

IMPROVING THE EFFECTIVENESS OF ADJUVANT PSYCHOLOGICAL TREATMENT FOR WOMEN WITH BREAST CANCER: THE FEASIBILITY OF PROVIDING ONLINE SUPPORT

JASON E. OWEN^{a,b,*}, JOSHUA C. KLAPOW^{a,b,c}, DAVID L. ROTH^{a,d}, LISLE NABELL^c and DIANE C. TUCKER^a

^a *Department of Psychology, University of Alabama, Birmingham, AL, USA*

^b *Department of Health Care Organization and Policy, University of Alabama, Birmingham, AL, USA*

^c *Center for Outcomes and Effectiveness Research and Education, University of Alabama, Birmingham, AL, USA*

^d *Department of Biostatistics, University of Alabama, Birmingham, AL, USA*

^e *Department of Hematology/Oncology, University of Alabama School of Medicine, Birmingham, AL, USA*

SUMMARY

Many well-designed studies have shown psychosocial treatments for cancer to be efficacious for improving patients' quality of life, but the actual impact of these treatments may be limited by low rates of participation. Web-based treatment formats could improve effectiveness by increasing availability and accessibility. Two phases of a feasibility study are reported in this article. In the first phase, we sought to assess internet access and perceived interest in online support among 136 women with breast cancer (June–October, 1999). Levels of interest in participating in an online psychosocial treatment were associated with age, outcome expectancy, and barriers to using the internet but not stage or time since diagnosis. In the second phase, we document accrual rates among several methods of recruitment during a randomized trial (February–December, 2001) and report changes over time in internet access. Recruitment rates were substantially higher when a study representative was available in clinic to provide information about the treatment than for all other methods of recruitment. Access to the internet increased between 1999 (63%) and 2001 (70%) and varied across age groups. These results suggest that internet-based psychosocial treatments, with notable limitations, are feasible for increasing the impact of psychosocial care. Copyright © 2003 John Wiley & Sons, Ltd.

INTRODUCTION

Adjuvant psychological therapy (APT)[†] for persons with cancer is widely reported to reduce emotional distress, prevalent within oncology

populations, and to improve patients' quality of life. However, the impact of APTs has been limited by the poor availability of therapy programs, inaccessibility of existing programs, and lack of professional involvement among health-care administrators and oncology teams. APTs that are designed to address existing limitations, specifically by making therapy programs more widely available, more easily accessible to patients, and more affordable can potentially increase the effectiveness of this class of therapies. Internet-based psychosocial treatments have the potential to address such limitations by expanding the availability and accessibility of APTs to patients with cancer. The specific goals of this study were to (1) examine the feasibility of providing online psychosocial treatment to women with breast cancer by exploring factors associated with interest in participation

*Correspondence to: Department of Psychology, 415 Campbell Hall, University of Alabama at Birmingham, Birmingham, AL 35294. E-mail: jowen@uab.edu

[†]The term 'adjuvant psychological therapy', after Cunningham (2000), will be used throughout this paper to describe those treatments referred to in previous papers as 'psychosocial interventions' (e.g. Meyer and Mark, 1995; Owen *et al.*, 2001). The term is considered to be a more precise description of the many treatments that have been provided to cancer populations with the intent of facilitating the psychological processes associated with healing. Use of the operative word 'therapy' is also more consistent than 'intervention' with existing treatments for cancer and existing treatments for psychosocial distress or disorder among patients without cancer.

and (2) to describe rates of recruitment success associated with several active and passive recruitment techniques for a clinical trial of an online psychosocial treatment.

Efficacy and effectiveness of APT

In evaluating the relative merits of psychological treatments, Chambless and Hollon (1998) distinguish between treatment *efficacy*, or the demonstration that a given treatment yields desirable results under controlled conditions, and treatment *effectiveness*, or the ability of the treatment to yield desirable results under the real-world circumstances of clinical practice. Arguments for the efficacy of APT for cancer-related distress are well-supported by a number of reviews and meta-analyses that describe the cumulative results of over 60 studies (Andersen, 1992; Compas *et al.*, 1998; Fawzy *et al.*, 1995; Meyer and Mark, 1995; Sheard and Maguire, 1999; Trijsburg *et al.*, 1992). Treatment effectiveness, on the other hand, has received considerably less attention. In order for APTs to become practical elements of patient care, they must first be available within or near the cancer centers where patients receive their care and be accessible at times and locations that will allow patients to actually become involved. Interest in psychosocial treatments is high among women with breast cancer (Liang *et al.*, 1990). Women with breast cancer often report tremendous distress and disruptions to lifestyle, including depression, fatigue, cognitive impairments, nausea/emesis, altered body image, and changes in social support networks, that have a negative impact on quality of life (Stevenson and Coles, 1993; Leedham and Ganz, 1999). Despite the need for APTs, poor accessibility and availability may be limiting treatment effectiveness. The impact of APTs is illustrated by the participation rates in controlled studies of psychosocial treatment. Participation rates are highest (70.3–100%) for studies involving APTs for cancer patients when they are provided as a standard of care, for example, an inpatient nursing support intervention (Maguire *et al.*, 1980; see also Maguire *et al.*, 1983; McArdle *et al.*, 1996; Wieder *et al.*, 1978) or relaxation training during chemotherapy or radiation (Bridge *et al.*, 1988; Elisabet Palsson and Norberg, 1995; Maunsell *et al.*, 1996; Vachon *et al.*, 1982; Walker *et al.*, 1999). For studies in which participation requires time or travel beyond what

would be required for standard medical treatment, participation rates are considerably lower (15.5–82%, median = 35.1%, Cunningham *et al.*, 1998; Donnelly *et al.*, 2000; Edgar *et al.*, 1992; Fukui *et al.*, 2001; Goodwin *et al.*, 2000; see also Goodwin *et al.*, 2001; Moorey *et al.*, 1998; Rustoen *et al.*, 1998; Shrock *et al.*, 1999; Youssef, 1984). In conceptualizing treatment effectiveness, a median participation rate of 35.1% is likely to be an overestimate. Recruitment success rates for the studies mentioned above are described, in most cases, for samples already meeting inclusion criteria for the study (e.g. patients available for follow-up or living within a one-hour radius of the treatment facility, see Goodwin *et al.*, 2000 for an exception). Only a handful of studies reported recruitment success rates among consecutively approached patients (Bridge *et al.*, 1988; McArdle *et al.*, 1996; Walker *et al.*, 1999).

Because the *availability* of APT for cancer has been largely limited to ongoing clinical trials in academic medical, treatment effectiveness is further limited in scope. Community-based support groups, such as those offered through the American Cancer Society (Coluzzi *et al.*, 1995), are generally available to patients in metropolitan areas, but only a small proportion of patients take advantage of these services. Further, studies examining the treatment efficacy for community-based support groups have not to this point demonstrated significant improvement in patient outcomes (Andersen, 1992; Gruber *et al.*, 1993; Jacobs *et al.*, 1983; Telch and Telch, 1986).

Improving effectiveness by using internet-based APT

An essential aspect of increasing the effectiveness of APT is to better understand the factors associated with participation in psychosocial care. Factors associated with participation in APT may be a function of perceived *interest* (e.g. cancer stage, time since diagnosis, existing social support, etc.), *availability* (e.g. existence and awareness of community-based support groups, professionally-lead therapy groups, or individual treatment options), or *accessibility* (e.g. the distance a participant would need to travel to a meeting place, time constraints associated with lifestyle, encouragement by friends or family, etc.). Previous studies suggest that factors predicting participation in face-to-face APT include recent surgery,

age (highest among women aged 50–65, Fukui *et al.*, 2001) and a desire to receive and give emotional support and information (Stevenson and Coles, 1993). Other studies suggest that refusal to participate in a psychosocial treatment is associated with progressive disease and lack of encouragement from family members (Gustafson *et al.*, 1993); hesitation to commit to regular group meetings (Cunningham *et al.*, 1998); busy home and work schedules (Fukui *et al.*, 2001); and an already adequate level of social support (Plass and Koch, 2001).

A small, emerging body of evidence suggests that some barriers to participation in APT can be overcome by the use of internet-based media. Internet-based APT obviates the need for a physical meeting place and the need for participants to travel from their homes (Winzelberg, 1997; Finn, 1995; Weinberg *et al.*, 1995a). Internet-based APT may be more accessible to patients who live at great distance from the clinic (e.g. in rural areas where support services are unavailable), who do not have a convenient means of transportation, or who are too physically debilitated or fatigued to travel. Users of online groups can access the group at any time of day or night (Weinberg *et al.*, 1996; Winzelberg, 1997; Finn, 1995; Weinberg *et al.*, 1995a). Winzelberg reported that 66% of the messages posted to an online group were sent between 6 pm and 7 am (1997). Initial reports suggest that women with breast cancer find internet-based discussion groups and bulletin boards to be helpful (Gustafson *et al.*, 1999; McTavish *et al.*, 1995; Weinberg *et al.*, 1995a, b; Owens and Robbins, 1996). However, rates of internet access, familiarity with the use of computers, and perceived benefits of online psychosocial services have not been evaluated within a general population of women with breast cancer. A detailed characterization of the population interested in internet-based APT is a prerequisite to assessing the potential impact of providing psychosocial interventions over the Web.

Effectiveness of patient outreach efforts

Almost nothing is known about which recruitment methods are most effective for making patients aware of psychosocial services and reducing barriers to involvement. In many oncology centers, brochures are the primary mechanism by which patients are informed about the availability

of APTs (e.g. Plass and Koch, 2001). Patients are often expected to seek psychosocial care independently, without referral or recommendation from their health-care team (Eakin and Strycker, 2001). Within clinical trials of APT, a number of active and passive recruitment mechanisms have been employed, including use of advertisements or brochures, announcements in the media, direct mailings to patients, referrals for psychiatric or psychological care, and direct patient contact. Goodwin *et al.* (2000) provide the most extensive description of recruitment methods to date but sources of referrals were not recorded for participants, therefore relative success rates could not be determined. In other types of clinical trials, recruitment methods have been explored in greater detail (Siminoff *et al.*, 2000; Tworoger *et al.*, 2002). The present study documented the referral source for all participants in an online psychosocial treatment group so that the relative efficacy of each could be determined.

Goals of the present study

The goals of the present study were (1) to evaluate the relationship between stage, time since diagnosis, age and *interest* in an internet-based APT; (2) to evaluate the *accessibility* of APT by examining rates of internet access among women with breast cancer and perceived benefits and barriers to participation in an internet-based APT; and (3) to evaluate the *efficiency* of several different recruitment strategies in making a clinical trial of an internet-based APT available to participants. Because little is known about rates of internet access and familiarity with computers among women with breast cancer, we sought to characterize computer literacy in this population and to identify factors that could increase the efficiency of recruitment into a larger, ongoing clinical trial of a structured, online psychosocial intervention. To better understand factors contributing to interest in participation, we also investigated potential mediating effects associated with interest. Consistent with previous research on social cognitive theory, we hypothesized that the effects of barriers and social support on interest would be mediated by self-efficacy and outcome expectancy (Bandura, 1997). We further hypothesized that social support would directly predict interest in an internet-based therapy.

METHODS

Participants

Women diagnosed with breast cancer were identified consecutively from appointments made in the Department of Hematology/Oncology at the University of Alabama at Birmingham Comprehensive Cancer Center. Of all patients seeking care at the UAB CCC, 10.6% have been diagnosed with breast cancer. Approximately 24% of the CCC's patients are from minority populations, 50% reside outside the eight-county region surrounding the CCC, and 10% travel from other states or countries for treatment. Patients with histologically confirmed cancer of the breast were eligible for participation regardless of time since diagnosis.

Phase I. During Phase I, 192 eligible patients were approached between June and October 1999, and 136 agreed to participate and complete the questionnaires described below (70.8% participation rate).

Phase II. In Phase II of the study, performed after the completion of phase I, 243 consecutive patients were recruited by direct contact with a study assistant for participation in a randomized clinical trial of an internet-based APT between April 2001 and April 2002. Additionally, 68 patients who self-referred to the clinical trial were included in the analyses of recruitment mechanisms. None of the patients in the second phase were asked to complete questionnaires.

Procedure

Phase I. During phase I, medical charts of patients scheduled to receive consultation for breast cancer were examined by a referring physician, and patient age, race, and clinical stage were recorded. As eligible patients checked in for scheduled appointments, a study assistant provided the patient with a brief description of the study, stating that the oncologist (L. Nabell) sought to better understand the needs of her patients. After receiving verbal consent, participants completed the brief questionnaire while waiting to see the oncologist. Upon completion of the questionnaires, participants were invited to participate in a pilot study for an internet-based APT.

Phase II. Phase II employed a number of recruitment mechanisms to enroll women with breast cancer into a randomized clinical trial of an internet-based APT. Direct patient contact required a study assistant to provide a brief description of the clinical trial, which involved 12 weeks of participation in an internet-based APT for small groups of women with breast cancer, to patients visiting one of three medical oncology clinics at the UAB Comprehensive Cancer Center. As patients waited to see their oncologist, they were informed of the availability of a computer-based support group and were asked whether they might be interested in getting further information about participation in a group. When patients declined to participate, the study assistant recorded the reason given by the patient (e.g. lack of access to the Internet). Patients who agreed to participate were later contacted by telephone and enrolled in the clinical trial. No questionnaires were administered during this phase of the study.

Additional recruitment efforts included (1) attending nursing in-service education programs to enable oncology nurses to refer patients, (2) placing full-color posters with business-reply postcards in each of 13 patient examination rooms in Hematology/ Oncology, (3) including business-reply postcards and brochures in American Cancer Society Reach to Recovery materials distributed by volunteers to newly diagnosed patients, (4) submitting a press release to facilitate outreach efforts through local and national print and television media, (5) contacting major oncology-related websites to request a link to the website for our internet-based APT, and (6) conducting physician education programs in four Birmingham-area hospitals. A detailed log of patient referrals was kept for each recruitment source throughout the recruitment period.

Measures

Phase I. Social support was assessed using the Medical Outcomes Study (MOS) Social Support Survey, which consists of 19 items based on a five-point Likert-type scale (Sherbourne and Stewart, 1991). The MOS Social Support Survey is characterized by high internal consistency ($\alpha=0.97$) and convergent validity for correlations with loneliness, family functioning, and psychological

well-being. In addition to an overall score, four subscale scores can be generated from this instrument: tangible support, affectionate support, positive social interaction, and emotional/informational support.

Two brief questionnaires were developed for the purposes of this study. The Computer Access Survey consisted of eight dichotomously scored items regarding the participants' access to computers, e-mail, the World Wide Web, and online sources of cancer information and support. The Computer Attitudes Survey was designed to sample constructs derived from the Health Belief Model (Rosenstock *et al.*, 1988) and Social Cognitive Theory (Bandura, 1986) that were hypothesized to predict intentions to participate in an internet-based APT. Each item of the Computer Attitudes Survey was measured using a seven-point Likert scale. These constructs included perceived benefits/outcome expectancy of face-to-face support services (three items, e.g. 'to what degree would your physical or mental well-being improve if you were able to share your feelings with other breast cancer patients?,' $\alpha=0.77$), perceived benefits/outcome expectancy of computer support services (three items, e.g. 'to what degree would your physical or mental well-being improve from using e-mail to share your feelings with other breast cancer patients?,' $\alpha=0.89$), perceived barriers to computer support services (two items, e.g. 'it would be difficult to share my feelings with others using a computer,' $\alpha=0.19$), and self-efficacy for computer use (three items, e.g. 'how confident are you that you could send an e-mail message on a computer?,' $\alpha=0.98$). Because the two items representing barriers to the use of computer support services (perceived difficulty sharing feelings over a computer, preference for face-to-face support) exhibited low internal consistency, these two items were entered separately in all models involving this construct. To calculate scale scores for each construct, Likert ratings for each item composing the scale were summed.

Additionally, participants were asked to self-report their annual household income, education, current use of a support group, and treatment status. Interest in participating in the internet-based APT was measured using a single, seven-point Likert scale ranging from 'not at all interested' to 'extremely interested'. Participants who were willing to take part in the pilot study of the internet-based APT were asked to provide

their name and phone number for a follow-up contact.

Phase II. Participants in Phase II of the study did not complete questionnaires. Study assistants recorded recruitment rates and reasons for refusal to participate in the clinical trial, including lack of access to the Internet.

RESULTS

Participants

Phase I. The 136 phase I participants completing questionnaires did not differ from the 56 non-participants in age (mean = 53.9 years, $t(176)=0.2$, $p=0.84$), ethnicity (84% white, 16% African-American, $\chi^2(1)=2.38$, $p=0.12$), or clinical stage (28.7% stage I, 40.1% stage II, 11.5% stage III, 19.7% stage IV, $\chi^2(3)=3.35$, $p=0.34$). At the time of the assessment, 38% of participants had undergone lumpectomy, 59% had undergone mastectomy, 48% had been treated with radiation, and 66% had been treated with at least one regimen of chemotherapy. Seventy-seven percent of the participants were in long-term follow-up and were not currently receiving radiation or chemotherapy, although many of the participants were taking tamoxifen for prevention of recurrence. Average length of education was 14 years, and median annual household income was \$45 000. Mean time since initial diagnosis of breast cancer was 29 months, and participants traveled an average of 75 miles from their home to the clinic one-way.

Phase II. Demographic and treatment data for the 243 participants in phase II were not recorded.

Patient characteristics and interest in internet-based APT: Phase II

In order to test the relationship between patient characteristics that could be quickly ascertained by chart review and interest in participation in an internet-based APT, simple correlations between interest and distance from clinic, age, education, income, and time since diagnosis were calculated. Analysis of variance (ANOVA) was used to evaluate the relationship between clinical stage, a categorical variable, and interest in participating, a continuous variable. Interest in participating was not statistically correlated with distance from clinic, education, income, or time since diagnosis but was significantly associated with age, $r=-0.29$,

$p=0.002$. Women below age 45 exhibited the highest level of interest (mean = 5.07, max = 7), with interest decreasing as age increased: women age 46–55, mean = 3.96; women age 56–65, mean = 3.85; women age 66–75, mean = 2.92; women age 75+, mean = 2.5. Clinical stage was not significantly associated with interest in participation.

Psychological characteristics and interest in internet-based APT: Phase I

Correlations between theoretical psychological constructs (outcome expectancy/benefits of internet-based APT, barriers to participation in internet-based APT, self-efficacy for computer use, and existing social support) and interest in participation were obtained (see Table 1). Multiple regression was employed to test the relationship between these variables as a set and interest in participation, and the combined set of variables significantly predicted interest, $R^2=0.51$, $p<0.0001$.

Structural equation modeling methods were employed using maximum likelihood estimates generated by SAS (v. 8.0) Proc CALIS to examine the predictive effects of outcome expectancy, barriers, self-efficacy, and social support to interest in participation in the context of a mediation model. Forty-one subjects were not included in this analysis due to incomplete data on one or more of the variables tested. Because the Proc CALIS procedure used listwise deletion and therefore excluded these 41 subjects from analysis, structural equation modeling was repeated using pairwise deletion and mean imputation. The pattern of results was unchanged, and data are presented for the model using listwise deletion. The hypothesized model, in which self-efficacy for computer use and outcome expectancy of compu-

ter support groups mediated the effects of social support and perceived barriers of computer support on interest in participating in a computer-based support group, did not provide an adequate fit to the data, $\chi^2(10, n=94)=27.9$, $p=0.002$. Using the Lagrange multiplier test, post hoc modifications were performed and tested using chi-square difference tests to develop a model with better fit to the observed data (Figure 1). The final model was obtained by adding a pathway from social support to outcome expectancy, $\chi^2_{diff}(1)=4.7$, $p<0.05$, and adding a covariance pathway between self-efficacy and outcome expectancy, $\chi^2_{diff}(1)=8.5$, $p<0.05$. Overall, the fit indices indicated that the final model provided adequate fit to the observed data (GFI = 0.97, CFI = 0.95, NFI = 0.93, $\chi^2(4) = 8.68$, $p = 0.07$).

Internet access among women with breast cancer: Phase I

Levels of access to the internet and computer services for phase I participants are shown in Table 2. Levels of internet access showed considerable variations across age groups. 90% of women aged 45 or below reported having access to the Internet compared with 63.3% of women aged 46–55, 65.6% of women aged 56–65, 28.6% of women aged 66–75, and 0% of women over the age of 75. In the phase II sample from 2001, access to the Internet increased to 69.1% from the 62.5% level observed for phase I.

Outcome expectancies for face-to-face and internet-based APT: Phase I

Among phase I participants, 29.6% reported more positive outcome expectancies of internet-based

Table 1. Correlations among psychological variables and regression on interest in participating in internet-based APT

Variable	Interest (DV)	1	2	3	4	5
1. Social support	-0.136	1.00				
2. Outcome expectancy	0.670***	-0.171	1.00			
3. Self-efficacy	0.456***	0.020	0.372***	1.00		
4. Difficult to share feelings using a computer	-0.293**	-0.071	-0.303**	-0.184	1.00	
5. More comfortable in face-to-face group than computer	0.487***	-0.099	0.477***	0.271**	-0.104	1.00
Means	4.11	87.1	4.19	5.05	3.56	3.81
(range)	(1–7)	(20.3–99.9)	(1–7)	(1–7)	(1–7)	(1–7)
Standard deviation	2.28	16.6	2.02	2.29	2.11	1.83

* $p<0.05$; ** $p<0.01$; *** $p<0.001$

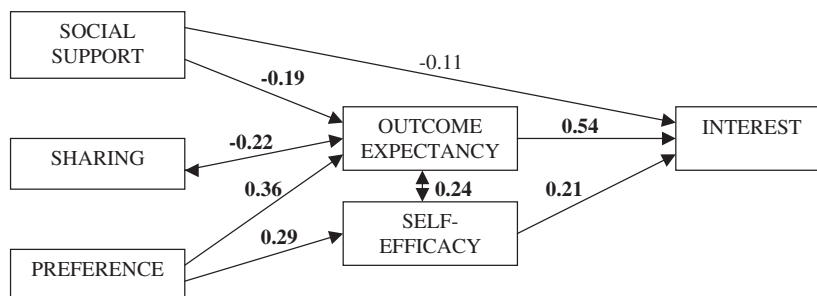


Figure 1. Path model and maximum likelihood estimates for predicting interest in participation in an internet-based psychosocial treatment.

Paths significant at the $p < 0.05$ level are shown in bold print; SOCIAL SUPPORT = total social support, SELF-EFFICACY = self-efficacy for computer use, SHARING = difficulty sharing emotions via e-mail, PREFERENCE = preference for face-to-face support over internet-based APT, reverse-scored, OUTCOME EXPECTANCY = -likelihood of physical or emotional benefit from participation in an internet-based APT, INTEREST = interest in participating in internet-based APT.

Table 2. Access to computers and the internet among women with breast cancer

Item	% of phase I participants ($n = 136$)
Have ever used a computer	73.3%
Own or lease a home computer	55.0%
Have access to a computer outside of home	69.2%
Have access to the internet	62.5%
Have own e-mail account	54.7%
Have interacted with other cancer patients using the internet	6.9%
Have used the internet as a source of cancer information	38.9%

APT than for face-to-face APT, 34.1% reported more positive outcome expectancies for face-to-face APT, and 36.3% reported outcome expectancies that did not differ between internet and face-to-face APT. Relative outcome expectancies for face-to-face or internet-based APT were not associated with access to the Internet, $\chi^2(2) = 1.56$, $p = 0.46$.

Success of recruitment strategies: Phase II

In phase II of the study, recruitment success for each recruitment strategy was estimated by several methods: the raw number of patients who indicated a desire to participate in the clinical trial of an internet-based APT, the number of patients who were actually enrolled into the trial, and the

cost per patient enrolled. Recruitment success associated with each recruitment strategy is displayed in Figure 2. Average costs associated with each strategy were calculated as a function of direct expenses for materials and the salary time of the predoctoral investigator who coordinated the recruitment effort (avg. \$6.97/hour). The costs per patient enrolled into the clinical trial are as follows: \$0 for referrals from patients already in the study, \$1.27 for clinic posters with business-reply postcards, \$1.39 for national print media reports and articles, \$3.10 for local print media reports and articles, \$6.97 for efforts to advertise the study on cancer-related web sites, \$22.63 for direct patient contact in local clinics, \$34.85 for local television and radio reports, and \$139.40 for outreach to nursing organizations and area hospitals. Across recruitment strategies, 66.3% of the patients who asked to be involved in the trial were later enrolled as participants in the trial. The remaining 34.7% either could not be contacted by study staff or refused participation after taking part in the informed consent process.

Among the 243 patients approached directly by a research assistant, 109 (44.9%) asked to be involved in the clinical trial. At the time this analysis was conducted, 69 of these 109 patients had been enrolled and randomized into the trial. The remaining 134 patients declined to enroll in the trial for a variety of stated reasons, including lack of access to a computer or the internet ($n = 47$), lack of familiarity with computers or the internet ($n = 20$), a desire for time to look over the study materials ($n = 19$), perception that breast

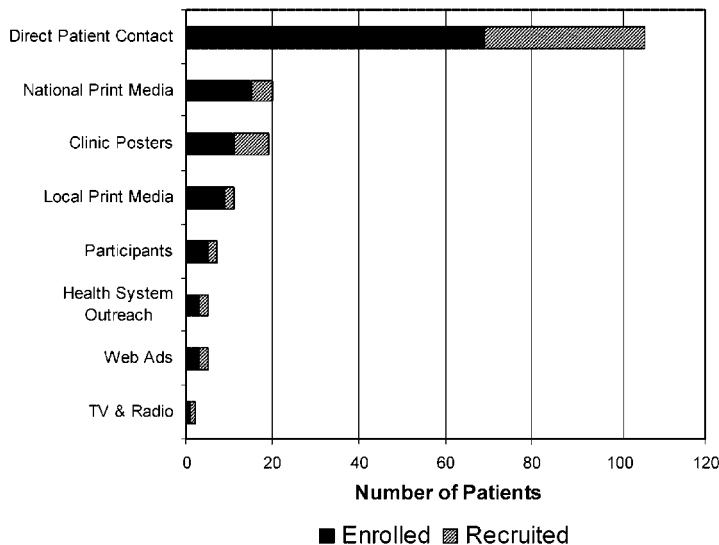


Figure 2. Number of patients recruited and enrolled into a clinical trial of internet-based APT by recruitment strategy.

cancer was 'behind' them ($n=12$), adequate existing support ($n=10$), being 'too busy' ($n=8$), being in a support group already ($n=3$), fear of interacting with others who might be depressed or sick ($n=1$) or feeling too sick to be involved ($n=1$). Thirteen patients did not provide a reason for declining to enroll.

DISCUSSION

Internet-based psychological therapy is a feasible compliment to face-to-face psychosocial care. An increasing percentage of women with breast cancer, nearly 70% in our most recent sample, has access to the internet, and nearly 66% report that internet-based APT is equally or more likely to result in improved physical and mental health than face-to-face therapy. When made aware of the availability of participating in internet-based APT, 45% asked to become a member of a small therapy group. Among patients who had access to the Internet and declined to participate, few cited logistical constraints as a reason for not being involved. Thus, by making an internet-based APT available, previous barriers to participation can be overcome, and the overall impact of adjuvant psychological therapy could be enhanced.

Patient characteristics associated with interest in being involved in an internet-based APT provide insight into how such services can be provided. First, it should be noted that the demographic profile of our phase I sample differed slightly from recent census data in the state of Alabama. Data from the 2000 census show that median educational attainment in the state was a high school diploma, and median annual household income was \$34,135 (U.S. Census Bureau, 2002). As is true for the general patient mix at the cancer center where the study was conducted, participants were slightly better educated and wealthier than the average citizen of the state. Second, interest was modestly associated with age. A majority of women under 65 had access to the Internet, and they express higher levels of interest in internet-based psychosocial services. Younger women are also more likely to have barriers to participation associated with lifestyle constraints (e.g. work responsibilities, caring for dependent children or older adults), making this group especially likely to take advantage of internet-based services. Other cancer populations with lower mean age at diagnosis may also be expected to benefit from internet-based services (e.g. Hodgkin's, acute lymphocytic leukemia, and cancers of the brain, ovary, testis, or thyroid). Third, neither stage nor time since diagnosis was related to interest. These

results suggest that the need for adjuvant psychosocial care is not attenuated with time.

Among the psychological factors hypothesized to predict interest in participation, outcome expectancies mediated the effects of social support, preference for face-to-face psychosocial care, and perceived difficulty sharing feelings on the Internet. Helgeson *et al.* (2001) have previously reported that patients with adequate social support do not benefit from participation in APT, yet they may serve a valuable role in sharing support with those who are less fortunate. In this study, women interested in participating in internet-based APT frequently reported to research assistants that they wished to be involved in order to help others without sufficient support, and providing such support may serve as a coping mechanism for these women. Patient outreach efforts designed to address outcome expectancies and perceived barriers to participating in internet-based therapy may serve to increase interest in participation. Familiarity with computers is a significant barrier to involvement in these services, particularly for elderly patients. Given that personal computers first became readily available to the general public within the last 20 years or so, self-efficacy for computer use would be expected to be related to age and should also change rapidly over the next several years as cohorts who are more familiar with computers reach ages that are associated with higher incidence rates of cancer.

The manner in which the availability of APT is communicated to cancer patients plays an important role in actual participation. In the present study, women who were approached face-to-face were more likely to indicate interest and to actually enroll in the trial. Although placing full-color posters with business-reply postcards in patient exam rooms resulted in nearly 20 interested patients and 11 who enrolled in the trial, over 500 postcards were taken, but not returned, by patients. Thus, the overall yield to the trial was approximately 1 enrolled participant for every 50 postcards distributed. Similarly, media exposure resulted in relatively few enrollments and even the high profile of a national magazine resulted in only 15 enrolled participants. Paid advertising in this magazine would have cost over \$10,000 and might not have been effective for recruitment purposes. Clinicians must also cede control of how the treatment program is described and presented to the media sources, which in some cases can limit

recruitment success. For example, the local television story that reported our work aired only during the late night news program and did not provide a web site address for interested patients to contact. Direct patient contact was more expensive than other forms of recruitment, but it offers a number of clear advantages. Interacting individually with patients, in the private setting of an exam room, can help communicate to patients that cancer-related distress is common for persons with cancer. In so doing, patients may attach less stigma to the notion of being involved in a psychological therapy or support group. Direct patient contact also minimizes the amount of energy a patient must expend to become involved, effectively reducing potential barriers to participation. However, in order for face-to-face recruitment to be effective rather than simply efficacious, it must become a standard of care in treatment centers where APT is available. Otherwise, participation in APT will be limited only to well-funded clinical trials in which a staff member can be paid to assist with recruitment. Further, because physicians are often unaware that patients are experiencing distress and seek supportive services such as those provided by psychological therapies (Burstein *et al.*, 1999; Cull *et al.*, 1995), functional collaborations with referring physicians and nursing staff are essential to both provide patients with information about available services and to encourage them to take advantage of these programs (Burton and Watson, 1999).

Our results suggest that few women with breast cancer acknowledge seeking supportive services to obtain support for themselves, but rather they express motivation to seek these services as a source of information, to alleviate depression or anxiety about cancer, to cope with side-effects of treatment, and to give support to others (Burstein *et al.*, 1999; Stevenson and Coles, 1993). For researchers and providers of psychosocial interventions, a needs-matching strategy, in which individual patient needs are matched with distinct types of APT, may be necessary to increase participation rates and to maximize the benefits of supportive services. In the context of interdisciplinary care, tailored educational strategies aimed at increasing perceived benefits and reducing perceived barriers to these services could greatly increase participation rates for psychosocial intervention studies. At a minimum, a simple and veridical endorsement from the oncologist could serve as a positive and highly effective

intervention in itself to increase perceived benefit and consequent likelihood of participation.

Limitations

Several limitations of the present study should be noted. First, because the samples obtained in the two phases of the study were non-overlapping, we were unable to measure within-subjects change over time in access to the Internet or perceptions about computer-based support services. Second, it is important to note that participants who expressed an interest in participating in computer-based support at one point in time do not necessarily maintain this interest or actually begin participation in a computer support group. Our data from phase II of the study suggest that approximately 63% of those who express interest in a computer-based support group will later provide informed consent and become enrolled in such a group. Third, the efficacy of internet-based APT for improving quality of life in breast cancer patients has only recently been examined in randomized trials (Lieberman *et al.*, 2003). Communication patterns in internet groups are likely to be substantially different than those that evolve in the context of a carefully facilitated therapy group (e.g. Yalom, 1995). A notable number of breast cancer patients are already turning to internet discussion groups and chat rooms to seek support and information (Sharf, 1997). Researchers have been limited to observational studies in evaluating the effect of participation in these kinds of widely available support networks (Epstein and Klinkenberg, 2001; Klemm *et al.*, 1999). Studies that are able to compare communication and outcomes associated with discussion groups and structured therapy groups on the Internet would be valuable to the advancement of this field.

The availability of internet-based APT will expand the arsenal of treatment options available to psycho-oncologists and oncology teams, particularly as efforts to increase access to internet technologies in hospitals and clinics continue to grow (Eng *et al.*, 1998). Psychosocial services (e.g. support groups, individual counseling, structured group interventions, pastoral care, information/resource support), largely neglected or underfunded in traditional health-care environments, may become more accessible to patients and less expensive for providers when offered online. Access to the Internet, and internet-based adju-

vant psychological therapy in particular, offers the potential to empower patients to enhance their ability to cope with their disease and to participate more actively in their recovery.

ACKNOWLEDGEMENTS

The present results are part of a larger ongoing study of the Internet as a source of support and information for women with breast cancer, supported by grant No. DAMD17-00-1-0121 from the Department of the Army Breast Cancer Research Program.

REFERENCES

- Andersen BL. 1992. Psychological interventions for cancer patients to enhance the quality of life. *J Consult Clin Psychol* **60**: 552–568.
- Bandura A. *Social Foundations of Thought Action: A Social Cognitive Theory*. Englewood Cliffs, NJ: Prentice-Hall, 1986.
- Bandura A. *Self-Efficacy: The Exercise of Control*. W.H. Freeman and Company: New York, 1997.
- Bridge LR, Benson P, Pietroni PC, Priest RG. 1988. Relaxation and imagery in the treatment of breast cancer. *BMJ* **297**: 1169–1172.
- Burstein HJ, Gelber S, Guadagnoli E, Weeks JC. 1999. Use of alternative medicine by women with early-stage breast cancer. *N Engl J Med* **340**: 1733–1739.
- Burton M, Watson M. *Counselling People with Cancer*. Wiley: New York, 1998.
- Chambless DL, Hollon SD. 1998. Defining empirically supported therapies. *J Consult Clin Psychol* **66**: 7–18.
- Coluzzi PH, Grant M, Doroshov JH, Rhiner M, Ferrell B, Rivera L. 1995. Survey of the provision of supportive care services at National Cancer Institute—designated Cancer Centers. *J Clin Oncol* **13**: 756–764.
- Compas BE, Haaga DAF, Keefe FJ, Leitenberg H, Williams DA. 1998. Sampling of empirically supported treatments from health psychology: smoking, chronic pain, cancer, and bulimia nervosa. *J Consult Clin Psychol* **66**: 89–112.
- Cull A, Stewart M, Altman, DG. 1995. Assessment of and intervention for psychosocial problems in routine oncology practice. *Br J Cancer* **72**: 229–235.
- Cunningham AJ, Edmonds CVI, Jenkins GP, Pollack H, Lockwood GA, Warr D. 1998. A randomized controlled trial of the effects of group psychological therapy on survival in women with metastatic breast cancer. *Psychooncology* **7**: 508–517.
- Cunningham AJ. 2000. Adjuvant psychological therapy for cancer patients: putting it on the same footing as

- adjunctive medical therapies. *Psychooncology* **9**: 367–371.
- Donnelly JM, Kornblith AB, Fleishman S *et al.* 2000. A pilot study of interpersonal psychotherapy by telephone with cancer patients and their partners. *Psychooncology* **9**: 44–56.
- Eakin EG, Strycker LA. 2001. Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: patient and provider perspectives. *Psychooncology* **10**: 103–113.
- Edgar L, Rosberger Z, Nowlis D. 1992. Coping with cancer during the first year after diagnosis. *Cancer* **69**: 817–828.
- Elisabet Palsson M, Norberg A. 1995. Breast cancer patients' experiences of nursing care with the focus on emotional support: the implementation of a nursing intervention. *J Adv Nurs* **21**: 277–285.
- Eng TR, Maxfield A, Patrick K, Deering MJ, Ratzan SC, Gustafson DH. 1998. Access to health information and support: a public highway or a private road? *JAMA* **280**: 1371–1375.
- Epstein J, Klinkenberg WD. 2001. From Eliza to Internet: a brief history of computerized assessment. *Comput Human Behav* **17**: 295–314.
- Fawzy FI, Fawzy NW, Arndt LA, Pasnau RO. 1995. Critical review of psychosocial interventions in cancer care. *Arch Gen Psychiatry* **52**: 100–113.
- Finn J. 1995. Computer-based self-help groups: a new resource to supplement support groups. *Soc Work Groups* **18**: 109–117.
- Fukui S, Kugaya A, Kamiya M *et al.* 2001. Participation in a psychosocial group intervention among Japanese women with primary breast cancer and its associated factors. *Psychooncology* **10**: 419–427.
- Goodwin PJ, Leszcz M, Quirt G *et al.* 2000. Lessons learned from enrollment in the BEST study a multicenter, randomized trial of group psychosocial support in metastatic breast cancer. *J Clin Epidemiol* **53**: 47–55.
- Goodwin PJ, Leszcz M, Ennis M *et al.* 2001. The effect of group psychosocial support on survival in metastatic breast cancer. *N Engl J Med* **345**: 1719–1726.
- Gruber BL, Hersh SP, Hall NRS *et al.* 1993. Immunological responses of breast cancer patients to behavioral interventions. *Biofeedback Self Regul* **18**: 1–22.
- Gustafson D, Wise M, McTavish F *et al.* 1993. Development and pilot evaluation of a computer-based support system for women with breast cancer. *J Psychosoc Oncol* **11**: 69–93.
- Gustafson DH, Hawkins R, Boberg E *et al.* 1999. Impact of a patient-centered, computer-based health information/support system. *Am J Prev Med* **16**: 1–9.
- Helgeson VS, Cohen S, Schulz R, Yasko J. 2001. Long-term effects of educational and peer discussion group interventions on adjustment to breast cancer. *Health Psychol* **20**: 387–392.
- Jacobs C, Ross RD, Walker IM, Stockdale FE. 1983. Behavior of cancer patients: a randomized study of the effects of education and peer support groups. *Am J Clin Oncol* **6**: 347–350.
- Klemm P, Hurst M, Dearholt SL, Trone SR. 1999. Gender differences on internet cancer support groups. *Comput Nurs* **17**: 65–72.
- Leedham B, Ganz PA. 1999. Psychosocial concerns and quality of life in breast cancer survivors. *Cancer Invest* **17**: 342–348.
- Liang LP, Dunn SM, Gorman A, Stuart-Harris R. 1990. Identifying priorities of psychosocial need in cancer patients. *Br J Cancer* **62**: 1000–1003.
- Lieberman MA, Golant M, Giese-Davis J *et al.* 2003. Electronic support groups for breast carcinoma: A clinical trial of effectiveness. *Cancer* **97**: 920–925.
- Maguire P, Tait A, Brooke M, Thomas C, Sellwood R. 1980. Effect of counselling on the psychiatric morbidity associated with mastectomy. *Br Med J* **281**: 1454–1456.
- Maguire P, Brooke M, Tait A, Thomas C, Sellwood R. 1983. The effect of counselling on physical disability and social recovery after mastectomy. *Clin Oncol* **9**: 319–324.
- Maunsell E, Brisson J, Deschenes L, Frasure-Smith N. 1996. Randomized trial of a psychologic distress screening program after breast cancer: effects on quality of life. *J Clin Oncol* **14**: 2747–2755.
- McArdle JMC, George WD, McArdle CS *et al.* 1996. Psychological support for patients undergoing breast cancer surgery: a randomised study. *BMJ* **312**: 813–817.
- McTavish FM, Gustafson DH, Owens BH *et al.* 1995. CHES: an interactive computer system for women with breast cancer piloted with an underserved population. *J Ambul Care Manage* **18**: 35–41.
- Meyer T, Mark M. 1995. Effects of psychosocial interventions with adult cancer patients: a meta-analysis of randomized experiments. *Health Psychol* **1**: 101–108.
- Moorey S, Greer S, Bliss J, Law M. 1998. A comparison of adjuvant psychological therapy and supportive counselling in patients with cancer. *Psychooncology* **7**: 218–228.
- Owen JE, Klapow JC, Hicken B, Tucker DT. 2001. Psychosocial interventions for cancer: review and analysis using a three-tiered outcomes model. *Psychooncology* **10**: 218–230.
- Owens BH, Robbins KC. 1996. CHES: comprehensive health enhancement support system for women with breast cancer. *Plast Surg Nurs* **16**: 172–175.
- Plass A, Koch U. 2001. Participation of oncological outpatients in psychosocial support. *Psychooncology* **10**: 511–520.
- Rosenstock IM, Strecher VJ, Becker MH. 1988. Social learning theory and the health belief model. *Health Educ Q* **15**: 175–183.

- Rustoen T, Wiklund I, Hanestad BR, Moum T. 1998. Nursing intervention to increase hope and quality of life in newly diagnosed cancer patients. *Cancer Nurs* **21**(21), 235–245.
- Sharf B. 1997. Communicating breast cancer on-line: support and empowerment on the internet. *Women Health* **26**: 65–83.
- Sheart T, Maguire P. 1999. The effects of psychological interventions on anxiety and depression in cancer patients: results of two meta-analyses. *Br J Cancer* **80**: 1770–1780.
- Sherbourne CD, Stewart AL. 1991. The MOS social support survey. *Soc Sci Med* **32**: 705–714.
- Shrock D, Palmer RF, Taylor B. 1999. Effect of a psychosocial intervention on survival among patients with stage I breast and prostate cancer: a matched case-control study. *Altern Ther Health Med* **5**: 49–55.
- Siminoff LA, Zhang A, Colabianchi N, Sturm CM, Shen Q. 2000. Factors that predict the referral of breast cancer patients onto clinical trials by their surgeons and medical oncologists. *J Clin Oncol* **18**: 1203–1211.
- Stevenson BS, Coles PM. 1993. A breast cancer support group: activities and value to mastectomy patients. *J Cancer Educ* **8**: 239–242.
- Telch CF, Telch MJ. 1986. Group coping skills instruction and supportive group therapy for cancer patients: a comparison of strategies. *J Consult Clin Psychol* **54**: 802–808.
- Trijsburg RW, van Knippenberg FCE, Rijpma SE. 1992. Effects of psychological treatment on cancer patients: a critical review. *Psychosom Med* **54**: 489–517.
- Twoogor SS, Yasui Y, Ulrich CM *et al.* 2002. Mailing strategies and recruitment into an intervention trial of the exercise effect on breast cancer biomarkers. *Cancer Epidemiol Biomarkers* **11**: 73–77.
- US Census Bureau. 2002. <http://www.census.gov/>
- Vachon MLS, Lyall WAL, Rogers J, Cochrane J, Freeman SJJ. 1982. The effectiveness of psychosocial support during post-surgical treatment of breast cancer. *Int J Psychiatry Med* **11**: 365–372.
- Walker LG, Walker MB, Ogston K *et al.* 1999. Psychological, clinical, and pathological effects of relaxation training and guided imagery during primary chemotherapy. *Br J Cancer* **80**: 262–268.
- Weinberg N, Schmale JD, Uken J, Wessel K. 1995a. Computer-mediated support groups. *Soc Work Groups* **17**: 43–54.
- Weinberg N, Uken JS, Schmale J, Adamek, M. 1995b. Therapeutic factors: their presence in a computer-mediated support group. *Soc Work Groups* **18**: 57–69.
- Weinberg N, Schmale J, Uken J, Wessel K. 1996. Online help: cancer patients participate in a computer-mediated support group. *Health Soc Work* **21**: 24–29.
- Wieder S, Schwarzfeld J, Fromewick J, Holland JCB. 1978. Psychosocial support program for patients with breast cancer at Montefiore Hospital. *QRB Qual Rev Bull* **4**: 10–13.
- Winzelberg A. 1997. The analysis of an electronic support group for individuals with eating disorders. *Comput Human Behav* **13**: 393–407.
- Yalom ID. 1995. *Theory and Practice of Group Psychotherapy* (4th edn). Basic Books: New York.
- Youssef FA. 1984. Crisis intervention: A group-therapy approach for hospitalized breast cancer patients. *J Adv Nurs* **9**: 307–313.