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Evaluation of a Web-Based Program for African American Young Breast Cancer Survivors

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Abstract

Introduction: Among women aged <45 years, African Americans have the highest breast cancer incidence rates of any ethnic/racial group and disproportionately higher rates of mortality. Young breast cancer survivors (YBCSs) may require psychosocial and reproductive health support when navigating diagnosis, treatment, and follow-up care. To address these needs, the Young Sisters Initiative: A Guide to a Better You! Program (YSI) was developed, implemented, and evaluated. The purpose of this study was to assess implementation and fidelity; identify barriers and facilitators to implementation; and explore audience access, use, and perceived value of the YSI.

Methods: A mixed-method, process evaluation of the YSI using interviews, an online screener, and post-use survey was conducted with data collected and analyzed from February through August 2013. Thematic analysis of qualitative data was conducted without qualitative data analysis software. Survey data were analyzed using PASW Statistics, version 18.

Results: YSI core elements were implemented as intended. A total of 1,442 people visited the YSI website; 93% of breast cancer survivors who visited the site (and consented to be in the study) were African American; 75% of post-use survey YBCS respondents were very or somewhat satisfied with the YSI; and 70% of YBCS respondents said the YSI content was somewhat or very useful.

Conclusions: Findings suggest the value of using the Internet, including social media, to provide African-American YBCSs who are newly diagnosed, in treatment, and post-treatment with reproductive and psychosocial information and support. Further implementation and evaluation of programs addressing the needs of YBCSs are needed.

Introduction

A cancer survivor refers to a person who lives from the point of diagnosis to the end of life. Young breast cancer survivors (YBCSs, defined as women diagnosed prior to their 45th birthday) may experience increased difficulty managing their diagnosis, treatment, and

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aftercare.² YBCSs often have more-aggressive cancers, requiring complex and multimodal treatments, some with severe side effects.^{3,4} Treatment-related concerns, both physical and psychosocial, can affect YBCSs' function in social roles common to their age cohort—as intimate partners, professionals, and mothers, among others.³ Infertility and premature menopause, which can result from cancer treatment, may negatively affect women's self-image, perceived sexuality, and sexual function.^{3,5,6} Reproductive health is a concern for YBCSs,^{7,8} yet only about half of cancer survivors of childbearing age receive reproductive health information from oncology care providers.^{9,10} Innovative strategies are needed to provide YBCSs with appropriate psychosocial and reproductive health information and support.

In September 2010, CDC funded the Breast Cancer in Young Women project to identify and strengthen real-world, evidence-based psychosocial and reproductive health support interventions for YBCSs. The formative research and literature review revealed that African-American YBCSs need psychosocial and reproductive health information and support, and that providing such support online had the potential to reach YBCSs who had limited access to other forms of support. CDC supported Sisters Network® Inc. (SNI), a national non-profit organization serving African-American breast cancer survivors (BCSs), to develop and implement the Young Sisters Initiative: A Guide to a Better You! (YSI), a program providing psychosocial and reproductive health support to African-American BCSs, focused on those diagnosed before age 45 years. This study is a process evaluation of the YSI conducted to assess implementation and fidelity; identify barriers and facilitators to implementation; and explore audience access, use, and perceived value of the YSI to provide psychosocial and reproductive health information and support (Table 1).

Methods

The YSI (www.sniyoungsisters.org) is an adapted, young survivor-focused online version of the previously developed Sisters Peer Counseling in Reproductive Issues after Treatment (SPIRIT) program, an evidence-based, psychosocial and reproductive health in-person and telephone support intervention for African-American BCSs of all ages. ¹⁰ Adaptation of the YSI was similar to the creation of SPIRIT: The developers worked with a trusted, credible community organization with access to the target population to ensure development of culturally appropriate materials. ^{11–13} The YSI is distinct from SPIRIT: It targets YBCSs specifically, with both tailored content and communication channels, disseminating information and support via the web and social media. A panel of subject matter experts in breast cancer, cancer and genetics, women's health, mental health, and cancer health disparities reviewed and pilot tested YSI content and presentation, providing feedback to ensure scientific accuracy and clarity. SNI and the panel also vetted YSI materials and content to determine that they were "culturally appropriate," that is, that they reflected: (1) the cultural values of the target group (i.e., African-American YBCSs); (2) group attitudes, expectancies, and norms; and (3) the behavioral preferences and expectations of group members as revealed in formative research. 14,15

The YSI uses a self-navigated web-only interface to provide African-American YBCSs with information about breast cancer and treatment, grouped into an eight-section workbook—

The YSI Guide—presented on the site and downloadable in whole or by section. Topics covered in the Guide include genetic testing, coping with emotional issues around diagnosis and treatment, and sexual and reproductive health issues that may arise from the time of diagnosis onward. The YSI also offers information sheets on talking to family about breast cancer and about dating after breast cancer. The YSI's presentation on the web was intended to provide access to YBCSs with few or no in-person resources. Formative research indicated that African-American YBCSs often sought information on the web; although lack of Internet access presented a hypothetical barrier, 80% of all African Americans are Internet users and >90% of younger African Americans use the Internet, 16 supporting the use of the web as a primary way to access YBCSs.

Process evaluations are critical to understanding how and why interventions are implemented as intended and achieved. ¹⁷ An embedded, mixed-method design was used to conduct qualitative and quantitative research to understand implementation, access to, and audience perception of the YSI. ¹⁸ The evaluation, conducted between February and August 2013, was guided by CDC's frame-work for program evaluation ¹⁹ and principles of collaborative and culturally responsive research design: Stakeholders (SNI, its advisory board, CDC, and the expert advisory group) participated in evaluation design and implementation, and their assessment of the program was integral to the evaluation. ^{20–24} SNI, ICF International, and CDC developed a logic model to identify the intervention's inputs, activities, and short- and long-term outcomes. The logic model guided decisions regarding evaluation questions, indicators to measure, and the optimal design given time and resources available. Although the study objective was to gather interim and ongoing feedback about intervention execution rather than outcomes, a short post-use survey of YSI visitors was fielded to assess visitors' use and perceptions of the YSI.

Qualitative evaluation data sources included baseline interviews with SNI staff (n=3) and partners (n=3), and post-implementation interviews with staff (n=3) and partners (n=2). Eligible interviewees were people recommended by SNI because of their participation in YSI recruitment or implementation. Phone interviews (30-45 minutes) were conducted with SNI staff members, including the Executive Director, Director of Programs, and the Affiliate Relations Manager, and partners from MD Anderson Cancer Center, Cancer Treatment Centers of America, and Cancer Support Community, Quantitative data sources included web metrics collected from the YSI site, a demographic screener for the site, and a brief post-use survey. During the evaluation period, participants were recruited by promoting the YSI URL on SNI's website and social media pages, by sending e-mail blasts to subscribers, during SNI webinars, and at the SNI Breast Cancer Walk. In all, 1,142 visitors to the YSI accrued a total of 1,966 page views; 476 (33%) completed the 5-minute, online demographic screener. Of those 476 visitors, 180 (38%) also completed a 20-minute, online post-use survey to assess perception of YSI access, content, materials, and participant satisfaction with YSI's provision of information and support. For context, online surveys commonly have response rates averaging 11% less than phone and mail surveys, with rates as low as 2%. ^{25,26} Participants were not incentivized for study participation and freely volunteered their time and effort. The design, recruitment, consent forms, data collection instruments, data collection, and management procedures were reviewed and approved by the ICF International IRB and free and informed consent of subjects were obtained.

Qualitative data (11 interviews) were analyzed using notes-based, thematic analysis²⁷ by a coder conducting deductive and inductive coding of interview data.²⁸ Survey data were exported into a statistical software package database (PASW Statistics for Windows, version 18.0) for management and analysis. Quantitative data (screener, survey, and web analytics) were analyzed using descriptive statistics (frequencies and percentages). Using Google Analytics, aggregate monthly data were collected on site use, referring sources, site entrances, and page and section views. The summation of data was used to assess how visitors accessed, used, and perceived the YSI.

Results

Based on interviews, YSI's core elements—organizational partnerships for promotion and web presence for dissemination—were implemented as intended from March through July 2013. As intended, all 61 internal and external SNI partners were engaged in some capacity in intervention implementation or evaluation. The structure of SNI's partnerships was informal with no written agreements; SNI obtained verbal agreement from board members and external partners to help develop and promote the YSI. The nine organizations on SNI's medical advisory board contributed to YSI development (e.g., logic model review, finalization of structure and content), and board members and 46 local chapters promoted the YSI by placing the YSI URL and promotional materials on their websites. Six external partners, including MD Anderson and associated hospitals, and the Texas Breast Health Collaborative, made phone calls or sent e-mails to members of their network to increase YSI awareness among YBCSs.

Interviewees commonly stated that the intended use of a web-based platform for intervention delivery was essential for YSI implementation. Psychosocial and reproductive health support information and materials from YSI were immediately available to members of the target audience with Internet access. Throughout implementation, the YSI was maintained through periodic website accessibility and functionality testing. Interviewees reported that early engagement of partners in promotion and recruitment, a stable website, in-person recruitment of YBCSs, and use of online communication channels (especially social media) to promote and recruit people to the YSI were critical practices for implementation with fidelity.

Based on analysis of interview data, implementation facilitators included working with a credible organization (SNI) with access to the target population, and SNI's engagement of existing internal and external partners in YSI design and promotion. SNI partnerships broadened networks for YSI promotion and recruitment. Use of communication strategies (e.g., e-mail, social media); consistent messaging, format, and "look" across the YSI; and availability of materials and support online, in print, and in person helped to establish an appealing and recognizable "brand," facilitating promotion and recruitment. A number of interviewees noted that CDC support and YSI promotion increased interest and credibility among YBCSs and other SNI constituents, as did linking YSI components to existing SNI programming and events.

The project's condensed timeline and limited resources for YSI implementation and evaluation were the primary barriers identified by interviewees; limited time, resources, and competing programming demands reduced partner and staff ability to maximize promotion and recruitment activities. Recruitment was also challenging because of the inability to incentivize study participants. The lengthy, systematic process to finalize YSI content and materials, coupled with required research approvals, was reported as a challenge to timely implementation.

During implementation from March through July 2013, a total of 1,442 individuals accessed the YSI. Most visitors exited the site once they encountered the registration page requesting screener completion, but more than one third (n=524) accessed the YSI one or more times, for a total of 1,996 unique page views. Visitors who accessed the site more than one time visited more web pages compared with those who visited the site once; on average, visitors to the site viewed 4.24 web pages per visit.

Of the 1,442 visiting the YSI, 476 completed the screener to gain full access to all pages of the YSI and indicate their willingness to participate in the study. Fifty-nine percent (n=279) of screener completers identified as black or African American; 59% (n=279) of screener completers also identified as BCSs (93% of the BCS screener completers were African American); and, most important for this study, more than a third (n=181) of the 476 individuals eligible to be served by the YSI were African-American YBCSs.

Visitors accessed the YSI in a variety of ways assessed by visitors' unique page views. The YSI received 1,319 page views through entry from a desktop computer and 647 from mobile devices (404) and tablets (243) (Figure 1). Most users (1,034) accessed the YSI by typing the YSI URL into a web browser; others accessed the site from Facebook (338), the link on SNI's program website (226), or links distributed via e-mails (200). Visitors also accessed the YSI via referrals including SNI's social networking site on the Ning platform and Twitter. YSI visitors from SNI's online community had a longer average stay on the site, suggesting that YSI promotion via SNI's social media site was an effective strategy to promote the intervention.

One hundred eighty visitors who completed the screener also consented to complete the post-use survey, including 161 BCSs of all ages. Nearly all YBCSs who responded to the post-use survey were African American. Specifically, all but one (99%) of the 77 YBCSs who responded to the survey identified as African American. Seventy percent of all respondents, and 75% of YBCS respondents, were very or somewhat satisfied with the YSI. Only 7% of YBCS visitors were very unsatisfied with the YSI (Table 2). Open-ended survey responses indicated that some visitors thought that the YSI content/text was too long; they stressed the need to have less text to keep the target audience engaged. Eighty-one percent of all visitors, as well as 81% of YBCSs, reported that they were either somewhat or very likely to recommend the YSI to others (data not shown).

Most post-use survey respondents said that the YSI was easy to access, navigate, and follow (Figure 2). Sixty-eight percent of all respondents and 70% of YBCSs reported that YSI content was either somewhat or very useful. A third (31%) of respondents said that the

"Helpful Web Sites and Resources" section offered the most helpful information. The highest percentage of respondents said the "Contact Us" (23%) and "Audio Resources" (23%) sections offered the least helpful information. Among respondents who reported a section of the Guide as the most helpful YSI section, 58% of all respondents (and 75% of YBCSs) said that "Section 7: Breast Cancer, Sexuality, and Dating" was the most useful. Free-text responses in open-ended survey items revealed that visitors did not commonly face access barriers. E-mail reminders and easy site access served as key facilitators to YSI access. Respondents also commonly said that the YSI design and organization made the site user friendly and that site materials were high quality, informative, and relevant for African American YBCSs.

Although survey findings indicated a high level of visitor satisfaction and positive perception of the YSI, some visitors reported that the large amount of presented information was overwhelming and recommended reducing the amount of content on the site and in the Guide. Suggestions for improvement included incorporating more interactive components (e.g., videos) into the site (data not shown).

Discussion

Interview and survey results suggest that the YSI was implemented with fidelity: It was developed and promoted by SNI and its partners as intended, and implemented as an online resource for ease of access, with content that a majority of users perceived as helpful. Among individuals who completed the demographic screener, 38% were African-American YBCSs. Organizational partnerships, use of social media for promotion, and CDC support were key implementation facilitators, and limited time and resources were key implementation barriers. Although only 476 people gained full access to the YSI, content was deemed useful by 70% of the YBCS visitors participating in the study. Visitors also suggested that streamlining log-in/registration and the amount of text on the site could improve the YSI.

Few online educational resources address YBCSs' specific needs. Though high-quality resources do exist (the Young Survival Coalition's ResourceLink Guidebook, Susan G. Komen's information on unique issues for young women with Breast Cancer, and Sharsheret's online resources), none of these resources target or tailor information to African-American YBCSs, particularly free, immediately accessible psychosocial and reproductive health information and support in a guidebook format.

Despite declines in overall cancer death rates, there are distinct, ongoing health disparities between African Americans and whites. In addition to prevention activities, there is a need for education and support tailored for the unique needs of African-American women diagnosed at young ages.²⁹ This evaluation illustrates that culturally appropriate cancer education and support strategies can be provided for African-American YBCSs so that they can directly access information about risk, treatment, and aftercare, potentially improving quality of life and even reducing disparities in cancer morbidity. In an increasingly Internet-dependent society, the YSI shows that it is possible to incorporate technology to design, develop, and implement online approaches to meet YBCS needs.

Despite a small sample size, this study makes important contributions to the development, marketing, and evaluation of web-based cancer support interventions for YBCSs and other vulnerable populations. Successful implementation with SNI illustrates the value of collaboration with organizations trusted by target audiences, particularly in terms of outreach. The successful recruitment of 1,142 people to the website indicates the value of partnerships and use of social media (Facebook, Twitter, and SNI's Breast Cancer Survivor Social Network site) to access and engage survivors. Finally, the positive response of users to YSI promotion, structure, and culturally appropriate content and resources supports the use of this approach to provide psychosocial and reproductive health support to African American YBCSs, and could serve as a model to create tailored programs for other vulnerable cultural groups of YBCSs or other cancer survivors.

The short implementation period (4.5 months) was a key limitation, as it resulted in a small sample size of users. Further, although the study collected and reported analytics data on all YSI visitors, it relied on results obtained from a non-probabilistic/convenience sample of visitors who consented to complete surveys. Convenience sampling is a common sampling method to obtain data easily from audiences which was determined necessary and cost effective for this evaluation, but had the potential to introduce bias (e.g., under- or over-representation of particular groups) in results.

Another limitation is reliance on interviews with active partners to assess implementation and fidelity; active partners and staff may have naturally had positive views about the implementation process and been more likely to participate in this study. However, interviews were the best way to gather information sufficient to understand and assess implementation processes. The interview guides included probing questions about core element implementation, including website accessibility testing, which partners were involved, and how and what they did to support implementation. Finally, although the YSI is promoted and accessible from Facebook, Twitter, and other social media, the evaluation focused on understanding YSI use via analysis of analytics and the post-use survey data; the study did not collect data on visitors' use or reaction to and perception of the intervention in social media. Because the YSI is accessible via social media, and social media resources are an important and trusted source of health information, ³⁰ future studies should examine how incorporating social media into the YSI may inform health choices, alert YBCSs to health issues, and improve understanding of breast cancer treatment and aftercare among YBCSs.

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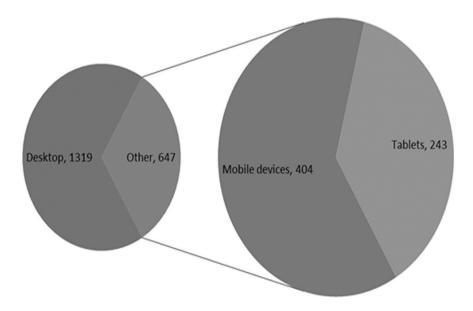


Figure 1. YSI visitors' devices used to access the YSI website.
*Devices used to access the YSI during evaluation period February 2013-August 2013. YSI, Young Sisters Initiative.

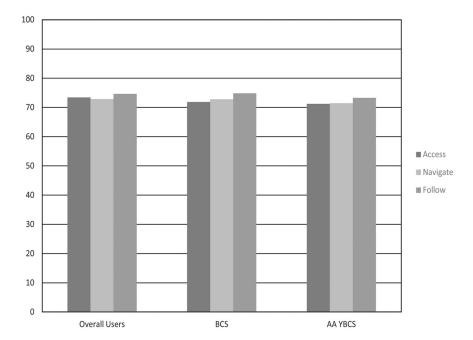


Figure 2. Ease of accessing, navigating, and following the YSI website across visitor types.

AA, African American; BCS, breast cancer survivors; YBCS, young breast cancer survivors; YSI, Young Sisters Initiative.

Table 1.

Data Collection Methods Used for the YSI Process Evaluation

Interviewing SNI staff a

Purpose: To determine the following:

- Marketing, recruitment, and implementation of the YSI; Fidelity to implementation of the YSI core elements; and
- Barriers and facilitators to YSI implementation.

To measure implementation: Description of core element implementation; number of partners involved and their roles and specific activities; types of recruitment and implementation activities, and activities and best practices to implement the YSI during the study period; and number of YSI visitors

To measure fidelity: Description of web-based presence and functionality testing, and partners involved and their roles.

To measure barriers and facilitators: Discussion about specific barriers and facilitators to partnerships, maintaining the YSI online, YSI promotion, and recruitment and use.

Interviewing SNI's YSI implementation partners

Purpose: To determine the following:

- Number of partners involved in YSI implementation;
- Types of partners collaborating to implement the YSI; and
- Partners' role and contribution to implementation of the YSI.

To measure implementation: Description of core element implementation; number of partners involved and their roles and specific activities; types of recruitment and implementation activities, and activities and best practices to implement the YSI during the study period; and number

To measure fidelity: Description of web-based presence and functionality testing, and partners involved and their roles. To measure barriers and facilitators: Discussion about specific barriers and facilitators to partnerships, maintaining the YSI online, YSI promotion, and recruitment and use.

Monitoring of YSI website, screening YSI visitors b

Purpose: To determine the following:

- Number of visitors to the YSI:
- Number of unique, first-time visitors to the YSI;
- Number of page views on the YSI;
- Most frequently visited YSI pages;
- Site and social media referral sources;
- Accessing devices (e.g., mobile, laptop);
- General referral sources (e.g., friends, family, newspaper); and
- Number and type of YSI visitors in the study.

To measure access (and use): Number of YSI visitors, number of page views, number of visitors viewing one or more pages, length of time on the YSI, number of visitors viewing one or more of the Guide sections, and number and type of referral sources (including social media sources). In addition, number of YSI visitors completing the demographic screener, demographics of YSI visitors completing the demographic screener, and number of African-American YBCS, YSI visitors completing the demographic screener.

Surveying visitors' perceptions of the YSI C

Purpose: To determine the following:

Visitors' perceptions of YSI structure, content, and resources.

To measure perceptions of the YSI: Number of post-use survey respondents; demographics of post-use survey respondents; reported perception of YSI site structure, content, resources, and usefulness; number of people satisfied with the YSI; and number of people willing to recommend the YSI to others.

SNI, Sisters Network Inc.; YBCS, young breast cancer survivors; YSI, Young Sisters Initiative.

^aAll interview data (n=11) were used to learn about implementation and fidelity. Phone interviews were conducted at baseline before the YSI launch (February/March 2013) and post-implementation of the YSI (July/August 2013). Interview sampling was "purposive" and as such the findings are neither quantitative nor generalizable.

^bGoogle Analytics data were used to monitor visitors' activity on the website (e.g., access and page views). YSI visitors were administered an online demographic screener (n=476) to gain full access to the YSI and to gather demographic data on study participants.

^CThe post-use survey (n=180) gathered information on YSI visitors' perceptions of the YSI to inform program improvement; it was not designed to produce data of sufficient rigor to allow evaluators to estimate population-based awareness and perceptions of the intervention.

Table 2.

Satisfaction with YSI across Visitor Types

How satisfied were you with the YSI program?	Overall visitors (N=180)	BCS visitors (n=161)	YBCS visitors (n=77) ^a
Very unsatisfied	9 (6.67%)	8 (6.67%)	5 (7.25%)
Somewhat unsatisfied	4 (2.96%)	3 (2.50%)	2 (2.90%)
Neutral	27 (20.00%)	25 (20.83%)	10 (14.49%)
Somewhat satisfied	34 (25.19%)	31 (25.83%)	19 (27.54%)
Very satisfied	61 (45.19%)	53 (44.17%)	33 (47.83%)
Missing	45	41	8

 $[\]overset{a}{7}\!\!$ 76 of YBCS visitors to the YSI were African-American women.

BCS, breast cancer survivors; YBCS, young breast cancer survivors; YSI, Young Sisters Initiative.