOX BELOW, I WILLINGLY AGREE TO PARTICIPATE IN THE RESEARCH THIS FORM DESCRIBES.

Name of Subject: \_\_\_\_\_

Date: \_\_\_\_\_

- I agree
- I do not agree

*Demographic and cancer-related variables*

What is your age? \_\_\_\_\_

What best describes your ethnic/racial background?

- |  |   |
|--|---|
| <input type="checkbox"/> White/European American       | <input type="checkbox"/> Black/African-American           |
| <input type="checkbox"/> Latina/Hispanic               | <input type="checkbox"/> Asian                            |
| <input type="checkbox"/> Indian subcontinent           | <input type="checkbox"/> Native Hawaiian/Pacific Islander |
| <input type="checkbox"/> Native American/Alaska Native | <input type="checkbox"/> Other (please specify _____)     |

What is the highest education level you have completed?

- |  |  |
|--|--|
| <input type="checkbox"/> Less than high school | <input type="checkbox"/> Four-year college (e.g., B. A., B.S.)           |
| <input type="checkbox"/> High school           | <input type="checkbox"/> Master's degree                                 |
| <input type="checkbox"/> Two-year college      | <input type="checkbox"/> Ph.D., M.D., other professional terminal degree |

What describes your total yearly household income?

- |   |  |
|---|--|
| <input type="checkbox"/> Less than \$50,000   | <input type="checkbox"/> \$75,000 to \$100,000 |
| <input type="checkbox"/> \$50,000 to \$74,999 | <input type="checkbox"/> More than \$100,000   |

What is your current or former occupation? \_\_\_\_\_

What is your current employment status?

- |                                     |  |
|-------------------------------------|--|
| <input type="checkbox"/> Employed   | <input type="checkbox"/> Homemaker                 |
| <input type="checkbox"/> Unemployed | <input type="checkbox"/> Disabled/on medical leave |
| <input type="checkbox"/> Retired    | <input type="checkbox"/> Student                   |

Before your most recent diagnosis, were you employed at least 30 hours per week or fewer than 30 hours?  At least 30 hours per week  Fewer than 30 hours per week

Are you:

Married/living as married

[If yes] How many years have you been married/living as married? \_\_\_\_\_

Never married

Divorced/separated

Widowed

Including any current marriage, how many times have you been married? \_\_\_\_\_

How often do you access the Internet?

- |   |  |
|---|--|
| <input type="checkbox"/> Never                  | <input type="checkbox"/> Once a week         |
| <input type="checkbox"/> Less than once a month | <input type="checkbox"/> 2-3 times a week    |
| <input type="checkbox"/> Once a month           | <input type="checkbox"/> Daily               |
| <input type="checkbox"/> 2-3 times a month      | <input type="checkbox"/> Several times a day |

How many hours per week do you spend online? \_\_\_\_\_

How comfortable do you feel using a computer?

Very comfortable

- Somewhat comfortable
- Somewhat uncomfortable
- Very uncomfortable

Is this your first diagnosis of breast cancer?

- Yes
- No

When were you first diagnosed with breast cancer (month and year)? \_\_\_\_\_

When was your surgery for breast cancer when you were originally diagnosed (month and year)?  
\_\_\_\_\_

What surgery did you have?

- Mastectomy       Double mastectomy
- Lumpectomy       Both mastectomy and lumpectomy
- Other

If Other, please specify what type of surgery you had for breast cancer when you were originally diagnosed: \_\_\_\_\_

Did you have chemotherapy after your original diagnosis of breast cancer?

- Yes
- No

If yes, when did you start chemotherapy for your original diagnosis of breast cancer (month and year)? \_\_\_\_\_

If yes, when did the chemotherapy for your original diagnosis of breast cancer end (month and year)? \_\_\_\_\_

Did you have radiation therapy after your original diagnosis of breast cancer?

- Yes
- No

If yes, when did you start radiation for your original diagnosis of breast cancer (month and year)? \_\_\_\_\_

If yes, when did the radiation for your original diagnosis of breast cancer end (month and year)?  
\_\_\_\_\_

Did you receive Herceptin or any other biological agent after your original diagnosis of breast cancer?

- Yes
- No

If yes, what was it called? \_\_\_\_\_

Did you take tamoxifen or any other hormonal treatment (for example, Arimidex [anastrozole], Aromasin [exemestane], or Femara [letrozole] after your original diagnosis of breast cancer?

Yes

No

If yes, what was it called? \_\_\_\_\_

When was your diagnosis of metastatic cancer (month and year)? \_\_\_\_\_

To what parts of your body has the cancer now spread? (Check all that apply)

Bone     Lung     Liver     Brain     Other

If Other, please specify the parts of your body to which the cancer has now spread: \_\_\_\_\_

When was your surgery for breast cancer after your diagnosis of metastatic breast cancer (month and year)? \_\_\_\_\_

What surgery did you have?

Mastectomy     Double mastectomy

Lumpectomy     Both mastectomy and lumpectomy

Other

If Other, please specify what type of surgery you had after your diagnosis of metastatic breast cancer: \_\_\_\_\_

Are you having chemotherapy for your diagnosis of metastatic breast cancer?

Yes, now

Yes, completed

No

If yes, when did you start chemotherapy for your diagnosis of metastatic breast cancer (month and year)? \_\_\_\_\_

If yes, when did or will the chemotherapy for your diagnosis of metastatic breast cancer end (month and year)? \_\_\_\_\_

Are you having radiation therapy for your diagnosis of metastatic breast cancer?

Yes, now

Yes, completed

No

If yes, when did you start radiation for your diagnosis of metastatic breast cancer (month and year)? \_\_\_\_\_

If yes, when did or will the radiation for your diagnosis of metastatic breast cancer end (month and year)? \_\_\_\_\_

Are you currently receiving Herceptin or any other biological agent?

Yes  
 No

If yes, what is it called? \_\_\_\_\_

Are you currently taking tamoxifen or any other hormonal treatment (for example, Arimidex [anastrozole], Aromasin [exemestane], or Femara [letrozole])?

Yes  
 No

If yes, what is it called? \_\_\_\_\_

Prior to your first cancer diagnosis, had you gone through menopause (i.e., no menstrual period for 12 months)?

Yes  
 No

*Self-Report Karnofsky Performance Status Scale*

From: Loprinzi, C. L., Laurie, J. A., Wieand, H. S., Krook, J. E., Novotny, P. J., Kugler, J. W., ... Moertel, C. G. (1994). Prospective evaluation of prognostic variables from patient-completed questionnaires. *Journal of Clinical Oncology*, 12, 601-607.

Which of the following phrases best characterizes you at this time?

- 1 = Normal, no complaints, no symptoms of disease
  - 2 = Able to carry on normal activity, minor symptoms of disease
  - 3 = Normal activity with effort, some symptoms of disease
  - 4 = Care for self, unable to carry on normal activity or to do active work
  - 5 = Require occasional assistance but able to care for most of personal needs
  - 6 = Require considerable assistance for personal care
  - 7 = Disabled, require special care and assistance
  - 8 = Severely disabled, require continuous nursing care
-

*Center for Epidemiologic Studies Depression Scale (CES-D)*

From: Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401.

Using the scale below, select the category that best describes how often you felt or behaved this way DURING THE PAST WEEK.

- 1 = Rarely or none of the time (less than 1 day)
- 2 = Some or a little of the time (1-2 days)
- 3 = Occasionally or a moderate amount of the time (3-4 days)
- 4 = Most or all of the time (5-7 days)

- \_\_\_ 1. I was bothered by things that usually don't bother me.
- \_\_\_ 2. I did not feel like eating; my appetite was poor.
- \_\_\_ 3. I felt I could not shake off the blues, even with help from family or friends.
- \_\_\_ 4. I felt that I was just as good as other people.
- \_\_\_ 5. I had trouble keeping my mind on what I was doing.
- \_\_\_ 6. I felt depressed.
- \_\_\_ 7. I felt that everything I did was an effort.
- \_\_\_ 8. I felt hopeful about the future.
- \_\_\_ 9. I thought my life had been a failure.
- \_\_\_ 10. I felt fearful.
- \_\_\_ 11. My sleep was restless.
- \_\_\_ 12. I was happy.
- \_\_\_ 13. I talked less than usual.
- \_\_\_ 14. I felt lonely.
- \_\_\_ 15. People were unfriendly.
- \_\_\_ 16. I enjoyed life.
- \_\_\_ 17. I had crying spells.
- \_\_\_ 18. I felt sad.
- \_\_\_ 19. I felt that people disliked me.
- \_\_\_ 20. I could not get "going."

GAD-7

From: Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Lowe, B. (2006). A brief measure for assessing generalized anxiety disorder. *Archives of Internal Medicine*, 166, 1092-1097.

Over the LAST TWO WEEKS, how often have you been bothered by the following problems?

- 0 = Not at all
- 1 = Several days
- 2 = More than half the days
- 3 = Nearly every day

- \_\_\_ 1. Feeling nervous, anxious, or on edge
- \_\_\_ 2. Not being able to stop or control worrying
- \_\_\_ 3. Worrying too much about different things
- \_\_\_ 4. Trouble relaxing
- \_\_\_ 5. Being so restless that it is hard to sit still
- \_\_\_ 6. Becoming easily annoyed or irritable
- \_\_\_ 7. Feeling afraid as if something awful might happen

If you checked off **any** problems, how **difficult** have these problems made it for you to do your work, take care of things at home, or get along with other people?

- \_\_\_ Not at all difficult
- \_\_\_ Somewhat difficult
- \_\_\_ Very difficult
- \_\_\_ Extremely difficult

*Impact of Event Scale – Revised*

From: Horowitz, M. J., Wilner, N., & Alvarez, W. (1979). The Impact of Event Scale: A measure of subjective stress. *Psychosomatic Medicine*, 41, 209-218.

Weiss, D. S. (2007). The impact of event scale: Revised. In *Cross-cultural assessment of psychological trauma and PTSD* (pp. 219-238). US: Springer.

Below is a list of comments made by people regarding stressful life events. Using the scale below, please select the answer choice for each item that best indicates how frequently these comments were true for you DURING THE PAST SEVEN DAYS with regard to YOUR EXPERIENCE WITH CANCER.

- 0 = Not at all
- 1 = A little bit
- 2 = Moderately
- 3 = Quite a bit
- 4 = Extremely

- \_\_\_\_\_ 1. I thought about it when I didn't mean to.
- \_\_\_\_\_ 2. I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.
- \_\_\_\_\_ 3. I had waves of strong feelings about it.
- \_\_\_\_\_ 4. I had dreams about it.
- \_\_\_\_\_ 5. Pictures about it popped into my mind.
- \_\_\_\_\_ 6. Other things kept making me think about it.
- \_\_\_\_\_ 7. Any reminder brought back feelings about it.

*Weekly Reminder Email: Example for PCO ONLY participants*

Dear *(participant name)*,

I hope you're doing well! This is your weekly reminder to log in to your website. Remember that you can use your website to share anything you'd like. Please let me know if you have any questions or concerns about your website.

Your login URL is: \_\_\_\_\_

Your web address to share with friends and family is: \_\_\_\_\_

Best,  
*(Research staff name)*

*Weekly Reminder Email: Example for PCO PLUS participants*

Dear *(participant name)*,

I hope you're doing well! This is your weekly reminder to log in to your website. Remember that you can use your website to share anything you'd like. Please let me know if you have any questions or concerns about your website.

Your login URL is: \_\_\_\_\_

Your web address to share with friends and family is: \_\_\_\_\_

Also, don't forget to stay connected to the other women in your Project Connect Online group. You can comment on their posts, send messages directly, and offer support in other ways that you think would be helpful. Visit their websites at:

\_\_\_\_\_

Best,  
*(Research staff name)*

*Website use questions at two- and four- month follow-up*

The following questions address your experience in using your personal Project Connect Online website.

How many people have you invited to view your website? Please provide your best estimate. \_\_\_\_

How have you invited people to view your website? Please click all that apply.

- |   |                                    |
|---|------------------------------------|
| <input type="checkbox"/> In person                            | <input type="checkbox"/> Facebook  |
| <input type="checkbox"/> Over the phone                       | <input type="checkbox"/> Twitter   |
| <input type="checkbox"/> By email                             | <input type="checkbox"/> Instagram |
| <input type="checkbox"/> By sending a letter through the mail | <input type="checkbox"/> By text   |
| <input type="checkbox"/> Other (please specify: _____)        |                                    |

In the **past four weeks**, how much **total time, in minutes**, did you spend on your website (for example, writing posts, posting photos, responding to visitors)? \_\_\_\_\_

In the **past four weeks**, how often did you check your website?

- Every day
- A few times a week
- Once a week
- Less than once a week

Using the scale below, please rate **how useful** your website is with regard to:

- 1 = Not at all useful
- 2 = A little useful
- 3 = Moderately useful
- 4 = Very useful
- 5 = Extremely useful

- 1. Allowing you to tell the story of your experience
- 2. Reducing your having to repeat information over and over
- 3. Making you feel connected to family and friends
- 4. Keeping others informed about how you're doing
- 5. Helping you feel cared for by others
- 6. Lettings others know what would be helpful to you
- 7. Allowing you to help the people who care about you
- 8. Reducing the amount of time you spend on the phone/talking with others
- 9. Giving you a place to express your emotions
- 10. Getting help from others

Using the scale below, please rate **how useful** you have found the following website features:

- 1 = Not at all useful
- 2 = A little useful

3 = Moderately useful  
4 = Very useful  
5 = Extremely useful

- \_\_\_\_\_ 1. Writing and publishing posts
- \_\_\_\_\_ 2. Adding photos
- \_\_\_\_\_ 3. About Me page
- \_\_\_\_\_ 4. My Special Requests page
- \_\_\_\_\_ 5. Useful Links page
- \_\_\_\_\_ 6. Contact Me page
- \_\_\_\_\_ 7. How You Can Help calendar
- \_\_\_\_\_ 8. Ability for friends and family to comment on your posts
- \_\_\_\_\_ 9. Approving and replying to comments
- \_\_\_\_\_ 10. Ability for friends and family to subscribe to your website
- \_\_\_\_\_ 11. Emailing subscribers directly from your website

*Website use questions at four-month follow-up only*

Have you had any challenges or technical difficulties with using your website?

Yes  No

If yes, please describe the challenges or technical difficulties you have had.

Has anything prevented you from using your website as you had hoped?

Yes  No

If yes, please describe what has prevented you from using your website as you had hoped.

Have you felt disappointed with anything about your experience with your website?

Yes  No

If yes, please describe what you have felt disappointed with.

Has anything surprised you about your experience with your website?

Yes  No

If yes, please describe what has surprised you.

Please indicate how positive or negative your experience has been with your personal website thus far:

|                  |                    |                      |         |                      |                    |                  |
|------------------|--------------------|----------------------|---------|----------------------|--------------------|------------------|
| 1                | 2                  | 3                    | 4       | 5                    | 6                  | 7                |
| Very<br>negative | Fairly<br>negative | A little<br>negative | Neutral | A little<br>positive | Fairly<br>positive | Very<br>positive |

What has been the most useful consequence of your website?

Do you have any recommendations or anything else you'd like to tell us about your experience with Project Connect Online?

*Additional website use questions for women in PCO PLUS at four-month follow-up*

The following questions address your experience communicating with other women in the Project Connect Online study.

- 1 = Every day
- 2 = A few times a week
- 3 = Once a week
- 4 = Less than once a week

- \_\_\_ 1. In the **past four weeks**, how often have you visited the websites of other women in this study?
- \_\_\_ 2. In the **past four weeks**, how often have you commented on the websites of other women in this study?
- \_\_\_ 3. In the **past four weeks**, how often have you sent a private message (through the Contact Me page) to other women in this study?
- \_\_\_ 4. In the **past four weeks**, how often have you contacted women in this study outside of your websites (for example, through email, texting, or phone calls)?
- \_\_\_ 5. In the **past four weeks**, how often have other women in this study commented on your website?
- \_\_\_ 6. In the **past four weeks**, how often have other women in this study sent you a private message (through the Contact Me page)?
- \_\_\_ 7. In the **past four weeks**, how often have other women in this study contacted you outside of your website (for example, through email, texting, or phone calls)?

How useful has it been to visit the websites of other women in this study?

- \_\_\_ Not at all useful                      \_\_\_ Very useful
- \_\_\_ A little useful                        \_\_\_ Extremely useful
- \_\_\_ Moderately useful

Please provide a brief explanation for your answer above. What has been useful (or not useful) about visiting the websites of other women in this study? \_\_\_\_\_

Please rate the extent to which you agree with each of the statements below regarding other women in the Project Connect Online study.

- |                   |          |                   |         |                |       |                |
|-------------------|----------|-------------------|---------|----------------|-------|----------------|
| 1                 | 2        | 3                 | 4       | 5              | 6     | 7              |
| Strongly disagree | Disagree | Slightly disagree | Neutral | Slightly agree | Agree | Strongly agree |

- \_\_\_ 1. The other women in this study are similar to me.
- \_\_\_ 2. The other women in this study are approachable.
- \_\_\_ 3. The other women in this study are likeable.

*Fidelity to Project Connect training sessions*

Rater Initials \_\_\_\_\_

Workshop date \_\_\_\_\_

- |   |     |    |
|---|-----|----|
| 1. Leader introduced herself and project rationale/background                                 | Yes | No |
| 2. Oriented women to training manuals, including Terms of Use                                 | Yes | No |
| 3. Discussed possible purposes for using a personal website                                   | Yes | No |
| 4. Discussed common concerns about using a website and how these can be proactively addressed | Yes | No |
| 5. Introduced “My Goals” Worksheet  | Yes | No |
| 6. Described what to include in a welcome email or post                                       | Yes | No |
| 7. Taught women how to log into their websites  | Yes | No |
| 8. Showed women how to update their password  | Yes | No |
| 9. Showed women how to choose a title and tagline   | Yes | No |
| 10. Explained privacy settings  | Yes | No |
| 11. Explained About Me and My Special Requests pages  | Yes | No |
| 12. Taught how to write a post  | Yes | No |
| 13. Taught how to add a photo   | Yes | No |
| 14. Taught how to add a website link  | Yes | No |
| 15. Taught how to review comments   | Yes | No |
| 16. Taught how to create a How you can help calendar  | Yes | No |
| 17. Discussed technical support   | Yes | No |
| 18. Provided time for women to work on their first post                                       | Yes | No |
| 19. Mentioned scheduling 1-week follow-up calls   | Yes | No |

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