



# Lessons Learned from the Young Breast Cancer Survivorship Network

Silvia Gisiger-Camata<sup>1</sup> · Timiya S. Nolan<sup>2</sup> · Jacqueline B. Vo<sup>1</sup> · Jennifer R. Bail<sup>3</sup> · Kayla A. Lewis<sup>4</sup> · Karen Meneses<sup>1,5</sup>

Published online: 30 November 2017

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## Abstract

The Young Breast Cancer Survivors Network (Network) is an academic and community-based partnership dedicated to education, support, and networking. The Network used a multi-pronged approach via monthly support and networking, annual education seminars, website networking, and individual survivor consultation. Formative and summative evaluations were conducted using group survey and individual survivor interviews for monthly gatherings, annual education meetings, and individual consultation. Google Analytics was applied to evaluate website use. The Network began with 4 initial partnerships and grew to 38 in the period from 2011 to 2017. During this 5-year period, 5 annual meetings (598 attendees), 23 support and networking meetings (373), and 115 individual survivor consultations were conducted. The Network website had nearly 12,000 individual users and more than 25,000 page views. Lessons learned include active community engagement, survivor empowerment, capacity building, social media outreach, and network sustainability. The 5-year experiences with the Network demonstrated that a regional program dedicated to the education, support, networking, and needs of young breast cancer survivors and their families can become a vital part of cancer survivorship services in a community. Strong community support, engagement, and encouragement were vital components to sustain the program.

**Keywords** Young breast cancer survivors · Survivorship · Education · Support · Community-based partnership

## Background

More than 26,500 young women, about 11% under the age of 45 years, are diagnosed annually with breast cancer in the USA [1]. Breast cancer, particularly when diagnosed at a young age, can present significant physical and psychosocial challenges that require adjustment in day-to-day living to manage treatment, recovery, and survivorship [2]. For example, young women

have a higher incidence of aggressive tumors leading to poorer prognosis compared with older women [3]. Young breast cancer survivors (YBCS) experience early menopause, infertility, fatigue, depression, and sleep problems [2, 4–9]. They also face unique psychosocial challenges of changes in work–life balance and perceived poor quality of life [4, 10]. Age-specific survivorship concerns of YBCS also include managing children and family relationships, sexuality, body image, fear of recurrence, cognitive changes, cognitive demands, and the demands of career and work [2, 5, 8, 10, 11]. Young women often seek connections with peer age survivors, as they face unique challenges in transition into survivorship care [12, 13].

Despite the unique psychosocial and survivorship challenges in facing breast cancer at a young age, there are few programs available to help YBCS. Here, we describe the development, implementation, and evaluation of the *Young Breast Cancer Survivorship Network* (herein named the Network), a regional program consisting of community and academic partners dedicated to education, support, and network for YBCS and their co-survivors (i.e., family, friends, and children).

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✉ Silvia Gisiger-Camata  
sgcamata@uab.edu

<sup>1</sup> School of Nursing, University of Alabama at Birmingham, Medical Towers Room 415A, 1720 2nd Avenue South, Birmingham, AL 35294-1210, USA

<sup>2</sup> College of Nursing, The Ohio State University, Columbus, OH, USA

<sup>3</sup> Department of Nutrition Sciences, University of Alabama at Birmingham, Birmingham, AL, USA

<sup>4</sup> Department of Biology, University of Alabama at Birmingham, Birmingham, AL, USA

<sup>5</sup> Comprehensive Cancer Center, University of Alabama at Birmingham, Birmingham, AL, USA

## The Young Breast Cancer Survivorship Network

The authors developed the Network in response to a 2011 need assessment conducted in North Central Alabama which found that survivorship services and programs addressing YBCS were disconnected, inadequate, and/or non-existent [14]. The Network aimed to develop collaborative partnerships among organizations that provided services for YBCS, to educate and support YBCS about survivorship, to increase family and public awareness about YBCS, and to extend the Network's outreach beyond the regional area. Figure 1 illustrates the Network's framework and associated activities. This paper describes the methods used to develop a network that would support YBCS and their co-survivors, and the results of formative and summative evaluations that were conducted on the effectiveness and sustainability of this network.

## Methods

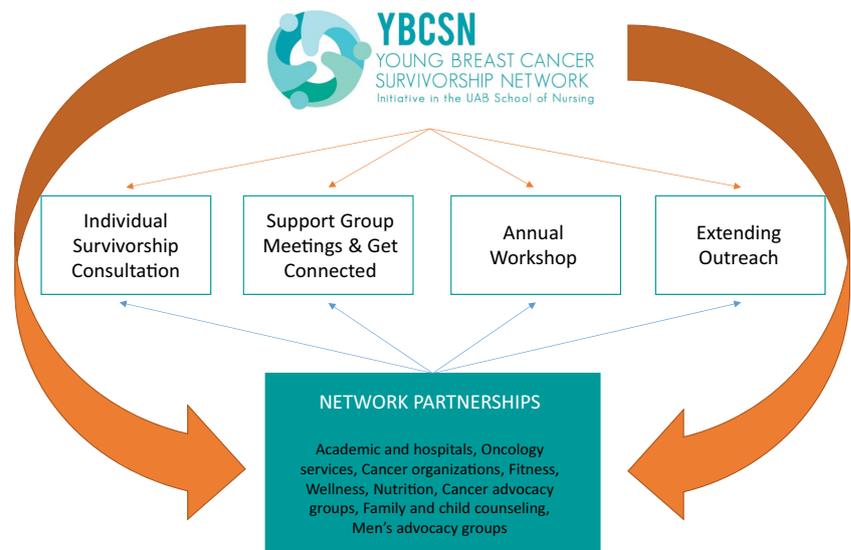
The Network was developed and implemented using a set of four guiding priorities: develop collaborative partnerships, educate YBCS, build awareness of the Network, and extend outreach. The first priority of the Network was to develop collaborative partnerships among organizations that provided services for YBCS. The authors contacted local hospitals and clinics that provided cancer treatment services for women with breast cancer. We began with the academic health sciences center and four existing hospital programs. We extended outreach to area health systems, cancer organizations, and breast cancer organizations for a total of 16 partners within the first year of the Network's existence. The Network partners met bi-monthly to describe services offered by their respective organization, which would appeal to YBCS. For example, a breast cancer advocacy program offered weekly yoga

classes and welcomed YBCS. A community-based organization provided children and family counseling for YBCS. One health system provided reproductive endocrinology services, for which YBCS were referred to for fertility management. The authors also developed the YBCS Advisory Board consisting of key community leaders, cancer advocates, breast cancer survivors, and health professionals to provide sound advice and opinions, as well as to champion the progress of the Network.

The second Network priority was to educate and support YBCS about survivorship. The authors conducted a literature review of quality of life concerns identified by YBCS. Such topics included concerns about physical side effects (e.g., menopausal symptoms, fatigue, pain, lymphedema, sexuality, and infertility) [4–6, 9], psychosocial concerns (e.g., anxiety, feeling of isolation, depressive symptoms, cognitive changes, family relationships, employment, and financial toxicity) [7, 8, 10–12], and cancer management concerns (e.g., follow-up management, adherence to hormonal therapy, nutrition, and physical activity) [13]. The authors conducted three discussion groups with a total of 20 YBCS to validate the topics and evaluate their preferences for receipt of information. The topics were assessed as highly relevant by discussion participants, with YBCS indicating they preferred having individual survivorship consultation and monthly support group meetings. The individual survivorship consultation was designed as a one-on-one discussion with a trained oncology nurse having cancer survivorship experience and was conducted either by telephone or in person. Information about the individual survivorship consultation was distributed through the Network partners, YBCS, and by word of mouth. Individual survivorship consultations were conducted from September 2012 to August 2016.

The Network's third priority was to increase community awareness about YBCS. This activity was accomplished

**Fig. 1** Network's framework and associated activities



through a workshop held annually since 2013. To date, five annual workshops have been conducted. The annual workshop topics, which varied each year, were based on suggestions from the Network partners, Advisory Board members, and YBCS feedback from annual workshops. Topics ranged from quality of life, managing survivorship, and health-promoting activities (e.g., nutrition, physical activity, stress reduction, and sleep). Two major concerns raised in the three YBCS discussion groups were their inability to attend survivorship programs due to lack of childcare, and a desire for their spouses and significant others to participate in the programs. To address these concerns, the annual workshop provided childcare with child-focused supervised educational and recreational activities (e.g., healthy eating, art projects, and outdoor playground time), and speakers and discussion groups focused on the emotional and social well-being of spouses and significant others. Network partners participated in the annual workshops with exhibit booths to provide information about their survivorship services.

Finally, in an effort to extend outreach to YBCS outside of the region, the authors launched the YBCSN website in 2013. The website included updates about the annual workshop, monthly support meetings, and special programs and offerings from Network partners. Relevant YBCS education and support (e.g., emotions, exercise, fatigue, fertility, managing health, nutrition, pain, sexuality, and work concerns) were provided in the form of one-page tip sheets with bulleted information tailored to YBCS. The website provided links to partner websites, a one-way blog, upcoming event information, and existing research among YBCS. Additionally, the Network website included resources for co-survivors (i.e., family, friends, and children).

## Results

**Network Partnerships** The Network grew from the initial 4 partners within one hospital setting to 38 community partners over a 5-year period. Partners represented hospitals and oncology services ( $n = 16$ ), cancer organizations ( $n = 4$ ), private community organizations focusing on fitness, wellness, and nutrition ( $n = 5$ ), cancer advocacy groups ( $n = 7$ ), family and children counseling ( $n = 1$ ), support groups ( $n = 2$ ), academic institutions ( $n = 2$ ), and a men's advocacy group ( $n = 1$ ). Bi-monthly meetings rotated among the different partner organizations. Visits to different facilities helped ensure mutual engagement, familiarity, and sharing of supportive services for YBCS. Once the Network partnerships were well established, bi-monthly meetings transitioned to annual encounters; partners then gathered to discuss collaboration for the annual workshop. Partners participated in the Network's annual workshop with educational and supportive activities that included speaking, moderating, leading supportive programs for

children and spouses, exhibiting resources, and greeting and registering attendees.

**Individual Survivorship Consultation** In 2015, the authors evaluated the value of individual consultation with respect to access, satisfaction with referred services, and perceived barriers. Seventy YBCS received an invitation to take part in an evaluation via telephone of which 32 YBCS completed. These YBCS reported high satisfaction (mean of 8.9 on a 10-point Likert scale) with the individual consultation received. Ninety-nine separate survivorship service referrals were received by YBCS, of which they accessed 39 services (39.4% referral uptake rate). Barriers to accessing survivorship services expressed by YBCS included lack of time, busy schedules with work and cancer follow-ups, stigma of counseling services, fear of opening up and dealing with the “can of worms,” cost of transportation, and distance.

**Support Group Meetings** Twenty-three support group meetings were held from October 2012 to May 2017. A total of 373 participants attended, representing an average of 13.8 attendees per meeting. They were asked to evaluate the meetings using a survey with 10 questions (8 Likert-type questions about program quality and 2 open-ended questions). Participants found that information from the support group was helpful (mean 9.7 on a 10-point Likert scale) and rated excellent the overall program (mean 9.8 on a 10-point Likert scale). Ninety-eight percent reported that support groups met their survivorship needs and 99% indicated the information was useful. Two additional questions were related to suggested topics for future programs. Participants indicated interest in chemobrain, stress management, and genetics.

During the first 4 years, monthly support group meetings followed a seminar format during either lunch or dinner. Subsequently, YBCS voiced the need of support meetings held during a time that was convenient to working women, outside the walls of a meeting room, and with activities designed to increase their connection with other YBCS. Thus, the “Get Connected” quarterly meetings were created and replaced the monthly support group meetings in the fall of 2016. From the outset, Get Connected was designed as an informal get together held on Saturdays. Get Connected activities were innovated and adventuresome (e.g., nature walk at local botanical gardens, art therapy, personal pampering activities) with a focus to encourage connections among YBCS. Evaluations for Get Connected were highly positive. Overall participants rated the program at 9.7 out of 10 points (0 being not at all and 10 being extremely) with regard to helpfulness in meeting their changing survivorship needs. Additional topics requested by YBCS included gardening, body image, aromatherapy, and art therapy for survivors and family.

**Annual Workshop** The Network delivered five annual workshops from 2013 to 2017. The annual workshops brought together 598 attendees including breast cancer survivors ( $n = 176$ ), co-survivors ( $n = 69$ ), children ( $n = 32$ ), and Network partners, advocates, volunteers, and others ( $n = 294$ ). An additional 27 survivors attended via livestream. A total of 243 attendees completed the workshop evaluations over the 5-year period. Table 1 shows that the annual workshops were highly rated, with respect to organization, topics, networking, relevance, support, and information learned.

**Extending Outreach** The Network’s website was evaluated using Google Analytics. From June 2014 to August 2016, 11,937 users accessed the website with a total of 13,860 sessions/visits and 25,213 page views. In September 2016, the Network’s website transitioned to a new platform that was user-friendly and easy to navigate. The website can be accessed at [www.surviveAL.org](http://www.surviveAL.org).

## Discussion

Over the 5 years of the Network’s existence, the four priorities of networking, educating, increasing awareness, and extending outreach were built on community collaboration, engagement, and commitment. During this time, there were several lessons learned.

First, a cancer survivorship program designed for YBCS can meet local and regional needs. The Network’s multi-component programs recognized and celebrated the numerous ways in which YBCS wished to communicate and receive education and support through multiple strategies and on many topics. YBCS accessed the Network according to their needs, values, and preferences. For example, YBCS who preferred private contact accessed the Network through individual consultation and the Network website. While those who

preferred social settings accessed the Network through support groups, Get Connected, and the annual workshops. In doing so, the Network helped reduce perceived and real barriers such as lack of cancer care specialized for YBCS, lack of connection to a community of YBCS, and lack of personal accessibility to survivorship care. Through the Network, YBCS learned about the diverse support services available to them.

Second, YBCS who remained committed and engaged through the Network’s growth and development gave sage advice and recommendations for change. Several YBCS served as speakers and advocates at support group meetings and the annual workshops. YBCS became further engaged and empowered through participation in the Network which, in turn, connected them with other Network partners. The Advisory Board assisted the Network in clarifying the meaning of outcomes and tailoring outreach components to the needs of YBCS.

Third, the number and type of Network partners further increased access to survivorship services. The Network used the existing capacity of its partners to disseminate and deliver the outreach components. Through the Network, YBCS learned about the diversity of support services.

Fourth, the Network’s use of social media helped to extend its outreach beyond the local and regional communities. Social media provides support, information, empowerment, and improvement in chronic disease [15]. In recent years, national programs dedicated to the needs of young women, including Sharsheret [16, 17], Young Survival Coalition [17], and the Gulf States Young Breast Cancer Survivor Network [17], expanded their reach through social media.

The final lesson learned is that sustainability of a survivorship program must be considered from the outset. While initial funds for the Network were provided by a community-based program, the funds were not given in perpetuity. We designed the Network to meet local and

**Table 1** Overall evaluation of the Network annual workshops ( $n = 243$ )

| Variable   | Participants who responded either “excellent” or “good” |                         |                         |                         |                         | Average (%) |
|--|---|-------------------------|-------------------------|-------------------------|-------------------------|-------------|
|  | Year 1 ( $n = 31$ ) (%)                                 | Year 2 ( $n = 27$ ) (%) | Year 3 ( $n = 45$ ) (%) | Year 4 ( $n = 81$ ) (%) | Year 5 ( $n = 59$ ) (%) |             |
| Organization and planning of workshop                | 100   | 100                     | 100                     | 96                      | 100                     | 99.2        |
| Session topics                                       | 96.7  | 100                     | 97.6                    | 98.7                    | 100                     | 98.6        |
| Availability of time for networking                  | 90.3  | 100                     | 89.7                    | 97.2                    | 96.3                    | 94.7        |
| Workshop met your goals and objectives for attending | 96.8  | 100                     | 97.5                    | 100                     | 100                     | 98.9        |
| Relevance of the content for your survivorship needs | 96.6  | 96.1                    | 94.9                    | 100                     | 98.2                    | 97.2        |
| Ability to use the information you learned           | 93.4  | 100                     | 97.6                    | 97.2                    | 100                     | 97.6        |
| Overall quality of the workshop                      | 100   | 100                     | 100                     | 100                     | 100                     | 100         |
| Overall opinion of the Network program               | 100   | 100                     | 100                     | 100                     | 100                     | 100         |
| How well did the workshop increase your support      | 83.9  | 100                     | 89.4                    | 98.6                    | 100                     | 94.4        |

regional needs, and we leveraged the Network to become part of the Gulf States Young Breast Cancer Survivor Network, a broader network with reach to YBCS across Alabama, Mississippi, and Louisiana [17].

## Conclusion

The 5-year experiences with the Young Breast Cancer Survivorship Network demonstrated that a regional program dedicated to the education, support, networking, and needs of YBCS and their families can become a vital part of cancer survivorship services in a community. Strong community support, engagement, and encouragement were vital components to sustain the program. Through the Network, YBCS were educated, supported, and were provided with a broad cluster of survivorship services and support. Lessons learned can serve as a model for other programs seeking to extend outreach to young breast cancer survivors in the future.

**Acknowledgements** The Network would like to acknowledge the following individuals for their valuable contribution: Rachel Benz MSN, RN; Yu-Mei Schoenberger PhD; Ann Wooten RN; and the Young Breast Cancer Survivors Network's staff.

**Funding Information** This paper was supported by the Women's Breast Health Fund of the Community Foundation of Greater Birmingham.

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