A One-to-One Mentoring Support Service for Breast Cancer Survivors

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ABSTRACT

Purpose: ABCD: After Breast Cancer Diagnosis (ABCD) is a Wisconsin-based mentoring service that pairs breast cancer survivors with women recently diagnosed with breast cancer. Since 1999, ABCD has trained volunteers to provide personalized information and emotional support. This review describes participants' perceptions of this survivorship program and its utility for breast cancer patients.

Methods: ABCD conducted 3 "program effectiveness" surveys between 2002 and 2006. Surveys were conducted over the telephone and used a 5-point Likert scale to elicit evaluations of the organization, mentors, resources, and other program dimensions.

Results: Survey results indicate that this model is a successful resource that could be replicated for breast cancer survivors nationally. Respondents were especially satisfied with the helpfulness of the program for them and their families, mentor confidentiality, and emotional support. Areas for improvement focused on mentee familiarity with the ABCD website and helpline and improvement in mentor knowledge. Approximately 60% of respondents would consider becoming mentors.

Conclusion: ABCD is a positive and successful program with consistent participant satisfaction. The program has expanded nationally to address the needs of survivors. This model could be further replicated to provide support to survivors, family, and friends at no cost.

INTRODUCTION

Breast cancer is the most commonly diagnosed cancer among women.[1] Because of screening and early detection, as well as improvements in treatment options, many women are living longer with breast cancer or are being cured entirely. According to the Centers for Disease Control, the number of cancer survivors in the United States has increased from 9.8 million in 2001 to 11.7 million in 2007, including more than 2.5 million breast cancer survivors.[2] An estimated 64.8% of cancer survivors live longer than 5 years after their cancer diagnosis and a large portion of these patients are breast cancer survivors.[2]

Cancer survivorship, defined as the time from diagnosis until the end of life,[3] was identified by the Institute of Medicine in 2006 as a distinct phase of the cancer journey that has been neglected in advocacy, education, clinical practice, and research.[4] Cancer survivors face unique physical and psychosocial challenges across the life course, including psychological distress, sexual dysfunction, infertility, impaired organ function, cosmetic changes, and limitations in mobility, communication, and cognition, among others.[4] In the face of these challenges, it is now widely accepted that survivors benefit from emotional and informational support throughout the cancer journey.[5-8] The documented benefits of participation in cancer support groups range from enhanced quality of life to prolonged survival,[9,10] indicating that support-based programs may be an important resource for addressing the needs of cancer survivors.

There is a growing interest in volunteer-based programs in particular because of their shared-experience element, accessibility, and cost effectiveness. According to a recent systematic review, there is a paucity of literature on volunteer-based support programs for people with cancer.[11] While evidence does suggest that most volunteer-based support programs are beneficial for participants, volunteer programs often face challenges with sustainability, as well as growth and application in multiple populations.[11] Here we present the case of ABCD: After Breast Cancer Diagnosis (ABCD), a structured volunteer program that has been in place for 15 years and recently has expanded to have a national presence.

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Table 1. Sample Survey Questions and Mean Likert Scale Responses

	2006	2004	2002
ABCD (After Breast Cancer Diagnosis) Organization	n = 139	n = 92	n = 53
ABCD is a reliable source for support	4.55	4.67	4.33
ABCD is a reliable source for information	4.37	4.47	4.09
It is easy to contact someone at ABCD	4.65	4.67	4.47
One-to-one contact is valuable	4.65	4.74	4.62
The ABCD organization is responsive in a timely manner	4.68	4.68	4.60
The ABCD program has helped me	4.41	4.47	—
The ABCD program has helped my family	3.84	—	—
Overall evaluation of ABCD	4.58	4.56	4.43
ABCD Mentors			
My ABCD mentor was well informed	4.48	4.52	4.31
My ABCD mentor was responsive to my questions/concerns	4.52	4.66	4.51
I felt comfortable sharing personal information with my mentor	4.46	4.55	4.41
My ABCD mentor provided emotional support	4.40	4.38	4.09
My ABCD mentor helped me get the additional breast cancer information I need	3.83	4.15	—
I trust my discussions with my mentor were kept completely confidential	4.77	4.74	4.74
Overall evaluation of ABCD mentor	4.35	4.41	4.31
ABCD Resources			
Not at all familiar with ABCD website	61%	65%	77%
Not at all familiar with ABCD helpline	38%	35%	44%

Mean Likert scale rating for all respondents, where 1 indicates "Strongly Disagree" and 5 indicates "Strongly Agree."

METHODS

Program Description

ABCD is a Wisconsin-based organization originally established to meet the needs of breast cancer survivors and their families in Eastern Wisconsin (http://www.abcdbreastcancersupport.org/). While ABCD is based in southeast Wisconsin and actively serves all of Wisconsin's 72 counties, its services are now available in communities nationwide. Milwaukee County, home to the organization's headquarters, has the highest rates of breast cancer in Wisconsin and includes the state's most socioeconomically diverse population.

Breast cancer survivors who are at least 1 year past the completion of treatment or people who have had experience with breast cancer with family members or friends can volunteer to serve as mentors with ABCD. New volunteers complete 12 hours of training, with instruction on breast cancer diagnosis, treatment options, psychosocial issues, resources for survivors, and health information privacy. The goal of the peer support is to decrease the survivor's sense of isolation, increase knowledge about the breast cancer experience, introduce possible coping strategies, and provide a sense of hope.

Program Process

ABCD staff pair mentors with mentees in a deliberate process tailored to the mentee's needs. A mentee who is seeking mentorship works with ABCD staff to complete an intake form that queries relevant information on demographics, health, and cancer status.

The mentor and mentee usually first communicate by telephone, and if they wish to continue the relationship, continued contact can be initiated. Matches are afforded a great deal of autonomy, with no direct supervision and no predetermined end to the relationship. ABCD does, however, conduct regular check-ins with both mentors and mentees to assess their satisfaction with the match and offer additional support where needed.

Survey and Data Collection

ABCD began matching survivors and mentors in September 1999. Since then, with the assistance of an independent marketing and survey firm, ABCD conducted 3 "program effectiveness" surveys, in 2002, 2004, and most recently in 2006. Survey questionnaires, designed collaboratively by the independent firm and members of the ABCD program committee, consisted of 8 questions about the ABCD organization, 12 questions about mentor services, and 9 questions addressing resources and other topics (Table 1). ABCD volunteers administered the survey as a 5-minute telephone interview, conducted in English. Mentors who volunteered as survey administrators did not contact their own mentees. Respondents were asked to evaluate the attributes of ABCD on a 5-point Likert scale, from 1 (strongly disagree) to 5 (strongly agree). Participants were informed that an independent marketing firm was assisting in data collection. Participants did not receive any incentive for their participation. The independent firm compiled and analyzed de-identified data for ABCD. With all data de-identified, this work was exempted from review by our institutional review board (IRB).

Analysis

We provide descriptive statistics to characterize the survey cohort. The independent firm calculated mean scores for each of the Likert-scaled questions. Chi-square tests were performed to identify significant associations between survey year and characteristics of the match. Number of surveys conducted was estimated from program participation levels for 2002 and 2004.

RESULTS

Survey Respondents

Analysis of the questionnaires was conducted to evaluate the respondent perceptions of the program and to identify areas in need of improvement. In the most recent survey, volunteers telephoned all survivors who had received mentoring services during the prior 2 years (N=265). One hundred thirty-nine women completed at least 75% of the questionnaire, for a participation rate of 52%. This participation rate is up from 45% and 25% in the previous 2 surveys (Table 2).

Table 2. Survivor Demographics Data

	2005-2006	2003-2004	2000-2002
Number of Survivors/Mentors[a]	**265**	**203**	**208**
Number of matches	303	233	247
Demographics of Patients/Survivors Receiving Matches			
Unknown	18	13	9
African American	27	18	8
Caucasian	254	169	191
Hispanic	4	3	—
Survey participation	52%	45%	25%

[a]The number of participants each year is less than the number of matches, as multiple participants (mentors) have multiple matches.

Figure 1. Estimated Length of Relationship with Mentor

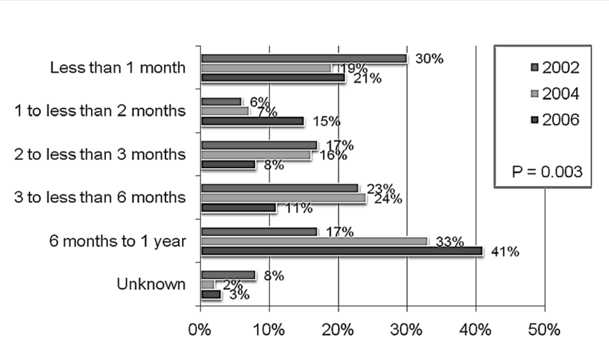
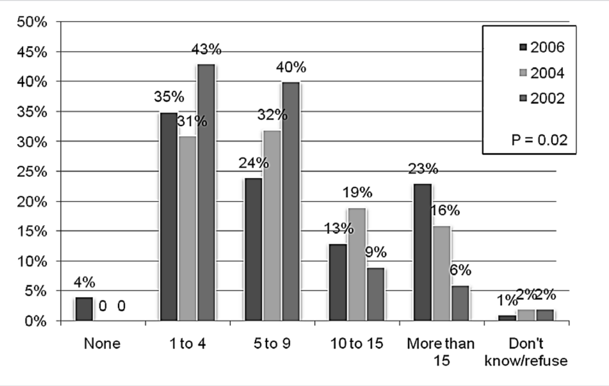


Figure 2. Estimated Number of Contacts with the Mentor



Over half of respondents learned about ABCD through health care settings, either directly from their physician/oncologist (23%), or nurse (12%), or from the hospital or clinic (22%). Others learned about the program from a friend or relative, through their church, or at an ABCD fundraising event. Estimated length of relationship with the mentor was asked of participants during the time period of most active treatments (1 year). For 41% of respondents, the mentor relationship lasted from 6 months to 1 year, an increase compared to the previous 2 surveys (33% and 17% respectively). Only 8% estimated the relationship lasted less than 3 months ($P = 0.003$) (Figure 1). The majority of respondents (71%) were involved with only 1 mentor while they received services at ABCD. The number of contacts between the mentor and survivor increased significantly over the years. In 2006, 23% of respondents reported they had had more than 15 contacts with their mentor throughout the relationship, compared to 6% and 16% in 2002 and 2004, respectively ($P = 0.02$) (Figure 2). Nearly all respondents (96%) would refer another breast cancer survivor to ABCD and 60% would consider becoming mentors themselves.

In the most recent survey, respondents gave a mean Likert rating of 4.41 in response to the statement: "The ABCD program has helped me." Respondents gave a mean Likert rating of 3.84 in response to the statement: "The ABCD program has helped my family" (Table 1). When asked about their familiarity with ABCD resources, 61% of respondents were not familiar with the ABCD website and 38% were not familiar with the ABCD helpline (Table 1). The statement with which respondents most agreed (mean Likert rating of 4.77) was: "I trust my discussions with my mentor were kept completely confidential" (Table 1). The lowest mean Likert score (3.83) came in response to the statement: "My ABCD mentor helped me get the additional breast cancer information I need."

DISCUSSION

This report from 3 surveys of a Midwest breast cancer support group demonstrates that survivors and their families and friends are very satisfied with ABCD's support services, and that the level of satisfaction has remained stable over the 3 surveyed time periods. More mentoring relationships are lasting longer and the number of contacts between mentors and mentees have increased over time. These findings reinforce the value of the program to survivors. Over 70% of respondents reported that they had contact with only 1 mentor, suggesting that ABCD's efforts to appropriately pair matches are largely successful. Finally, participation in the program has increased over time and has expanded nationally. This model could be replicated for breast cancer survivors in other communities.

Social support resources for breast cancer patients have been evaluated extensively in the existing literature.[12] Programs that have been piloted and implemented include group mentoring[9,13] and one-to-one mentoring in person,[11] via telephone,[7] or over the Internet.[14] In some programs, such as Reach to Recovery, mentors are fellow breast cancer survivors,[11] while other programs offer mentorship by someone trained in a health care field such as a registered nurse, or someone trained in counseling such as a psychologist.[6] Though it is clear that each of these modalities can provide benefit to the survivor, there is no data to suggest a benefit to using 1 modality over another.[12] Our study adds to the literature by describing a model for a successful one-to-one mentoring program that can provide support to women diagnosed with breast cancer.

Many survivorship programs serve women with breast cancer, but the context of that service is key; it is important that programs provide adequate support through a forum that is safe and educational. This point is especially important in the light of evidence that some programs actually can cause harm. For example, 1 randomized controlled trial of peer-to-peer interactions in an unstructured, unmediated online format found that participants in the experimental arm experienced decreased quality of life and increased stress compared to participants in the control arm.[13] Some evidence suggests that the time spent screening, training, supervising, and retraining mentors may be a crucial factor in the success of the mentor-survivor relationship.[7] ABCD provides 12 hours of training for potential mentors, followed by a post-training evaluation to assess the readiness of potential mentors. In addition, ABCD offers continuing education opportunities 3 to 4 times a year to keep mentors informed about available resources, new or different medical treatments, and coping strategies for psychosocial issues. This analysis demonstrates consistently across all 3 survey periods that mentees have reported: that ABCD is a reliable source of support (mean Likert ratings: 4.33 [2002], 4.67 [2004], 4.55 [2006]); and that their mentor has provided them with emotional support (mean Likert ratings: 4.09 [2002], 4.38 [2004], and 4.40 [2006]).

While all mean Likert ratings were above 3.5, in the future ABCD may focus additional efforts on components of the program that were not rated as highly as others such as training mentors to more effectively provide information to mentees, assessing the support needs of participants' families, and raising awareness of the website and expanded helpline. Although we describe a successful peer support program for breast cancer survivors, there are some limitations with the data. First, the survey initially was designed with the goal of expanding marketing of ABCD. While the data speak to respondents' impressions of the program, future surveys designed by experts in health program evaluation may provide additional relevant information. Second, while demographic information is available for all survivors involved with ABCD, we do not have specific demographic data for the subset of women who responded to the survey. While the response rate to these surveys has increased significantly over time, there is still the possibility for selection bias, where participants who are most and least happy with ABCD's services may be most likely to respond. The survey was administered only in English, which excluded participants who were not comfortable communicating in English. Since the last survey was conducted in 2006, ABCD has taken steps to address this limitation by training and matching several mentors who are bilingual in English and Spanish and can provide services to Spanish-speaking survivors. Finally, ABCD does not have records of the total number of survivors invited to participate in the first 2 surveys. Instead, they estimated the numbers, and in turn the response rates, based on their mailing lists.

Since the completion of the 2006 survey, a follow-up survey has not been conducted due to programmatic changes and the rapid expansion of the program. In 2012, ABCD expanded its helpline staff, bringing on volunteers and staff members from the recently closed Y-ME, one of the oldest breast cancer support organizations in the world. ABCD's goals are to eventually further expand its helpline into a 24/7, survivor-staffed resource serving all 50 states and to increase the number of mentee-mentor matches.

ABCD currently is designing a new survey as part of a prospective study to evaluate the experiences of both mentees and mentors. This kind of ongoing, systematic evaluation is crucial as ABCD expands its reach in the United States. Records from 2013 identify 531 matches for which 1593 one-to-one services were provided. ABCD now has mentors and matches throughout the nation, with particularly strong mentor cohorts and programming arms in Washington DC, Chicago, Miami, San Antonio, Phoenix, and southern California.

In summary, surveys of ABCD participants from 3 time points indicate that women appreciate the support services provided by ABCD and believe ABCD programming is an effective resource for survivorship care. Meanwhile, ABCD's expansion and continued growth since the last survey suggests that the ABCD mentoring program is a replicable model for one-to-one mentoring support services. As the numbers of breast cancer survivors grow and as breast cancer treatments continue to improve and become more complex, it is likely that there will be growing demands for information and support among this population. ABCD is poised to contribute to meeting this demand; the organization serves as a model program for providing enduring and effective peer support to breast cancer survivors using local resources at no cost to the survivor.

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