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“When I Needed It”: Evaluation of the Use and Timing of Sharsheret’s Thriving Again Program for Young Breast Cancer Survivors

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Abstract

Approximately 11% of all new breast cancer cases in the USA occur in women aged 45 years or younger. In 2011, CDC funded seven organizations to develop or enhance programs for young breast cancer survivors (YBCS). This paper analyzed program evaluation data collected by one of these organizations to gain a more nuanced understanding of how recipients used the newly developed program and resources for YBCS. Sharsheret’s Thriving Again program was evaluated through a web-based survey of survivorship program participants. The evaluation asked questions about participant demographics, use of the kit’s survivorship care plan (SCP), satisfaction with the timing of survivorship kit receipt, and factors related to survivors’ use of additional Sharsheret programs. We conducted bivariate analyses of survey responses and calculated chi-square statistics for significance testing. Of the 163 women who responded to the survey, 43% were diagnosed with breast cancer at or before age 45 and 69% were of Jewish descent. The majority of women who used the SCP found it helpful to facilitate cancer treatment (94%), follow-up (85%), or discussions with providers (91%). A total of 75% of women who received the SCP kit while either recently diagnosed or undergoing treatment were satisfied with the timing of receipt. Survey respondents found the Thriving Again program and survivorship kit beneficial and indicated timing preferences for when to receive resources and support. Supporting the self-efficacy of cancer survivors may improve survivors’ quality of life and is an important aspect of survivorship programs.

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Conflict of Interest The authors declare that they have no conflict of interest.

Ethical Approval The article does not contain any studies with animals performed by any of the authors. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed Consent Secondary data for this evaluation study were derived from a previously fielded program evaluation survey. Original participant consent was assumed by response to the evaluation survey.

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Disclaimer The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Keywords

Breast cancer survivorship; Breast cancer in young adults; Support; Education; Survivorship care plans; Resources

Background

Although most breast cancers occur in women who are 50 and older, approximately 11% of all new cases of breast cancer in the USA occur in women younger than 45 years of age [1, 2]. Although breast cancer diagnosis and treatment may be difficult for women of any age, young survivors face unique physical and psychosocial challenges. Young women with breast cancer may undergo treatment-induced menopause, which can result in weight gain, fatigue, and sleep disturbances, among other physical symptoms [3]. Additionally, breast cancers occurring in younger women are typically more aggressive and can result in a worse prognosis than breast cancers developing in post-menopausal women [2–5]. Breast cancer at an early age often indicates genetic mutations (*BRCA1*, *BRCA2*, *or TP53*) or family history of the disease, making these women more susceptible to secondary breast and ovarian cancer diagnoses [6]. Women of Ashkenazi Jewish descent are at particular risk of developing breast cancer at a younger age because approximately one out of 40 women of this population carries a BRCA gene mutation [7].

Psychosocial difficulties young breast cancer survivors (YBCS) often face are related to the adolescent and young adult (AYA) paradox which is the “disjuncture between developmental experiences and expectations of young adults and the ways in which the cancer experience has been implicitly defined or understood in terms of middle and late adulthood” [8]. Such developmentally discordant experiences of YBCS include confronting treatment-related fertility issues, including premature menopause, feeling out of sync with peers, needing to put a career on hold, and undergoing cancer treatment while also caring for young children [3, 9–12]. Despite the unique challenges YBCS face, until recently, there had been few programs to help these young women deal with these issues [13].

In September 2011, The Centers for Disease Control and Prevention (CDC) awarded funding to seven organizations for a new three-year cooperative agreement, “Developing Support and Educational Awareness for Young (<45) Breast Cancer Survivors in the United States,” as part of a broader effort to support breast cancer awareness in young women [14]. This program provided resources to organizations to establish or enhance existing support services for YBCS and their families and to develop tools and resources intended to increase patient and provider knowledge of health behaviors and other strategies for reducing disease risk and improving overall health, wellness, and quality of life [14].

One of the funded programs was Sharsheret®, a national, not-for-profit organization that supports young Jewish women and their families facing breast cancer. Founded in 2001, Sharsheret offers a community of support to Jewish women diagnosed with breast cancer, or at increased genetic risk for developing breast cancer, by offering women culturally relevant connections with resources, health professionals, and a network of peers. Although Sharsheret focuses on working with Jewish women, they serve any woman with breast cancer (at any point along the cancer survivorship continuum) who contacts them. With the CDC funding, Sharsheret developed the Thriving Again® program, consisting primarily of customizable survivorship kits. The Thriving Again survivorship kits contain various resources for recipients tailored to meet their needs. YBCS can select from a variety of printed resources addressing topics such as exercise after treatment, communication with family members and friends, smoking cessation, and fear of recurrence. Recipients can also select among several cookbooks and fitness DVDs. All kits contain a survivorship care plan (SCP) for YBCS to complete with their health-care team, which includes a self-assessment of psychosocial concerns that may affect YBCS throughout survivorship. Offering SCPs in the kits is consistent with the American College of Surgeons' Commission on Cancer (CoC) requirement that its accredited facilities must provide SCP to at least 75% of survivors treated in each of its accredited facilities (to be phased in over a 3-year period) [15]. The purpose of this paper is to offer a nuanced understanding of how recipients used components of the Thriving Again program, through an evaluation of program participants, placing particular emphasis on the survivorship kits and SCP usage. Consideration was also given to survivors' satisfaction with the point along their survivorship journey at which they received the Thriving Again survivorship kit.

Methods

Thriving Again Program

Over the course of the 3-year cooperative agreement, Sharsheret distributed a total of 1465 tailored Thriving Again survivorship kits to women with breast cancer and 187 kits to health-care providers for sharing with the YBCS population they serve. In addition to receiving the survivorship kit, YBCS were directly linked to two other Sharsheret programs: Genetics for Life® and health-care teleconferences. Over the course of the grant period, 380 guided conversations about genetics took place between callers and the Sharsheret Support Team. As part of the Thriving Again program, Sharsheret developed five nationally available teleconferences that focused on addressing the concerns of YBCS. Topics included overall breast cancer survivorship, managing relationships, genetics, long-term effects of breast cancer treatment, and nutrition and exercise for breast cancer survivors. Over the course of the grant period, over 600 people participated in the YBCS-focused teleconferences. Audio recordings and written transcripts of the teleconferences were posted to the Sharsheret website (http://www.sharsheret.org/) for participants to reference later and for new visitors to access at their convenience.

Program Evaluation Survey

Evaluation surveys were distributed to recipients to gauge satisfaction with the Thriving Again program overall, including linking to other Sharsheret programs, and to improve and further refine the survivorship kits. The surveys particularly focused on the use of survivorship kit materials and the SCPs included in those kits.

The self-report, web-based survey was developed and conducted by Sharsheret, with limited input from CDC. The survey included questions addressing basic demographic information, background information about the timing of kit receipt, use of the SCP, the usefulness of the printed resources a survivor selected (and received) as part of her kit, and whether the survivor accessed additional Sharsheret programs, i.e., teleconferences and Genetics for Life. Questions were primarily closed-ended and several included Likert-type scales.

Breast cancer survivors who contacted Sharsheret and received a Thriving Again survivorship kit between September 1, 2012, and April 30, 2014, were invited to complete an online or paper survey evaluating Sharsheret’s survivorship support services. The survey was sent in two waves. In February 2014, 717 emails were sent electronically to all women who received a survivorship kit before January 1, 2014. A total of 85 responses were collected during the first wave. In May 2014, 930 emails were sent electronically and 42 paper surveys (requested by women in lieu of the online survey) were mailed to women who received a survivorship kit before April 30, 2014. A total of 78 responses were collected in wave 2, resulting in a total survey sample size of 163. Data collection was anonymous, although survey links were unique to individuals so Sharsheret could track non-response and check for duplicate responses. While women who responded to wave 1 did not receive a second email, non-respondents from wave 1 did receive an email in wave 2, resulting in a response rate of 16%. While lower than expected, this response rate is not unusual for this type of web-based evaluation [16, 17].

Data Analysis

Electronic data files from survey waves 1 and 2 were downloaded from electronic submission form, imported into SAS 9.3 (SAS Institute Inc., Cary, NC), and merged together to form the analytic dataset.

We included the following demographic variables and clinical characteristics in our analysis: current age at time of survey completion, marital status, having any children, census region of residence, race/ethnicity, Jewish descent, Jewish identity (Chassidic, Conservative, Orthodox, Reform, Spiritual, Traditional, Unaffiliated, Other), education level, stage at diagnosis, treatment status, age at breast cancer diagnosis, and identity as a cancer survivor. We combined categories for certain variables from their original survey format such as current age (21–34, 35–40, 41–45, 46–50, and 51 years and older), marital status (single, never married, married, divorced/separated, unmarried, and widowed), age at diagnosis (≤45 vs. >45 years), Jewish identity (Chassidic/Orthodox vs. other affiliation), treatment status (currently in initial treatment or on hormonal therapy vs. not currently in treatment/other), identity as a cancer survivor (yes vs. no, I do not consider myself a survivor), and timing of receipt of the Thriving Again kit (when first diagnosed or while undergoing treatment for breast cancer, while undergoing treatment for metastatic disease, 1–5 years after treatment was completed, and more than 5 years after treatment was completed). Outcomes of interest included completion and frequency of use of the Thriving Again SCP, factors associated with participation in teleconferences and the Genetics for Life program, and satisfaction with the timing of receipt of the Thriving Again survivorship kit. For each care plan component (tracking treatment and medical information, using it to plan follow-up screenings and appointments, using it to guide conversations with a doctor or medical team, and using the self-assessment tool), frequency of use was collapsed into two categories: often/sometimes vs. never. Women were counted as having participated in the Genetics for

Life program if they had spoken with Sharsheret's certified genetic counselor when they ordered their Thriving Again kit ($n = 24$) or if they indicated on the survey they would like to be connected to the genetic counselor ($n = 10$). Women who did not express interest in referral because they had already spoken with a genetic counselor and did not have any additional questions or concerns ($n = 72$) or who did not answer the questions ($n = 17$) were excluded from the analysis of participation in Genetics for Life. All other women who answered "no" to both questions on whether they had spoken with Sharsheret's genetic counselor or would like a referral were counted as "no" responses ($n = 40$). Satisfaction with the timing of receipt of the survivorship kit was measured by this question: "How did you feel about the timing of receiving your kit? ('exactly when I needed it' or 'would have liked to receive it at another time')." For women who stated they would have liked to receive the Thriving Again kit at a different time, a follow-up question was asked when they would have preferred to receive the kit (when first diagnosed, while undergoing treatment for breast cancer, when treatment was completed, or "other").

We conducted a descriptive analysis examining demographic and clinical characteristics of women receiving Sharsheret services. We examined, in a bivariate analysis, factors associated with completing the Thriving Again care plan, participating in teleconferences, and using the Genetics for Life program. We assessed women's current status within the cancer care continuum (i.e., whether currently undergoing treatment and length of time as a cancer survivor) and how they felt about the timing of receiving the Thriving Again survivorship kit (received kit exactly when resources were needed vs. preferred to have received the kit at another time point in their survivorship journey) in a bivariate analysis. Among women who reported completing the Thriving Again care plan and answered questions about its use ($n = 66$), we assessed which components of the care plan were used. All p values were from chi-squared tests with the significance level set at $p < 0.05$.

Results

Demographic characteristics of the 163 respondents are listed in Table 1. Slightly less than half of survey respondents (48%) were under 50 years old when surveyed and were diagnosed with breast cancer at or before age 45 (43%). A majority of respondents were married (60%), reported being of Jewish descent (69%), and were college graduates or held advanced degrees (78%). The majority of women was diagnosed with either stage I (31%) or stage II (34%) breast cancer, and nearly half reported being on either hormonal therapy or their initial course of treatment (45%). Most women (84%) self-identified as cancer survivors.

Of the women who reported either beginning or completing the Thriving Again SCP ($n = 62$), most (94%) used it to keep track of medical information and treatments (Table 2). Women also used the care plan to guide conversations with medical professionals (91%) and to plan follow-up appointments and screenings (85%). Finally, many women (89%) used the care plan's self-assessment to help them determine what additional resources or support they needed.

Seventy-five percent of women who received the Thriving Again kit while either recently diagnosed with breast cancer or undergoing treatment reported receiving the kit “exactly when [they] needed it,” compared with 28% of women who received the kit longer than 5 years after completing treatment (Table 3). Additionally, 62% of women who received the kit 1–5 years after completing treatment indicated they received the kit exactly when they needed it, while 38% of those women reported they would have preferred receiving the kit at another time, specifically, either when first diagnosed or during treatment (71% of the 29) (data not shown).

Overall, 47% of women either initiated or completed the Thriving Again SCP, over one third participated in a teleconference, and 46% of eligible women participated in Genetics for Life (Table 4). Women who participated in the Genetics for Life® program more frequently reported having spoken with one of Sharsheret’s clinical team members beforehand, compared with women who did not use Genetics for Life (77 vs. 50%; $p < 0.05$). However, contact with Sharsheret’s clinical team members was not associated with either completing the SCP or participating in teleconferences. Neither demographic factors nor the timing of receipt of the Thriving Again kit was associated with teleconference participation, completion of the SCP, or use of Genetics for Life.

Discussion

Our analyses of the Sharsheret evaluation ascertained that survey respondents found the Thriving Again program and survivorship kit beneficial, particularly the SCPs. Respondents also indicated preferring to receive resources and support early in their survivorship journey, as opposed to 5 or more years after treatment completion.

The breast cancer survivors in this evaluation who reported using their SCPs overwhelmingly used them in ways outlined by the National Academies’ Health and Medicine Division (formerly the Institute of Medicine) [18], i.e., to keep track of medical and treatment information, to guide discussions with their health-care professionals, and to plan future care. Survivorship care planning, including the development of SCPs themselves, has long been identified as being an important component of patient-centered care [19–21]. Outcomes research on SCPs is limited. A recent systematic review of qualitative studies of the experience of cancer survivors using SCPs found support for the use of care plans, but a lack of consensus on care plan format, content, and development (who should be responsible for creating the plan) [22]. Our results, which indicate that breast cancer survivors used the SCPs primarily as a tool to help them remember their medical information and to help guide conversations with their providers, are consistent with Earle and Ganz’s view that, in survivorship care planning, providers should “not let the perfect be the enemy of the good” [23]. The SCPs in this kit were intended to function as part of a larger survivorship care planning effort, specifically to stimulate greater communication between cancer survivors and their health-care providers about long-term care and concerns [19, 20, 24]. The successful use of the SCPs in these kits demonstrates their value as a means to an end, rather than an end in itself.

The breast cancer survivors’ satisfaction with the timing of receipt of the Thriving Again survivorship kit is notable. Since most women in this evaluation who received the kit either when first diagnosed or while undergoing treatment (for stage I–III breast cancer) felt they had received it when they needed it, this speaks to the desire for survivors to obtain personal, age-specific resources and information on follow-up care [25]. This finding may extend to the care plan itself. One recent systematic review concluded that cancer survivors prefer to have care plans completed by 6 months post-treatment, while also expressing interest in having the plan include healthy living recommendations, psychosocial and spiritual concerns, signs and symptoms of recurrence, late and long-term effects of treatment, follow-up recommendations, and a treatment summary [26]. In our evaluation, those who received the kit between 1 and 5 years after treatment were also satisfied with the timing, although slightly less so. Taken together, these findings may indicate a desire to have access to resources early in the disease trajectory to maximize self-efficacy, a major theme among young adult cancer survivors [12]. Research on breast cancer survivors has shown that self-efficacy is enhanced when psychosocial care, including support provided by the Thriving Again program, is customized to focus on survivors’ needs throughout the cancer survivorship continuum [27].

Strengths and Limitations

One strength of this evaluation is its unique focus on young, Jewish women with breast cancer. This is an important population to focus on, since, as previously noted, women of Ashkenazi Jewish descent have a higher risk of developing breast cancer at a younger age higher than women of other ethnic groups [7]. Another strength of this evaluation is in its focus on survivors’ satisfaction with the timing of receiving resources, including SCPs, since utility to survivors must be kept in the forefront of the survivorship care planning process [23, 24].

This evaluation also has several limitations. First, the evaluation was web-only, that is, it did not include follow-up by other media (e.g., paper survey, telephone, and text messages), and had a low response rate (16%). As previously noted, however, response rates for web-only surveys vary widely [28–30], and rates of under 20% are not unusual [16, 17]. Furthermore, the response rate may have been vulnerable to selection bias. The cross-sectional nature of the evaluation may also be considered a limitation, since some women surveyed had not yet used all of the Thriving Again resources, particularly the SCP. Additionally, the evaluation design did not include a comparison group of women who did not receive Thriving Again materials or who received other materials. Limitations also included the small sample size, which hindered our ability to conduct age-specific analyses and comparisons. Related to this, we were unable to fully assess YBCS in this evaluation, given that less than half of survey respondents were 45 years of age or younger. While the intended audience of Thriving Again is YBCS, the program sent survivorship kits to all women who asked for one. Therefore, women of different age groups responded to the survey.

Since YBCS face a unique set of challenges, they also must receive a unique constellation of survivorship support services. YBCS, as well as other cancer survivors, may want to have control over the types of survivorship information they receive and when they receive it.

Survivorship programs foster self-efficacy when they not only encourage survivors to tailor their own survivorship materials from a broad selection of relevant resources but also consider the timing of providing particular resources to survivors. Findings from this evaluation may be helpful to other survivorship programs for YBCS. Most notably, other programs may need to be aware of how patients use SCPs and when survivors feel they most need resources and support.

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Table 1

Demographic and other characteristics of breast cancer survivors responding to Sharsheret Thriving Again survey ($n = 163$)

Characteristic	***n* (%)**
Current age, years	
21–34	10 (7.2)
35–40	11 (7.9)
41–45	19 (13.7)
46–50	26 (18.7)
51 and older	73 (52.5)
Age at diagnosis, years	
≤45	57 (42.9)
>45 and older	76 (57.1)
Marital status	
Married	83 (60.1)
Single, never married	22 (15.9)
Divorced/separated	26 (18.8)
Unmarried (LGBT)	4 (2.9)
Widowed	3 (2.2)
Census region of residence	
Northeast	58 (46.4)
Midwest	10 (8.0)
South	35 (28.0)
West	22 (17.6)
Race/ethnicity	
Black or African American	12 (8.8)
Caucasian	119 (86.9)
Hispanic/Latina	3 (2.2)
Other	3 (2.2)
Of Jewish descent	96 (69.1)
Jewish identity	
Orthodox/Chassidic	36 (38.3)
Other affiliation	58 (61.7)
Education level	
Advanced/professional degree	58 (42.0)
College graduate	50 (36.2)
High school graduate	7 (5.1)
Some college or technical school	21 (15.2)
Some high school (9–12)	2 (1.5)
Stage	
DCIS	16 (12.7)
Stage I	39 (31.0)

Characteristic	***n* (%)**
Stage II	43 (34.1)
Stage III	17 (13.5)
Stage IV	11 (8.7)
Treatment status	
Currently in initial treatment or on hormonal therapy	62 (44.6)
Not currently in treatment/other	77 (55.4)
Had children at time of diagnosis	100 (71.9)
Identify as cancer survivor	106 (84.1)

Table 2

Recipients' use of the Thriving Again care plan ($n = 66$)[a]

I use care plan to	Often/sometimes *n* (%)	Never *n* (%)
Keep track of medical information/treatments *	62 (93.9)	4 (6.1)
Help plan follow-up appointments/screenings *	56 (84.9)	10 (15.2)
Help guide conversations with doctor *	60 (90.9)	6 (9.1)
Gauge issues struggling with and determine additional resources/support needed through the self-assessment *	59 (89.4)	7 (10.6)
Is there anything else you would care to share about the care plan?		
Illustrative quote	"It was the perfect motivational tool to get all of my stacks of cancer information, tests, scans and other medical records organized and [usable]."	"Would have been very helpful to have when I first completed treatment. [I] would probably still be using it, but now it's hard to start, since haven't been using it from the beginning."

* $p < 0.05$ from chi-squared tests of equal proportions

[a] This analysis was limited to women who indicated that they either began or completed their care plan and answered questions on how they used their kit ($n = 66$)

Table 3

Timing of receipt of Thriving Again survivorship kit ($n = 163$)

Timing of kit receipt[*]	**Received kit when needed it ($n = 99$)** ***n*, (row %, column %)**	**Preferred another time ($n = 64$)** ***n*, (row %, column %)**
When first diagnosed or while undergoing treatment for breast cancer	36 (75.0, 36.4)	12 (25.0, 18.8)
While undergoing treatment for metastatic disease	8 (80.0, 8.1)	2 (20.0, 3.1)
1–5 years after treatment completed	47 (61.8, 47.5)	29 (38.2, 45.3)
More than 5 years after treatment completed	8 (27.6, 8.1)	21 (72.4, 32.8)

[*] Statistically significant, $p < 0.05$ from chi-squared test

Table 4

Factors related to using survivorship care plan and other Sharsheret programs ($n = 163$)

	Initiated/completed Thriving Again care plan		Participated in teleconference		Participated in Genetics for Life	
	Yes ($n = 75$)	**No ($n = 84$)**	**Yes ($n = 55$)**	**No ($n = 94$)**	**Yes ($n = 34$)**	**No ($n = 40$)**
Spoke with member of Sharsheret clinical team						
Yes	48 (64.0)	49 (58.3)	37 (67.3)	56 (59.6)	26 (76.5)*	20 (50.0)*
No	27 (36.0)	35 (41.7)	18 (32.7)	38 (40.4)	8 (23.5)*	20 (50.0)*
Timing of Thriving Again kit						
Received kit at an appropriate time	50 (66.7)	46 (54.8)	35 (63.6)	56 (59.6)	22 (64.7)	25 (62.5)
Preferred another time	25 (33.3)	38 (45.2)	20 (36.4)	38 (40.4)	12 (35.3)	15 (37.5)
Stage						
DCIS	6 (10.3)	10 (14.7)	6 (12.8)	10 (12.7)	0 (0.0)	4 (12.1)
Stage I/II/III	47 (81.0)	52 (76.5)	38 (80.9)	61 (77.2)	25 (89.3)	28 (84.9)
Stage IV	5 (8.6)	6 (8.8)	3 (6.4)	8 (10.1)	3 (10.7)	1 (3.0)
Identify as cancer survivor						
Yes	52 (89.7)	54 (79.4)	41 (85.4)	65 (83.3)	26 (89.7)	30 (90.9)
No	6 (10.3)	14 (20.6)	7 (14.6)	13 (16.7)	3 (10.3)	3 (9.1)
Age at diagnosis, years						
≤45	22 (36.1)	35 (48.6)	25 (50.0)	32 (38.6)	15 (51.7)	12 (32.4)
>45 and older	39 (63.9)	37 (51.4)	25 (50.0)	51 (61.5)	14 (48.3)	25 (67.6)

* Statistically significant, $p < 0.05$