



Specialized programs to support young women with breast cancer

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Purpose of review

Because of the recognized impact of breast cancer and its treatment on a young woman's life, initiatives are being established worldwide. The main aim of this review was to describe existing specialized programs that support young women with breast cancer (YWBC), advances to date, current challenges and future actions.

Recent findings

Current programs for YWBC are now educating professionals, patients, and communities on their specific needs. Also, support groups have helped break isolation and connect YWBC together. Research on biology, treatment, adverse effects, risk factors, genetics, and social aspects on YWBC is now being actively conducted. In low- and middle-income countries, the particular issues of young women are, however, still not systematically addressed, because of scarce funding, lack of awareness of YWBC needs, and deficient provider training.

Summary

Practice guidelines and algorithms should be disseminated and available for their widespread use to allow standard clinical and supportive care for YWBC even in oncologic centers where no specific programs exist. Also, cancer centers should formally commit to financing, at least partially, dedicated services, and existing programs for YWBC, guaranteeing their continuity. Finally, interinstitutional and international collaborations should be encouraged to facilitate adequately powered research, to avoid repetitive efforts, and to promote knowledge sharing and translation.

Keywords

specialized programs, supportive care, young women with breast cancer

INTRODUCTION

Young women with breast cancer (YWBC) face not only the threat of a potentially fatal illness and burdensome treatment, but have the added load of unique concerns. Available evidence suggests there is a lack of awareness of the special needs of this population by cancer specialists [1^{*}]. Attention to important supportive care and survivorship issues including fertility, menopausal concerns, body image, sexual functioning, genetic risk, and psychosocial health have been repeatedly found to be deficient in treatment of YWBC [2–5], and discussions and referrals often do not happen [6].

Since the early 2000s, initiatives that aim to improve awareness and knowledge among patients and providers about the specific needs of YWBC have been actively conducted [1^{*}]. Comprehensive programs for YWBC have been created in countries worldwide, predominantly in the USA and Canada.

The main aim of this review was to describe existing specialized programs that support YWBC. We have conducted an Internet search using the following keywords: 'young,' 'women,' 'breast cancer,' 'patients,' 'programs,' and 'networks.' We identified several initiatives and contacted their coordinators via e-mail to clarify their structure

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Curr Opin Support Palliat Care 2015, 9:000–000

DOI:10.1097/SPC.0000000000000155

KEY POINTS

- Specialized programs for young women with breast cancer have been created, predominantly in developed countries, that aim to improve supportive care, promote research, and educate public, patients, and providers.
- In low- and middle-income countries, limited initiatives have been undertaken to address the particular issues of young women because of scarce funding, lack of awareness of their particular needs, and deficient training among providers.
- Even in developed countries, funding is a constant struggle for sustainability of existing programs, as they frequently depend on finite grants from governmental and nongovernmental organizations.
- Implementation of practice guidelines and algorithms will allow standard clinical and supportive care for all young breast cancer patients, even in oncologic centers where no specific programs exist.
- Interinstitutional and international collaborations should take place to make the most of available resources, to avoid repeating efforts, and to promote fund sharing.

and impact, as well as to identify challenges faced. Also, we reached out to attendees and abstract authors of the 2nd Breast Cancer in Young Women Conference, held in Dublin, Ireland, in November 2014. Additionally, we contacted breast cancer leaders in different countries and inquired about existing programs in the region. The flowchart in Figure 1 shows the selection process for the programs described in this review. Table 1 lists the 21

programs included with their acronym, location, activities, and special characteristics. We recognize that some existing programs and/or initiatives are not included in this review, as our identification process may have missed them.

STRUCTURE OF PROGRAMS FOR YOUNG WOMEN WITH BREAST CANCER

Comprehensive programs for YWBC often consist of a team of providers including medical, radiation, and surgical oncologists, a navigator or program coordinator, nurses, psychologists, social workers, research coordinators, and other experts. This multidisciplinary care ensures that all aspects involved in the needs of YWBC are adequately addressed. Also, young breast cancer survivors have been included as part of the steering committee in programs such as PYNK: Breast Cancer Program for Young Women (PYNK) at Sunnybrook Health Sciences Centre at Toronto, Canada, and the Program for Young Women with Breast Cancer in Mexico (PYWBCM) at Mexico City and Monterrey. To address the most common YWBC’s needs, different programs have incorporated genetic counseling, fertility consultations, sexual health rehabilitation, nutrition assessments, and supportive care.

The role of the navigator has been highlighted as the cornerstone of some of these programs, as he/she acts as an advocate for the patient, from diagnosis through follow-up. The navigator’s responsibilities include the following: introducing new patients to the program; assisting patient and providers with timely referrals to genetics, fertility, plastic surgery, among others; providing education

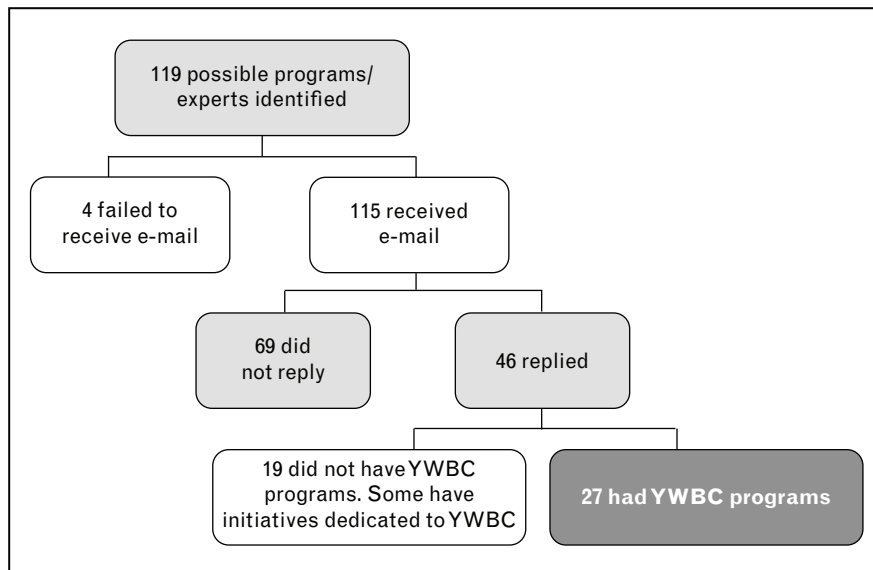


FIGURE 1. Selec-on process of described programs.

Table 1. Programs included, location, activities and special characteristics

Program	Acronym	Country	Activities	Special characteristics
1. Arizona Young Breast Cancer Survivor Support Initiative	AYBC	US	Survivorship Education	Online resources for young survivors
2. LiveWell Center for Young Women with Breast Cancer	LiveWell	US	Clinical care Supportive care Navigation Education Research	Higher proportion of younger patients (18–24%) Development of mobile app
3. Living Beyond Breast Cancer Young Women’s Initiative	YWI	US	Advocacy Supportive care Education	Young Advocate Training Program
4. Sharsheret: Your Jewish Community Facing Breast Cancer	Sharsheret	US	Supportive care Navigation Education Research Survivorship	Culturally guided for young Jewish women
5. SurviveDAT	SurviveDAT	US	Survivorship Supportive care Navigation	Will expand to form Gulf States Young Breast Cancer Survivor Network (Louisiana, Alabama, Mississippi)
6. Young and Strong: a Program for Young Women with Breast Cancer	Y&S	US	Education Clinical care Supportive care Navigation Survivorship Research	Largest young women cohort
7. Young Breast Cancer Survivorship UCLA-Livestrong	YBCS	US	Supportive care Survivorship Education	Skill-building strategies to combat psychosocial challenges from daily life
8. Young Survival Coalition	YSC	US	Advocacy Supportive care Education	First advocacy program Research Think Tank Global presence
9. Young Women’s Breast Cancer Program	YWBCP	US	Education Clinical care Supportive care Survivorship Research	First program in the US dedicated for YWBC
10. Young Women’s Breast Cancer Translational Program	YWBCTP	US	Clinical care Supportive care Navigation Research	Pregnancy-associated breast cancer translational research

Table 1 (Continued)

	Program	Acronym	Country	Activities	Special characteristics
11.	Young Women's Breast Support Group	YWBSG	US	Supportive care Survivorship Advocacy	Lymphedema therapy and post treatment exercise program
12.	Canadian Breast Cancer Network	CBCN	Canada	Education	Workshops and resources
13.	Cancer Fight Club	CFC	Canada	Supportive care Survivorship	Dance and cooking classes, exercise evenings, café nights, etc.
14.	PYNK: Breast Cancer Program for Young Women	PYNK	Canada	Clinical care Supportive care Research Navigation Education	First program in Canada dedicated for YWBC
15.	Reducing the bURden of Breast cancer in Young women	RUBY	Canada	Research Navigation	Pan-Canadian prospective cohort
16.	Rethink Breast Cancer	Rethink	Canada	Advocacy Supportive care Education	LiveLaughLearn covers topics from coping to chemotherapy to finding a cute bikini that can hold a prosthesis
17.	Young Adult Cancer Canada	YACC	Canada	Advocacy Survivorship	Break isolation and connect young adults together
18.	Team Shan Breast Cancer Awareness for Young Women's	Team Shan	Canada	Education	Awareness and education for well young women
19.	Program for Young Women with Breast Cancer in Mexico	PYWBCM	Mexico	Clinical care Education Supportive care Research	First program in Latin America
20.	Champalimaud Cancer Center		Portugal	Research	Quality of life with hypofractionated radiation therapy
21.	Young Women's Breast Cancer Service	YWBCS	Israel	Clinical care Education Navigation Supportive care Research	Based on PYNK and Y&S concept, first program in Middle East
22.	St. Luke's International Hospital – Pink Ring		Japan	Survivorship Supportive care	Focuses on survivorship and employment issues
23.	National Cancer Center		Japan	Survivorship Research Clinical care	Appearance and Employment support programs
24.	Japanese Society for Fertility Preservation		Japan	Clinical care Research	Network of oncologists and reproductive specialists
25.	Cancer Solutions	Cansol	Japan	Survivorship	Job-placement service company

Table 1 (Continued)

Program	Acronym	Country	Activities	Special characteristics
26. Keep A Breast	Keep a Breast	International	Advocacy Education	'Check Yourself!' mobile app Presence in United States, Canada, Chile, Europe and Japan
27. International Breast Cancer Study Group's Program for Young Patients	IBCSG PYP	International	Research	HOHO and POSITIVE studies

and personalized support to patients; and offering enrollment to clinical trials. Patient navigation is an effective strategy to significantly decrease anxiety and increase patient satisfaction among women with newly diagnosed breast cancer [7]. The Young Women with Breast Cancer Translational Program (YWBCTP) at the University of Colorado in Denver, Colorado; the Young and Strong: A Program for Young Women with Breast Cancer (Y&S) at Dana Farber Cancer Institute (DFCI) in Boston, Massachusetts; the LiveWell Program for Young Women with Breast Cancer (LiveWell), part of Johns Hopkins' Sydney Kimmel Cancer Center in Baltimore, Maryland; Sharsheret: Your Jewish Community Facing Breast Cancer's (Sharsheret); the Young Women's Breast Cancer Service (YWBCS) at the Sheba Medical Centre in Israel, PYNK and PYWBCM, emphasized their navigation services. Different healthcare professionals such as nurses, social workers, and psychologists provide patient navigation.

The impact of nonlife threatening and long-term adverse effects of anticancer treatment is often overlooked in young breast cancer survivors [8]. Some programs offer activities designed to enhance the health and wellness of this population, by helping them develop strategies to combat psychosocial challenges in their daily lives. The Young Breast Cancer Survivorship (YBCS) program at the UCLA-Livestrong Survivorship Center of Excellence of the Jonsson Comprehensive Cancer Center in Los Angeles, California, provides a regionally refined online resource library. Their 'Life After Breast Cancer' (LABC) program, an interventional one-day workshop, provides support on psychosocial issues such as fear of recurrence, sexuality and intimacy, relationships, and returning to 'normal' after treatment. The Young Adult Survivorship Group of the Young Women Breast Cancer Program (YWBCP) at the Washington University School of Medicine in St. Louis, Missouri, offers a biweekly exercise class, providing instruction to return to a healthy lifestyle. The 'Get Real and Heal' by the Young Women's Breast Support Group (YWBSG) at the University of North Carolina, in Chapel Hill, North Carolina, is an active lymphedema therapy and posttreatment

program that focuses on exercise as well as some stress reduction and nutritional sessions. In Japan, several initiatives dedicated to improving the quality of life of young breast cancer patients and survivors are currently taking place: first, the St. Luke's International Hospital in Japan has a support community for young breast cancer survivors, Pink Ring, which focuses on several survivorship issues; second, the National Cancer Center addresses employment and physical appearance problems; third, the Japanese Society for Fertility Preservation is a network of oncologists and reproductive specialists who developed a fertility guideline for YWBC; and fourth, Cancer Solutions (Cansol) a private job-placement service company for cancer survivors. The SurviveDAT program at the Louisiana State University Health Sciences Center and Mary Bird Perkins Cancer Center in Louisiana will expand to form the Gulf States Young Breast Cancer Survivor Network, which will offer online support and social media for young breast cancer survivors in Louisiana, Alabama, and Mississippi. The Arizona Young Breast Cancer Survivor Support Initiative also offers online resources for family members.

SUPPORT GROUPS FOR YOUNG WOMEN WITH BREAST CANCER

Breast cancer support programs have proven to be effective in enhancing the quality of life of breast cancer patients [9]. The LiveWell program, in partnership with YSC, provides monthly group support for early-stage patients, and plans to create a group for young patients with metastatic disease. PYNK's nurse navigator facilitates a monthly 2-hour social networking event called 'In the PYNK'. The YWBSG serves a source of peer support where YWBC talk about sexuality issues, integrative approaches to achieving wellness after treatment, relationships, and surgeries. *Rethink* Young Women's Network (RYWN) is a group comprised of women that provide input and feedback on *Rethink's* resources and campaigns.

Other programs offer diverse recreational activities, such as the creative arts program by the

YWBCP. Although the CancerFightClub program at the Jewish General Hospital in Montreal, Canada, hosts dance and cooking classes, exercise evenings, personal training programs, young adults cancer retreats for early-stage and metastatic patients, workshops, community events, and café nights.

Peer-to-peer (one-on-one) programs allow YWBC to connect with one another, sharing advice and their experiences throughout their disease, and can be effective in enhancing the quality of life of breast cancer patients [9,10]. Currently, YWBCP, Y&S, YSC, YACC, and Sharsheret offer peer-to-peer support. Additionally, YSC trains peer mentors to respond to young women requesting one-to-one support through their SurvivorLink Program. Furthermore, Sharsheret's Peer Support Network specifically connects Jewish patients through a national network of more than 4500 women.

It has been shown that family members and partners experience similar levels of distress to cancer patients themselves following diagnosis and have a wide range of information requirements, which need to be addressed [11,12]. *Rethink's* Support for Young Families has developed two resources to promote discussion and help develop coping skills for the whole family: *A Guide for Kids + A Guide for Parents*. 'Out of the Blue,' a support group for the male partner of PYNK patients, is currently under development by the program's nurse navigator and social worker.

EDUCATION FOR PATIENTS

YWBC often feel isolated and consider that they lack information [13]. Accumulation of knowledge and confidence for patients' own health is essential to sustain patients' involvement in their treatment and encourage patient activation [14]. Such implications have resulted in the creation of a variety of educational programs.

The YBCS program offers a unique online resource library that works as a tailored search engine on the type and location of required services. *Keep A Breast Foundation* offers 'The Traveling Education Booth,' an interactive education platform, and the free 'Check Yourself!' mobile application in four different languages, which gives an overview of the breast self-exam and automatic monthly reminders. 'LiveLaughLearn' from Rethink Breast Cancer (Rethink), in Canada, is a video series that covers topics from the benefits of physiotherapy, coping with chemotherapy, and finding a bathing suit that can hold a prosthesis; and, their 'Cancer Fabulous Diaries,' features interviews, essays and tips of how to navigate the experience of breast cancer. The Young Women's Initiative (YWI) from

Living Beyond Breast Cancer (LBBC) offers webinars, Twitter Chats, sessions, publications, and advocacy trainings. The Canadian Breast Cancer Network offers a free, print resource called 'Never Too Young, Psychosocial Information and Support for Young Women with Breast Cancer.' The Reducing the bUrden of Breast Cancer in Young Women (RUBY) project in Canada and the LiveWell program are currently developing web-based resources. The PYWBCM is currently working on the first Spanish resources solely dedicated to YWBC through the development of an educational manual, fact sheets, seminars, and mobile application.

The YWBCP offers an annual education symposium where health professionals, local cancer organizations, and survivors present on a variety of topics, and a monthly support and education program. The Young Survival Coalition (YSC) hosts a national Summit for YWBC and as of June 2015, will hold 1-day regional symposiums throughout the USA. Young Adult Cancer Canada (YACC) offers three Retreat Yourself programs a year, one Retreat Yourself Adventure, an annual Survivor Conference, and peer-led social events that are offered in six cities in Canada. Y&S partners with the Adult Survivorship Program and the Sexual Health Program from the DFCI on biannual sexual health workshops tailored specifically for YWBC. PYNK's nurse navigator recently piloted a 2-hour seminar about intimacy and sexuality, and similar events will be held every few months.

EDUCATION FOR THE PUBLIC

Other important aspect of young women's health is to increase awareness and educate the public about early detection, risk reduction, and prevention of breast cancer. This can ultimately impact earlier-stage diagnosis of breast cancer among this population. To address this issue, the Team Shan Breast Cancer Awareness for Young Women's (Team Shan) program focuses on education and awareness efforts specifically targeted to young women in communities, high schools, and colleges on breast cancer risk.

EDUCATION FOR HEALTHCARE PROVIDERS

Although most breast cancer patients receive the necessary information from healthcare providers on treatment options and procedures at diagnosis, they often fail to receive support and guidance in dealing with the possible physical, emotional, social, and psychological effects of cancer [4]. Education of healthcare providers on the specific issues of YWBC

is an important aspect that some of the programs cover to ensure that adequate care is delivered.

Y&S provides physicians with clinical checklists, updates, and education about issues unique to YWBC, as well as peer-to-peer support and tumor board reviews in real time as clinical issues arise. The YBCS staff is currently developing a training program on the 'Life After Breast Cancer' Psychosocial Program for it to be institutionalized and offered throughout the local community. PYNK offers evening education events for primary care physicians and general surgeons, and presentations at Grand Rounds at various institutions. The PYWBCM is currently working on a series of online resources featuring recorded sessions from international experts that will be subtitled in Spanish, slides presentations, and book chapters.

ONGOING RESEARCH

Research will provide healthcare professionals with further information to better understand and manage the specific needs of YWBC, and to design possible targeted solutions.

Helping Ourselves, Helping Others: The Young Women's Breast Cancer Study as part of the Y&S program is a longitudinal cohort study of YWBC that investigates short and long-term disease and treatment issues, tumor biology and the relationship to patient outcomes, and psychosocial concerns [15]. To date, more than 1250 patients have been enrolled in different institutions across the USA and nine manuscripts have been published in peer-reviewed journals. Additionally, the International Breast Cancer Study Group (IBCSG)'s Program for Young Patients (PYP) is running this study in selected institutions in Switzerland and Italy, with the original instruments adapted to the socio-demographic and psychological context in Europe. To date, 257 patients have been accrued out of the 300 planned for this cohort. Likewise, the YWBCS, in collaboration with the IBCSG's PYP and based on the HOHO trial, uses the same questionnaire adapted culturally for local needs. So far, 120 women have been recruited in Israel.

Women in PYNK are asked to give informed consent for the collection and storage of blood and tumor specimens, and for their clinical information, including cancer risk factors and treatment, to be stored in a prospective database. After discharge (after a minimum of 5 years in the program), patients complete annual questionnaires to keep track of outcomes such as fertility difficulties, pregnancies, and cancer recurrences [16]. Additionally, they published the first article on the effects of

breast cancer diagnosis on young women's relationships with their mothers [16].

PYWBCM currently has the first cohort in Latin American that includes Mexican YWBC from two different institutions. The main objectives are as follows: first, to collect tumor and blood samples for future translational collaborative projects; second, to assess the needs in a different cultural and socioeconomic environment, and to adapt, test, and refine the components of the Y&S program based on these findings; third, to evaluate the impact of diagnosis and treatment on quality of life, cognition, and sexuality; and fourth, to determine the prevalence of genetic mutations in Mexican YWBC in collaboration with City of Hope, in California, and Women's College Hospital, in Toronto, Canada. In partnership with the Massachusetts General Hospital, a database is currently being developed for the registry of clinical and outcome data in different Latin American countries, where further research is essential to characterize the growing number of this specific population [17].

The YWBCP collaborates with the Ohio State University on a genetics research focused on early-onset breast cancer. Over 2200 young US survivors have participated.

RUBY is a Canadian nationwide collaboration consisting of two components: a prospective cohort study that will recruit 1200 women across Canada aged 40 or younger; and the merging of multiple, retrospective data sets that will result in over 3000 cases with robust treatment, tumor data, and long-term follow-up. The main objectives are as follows: first, to evaluate the contribution of 25 genes linked to breast cancer and to determine which genes (other than BRCA 1 and 2) should be introduced into clinical genetic testing; second, to explore associations between increased breast cancer risk for young women and unhealthy lifestyle; third, to create a site-specific intervention model to aid discussions about fertility preservation and to determine predictors of premature ovarian failure; and fourth, to identify modifiable mechanisms of treatment delay, impact of breast-conserving therapy, and provision of optimal care through multidisciplinary care conferences.

Sharsheret will establish a new partnership with public health scientists at Georgetown Lombardi Comprehensive Cancer Center to conduct an evaluation of the support interventions provided.

The YWBCTP is focused on translational research to identify the mechanisms that increase metastasis and death in young onset breast cancer, with special emphasis on pregnancy-associated breast cancer. Currently, the YWBCTP is building on its prior research and investigating the potential

for drug-targeted prevention in postpartum breast cancer and immune modulatory therapy to reduce the increased risk of metastasis and improve outcomes for YWBC. The YWBCS is conducting translational research comparing breast cancer biology in older and younger women and has ongoing studies in collaboration with its onco-genetics department and fertility preservation department.

Researchers at the Champalimaud Cancer Center in Lisbon, Portugal, are evaluating the impact of radiation therapy on quality of life in YWBC. About 150 breast cancer patients under 45 years of age are being treated with intensity-modulated radiotherapy based, hypo-fractionated (15 fr) whole breast irradiation and are being monitored on tolerance, cosmetic outcome, and influence on psychological, economical, and professional aspects of this short regimen. Until now, median follow-up reaches 2 years, however, and update is planned for 2016.

The IBCSG's PYP study *POSITIVE* will assess the risk of breast cancer relapse and factors associated with pregnancy success after temporary interruption of endocrine therapy. A total of 500 patients are planned to be recruited in 21 countries.

ADVANCES TO DATE

Because of the recognized impact of breast cancer and its treatment on a young woman's life, more initiatives are being established worldwide and current programs for YWBC are now educating professionals, patients, and communities, and providing psychosocial support and resources on their specific needs. Also, support groups have helped break isolation and connect YWBC together. Ultimately, research on biology, treatment, adverse effects, risk factors, genetics, and social aspects on YWBC is now being actively conducted.

CURRENT CHALLENGES

Although developed countries are actively running initiatives that target YWBC and their providers, in low- and middle-income countries (LMICs), the particular issues of young women are not systematically addressed, in spite of specific recommendations regarding supportive care for this population in these limited settings [18¹¹]. The awareness of the need of such supportive care has increased in some LMICs. For example, in certain Latin American countries, fertility, genetics, and psychological services are now available, but mostly in private health settings. Only initiatives are starting to emerge, as no specific programs for YWBC exist because of the lack of funding sources.

Even in developed countries, funding is a constant struggle for continuity of existing programs. Most of the described programs reported that funding was the greatest challenge faced. Currently, most of the programs in the USA and Canada have to rely on limited grants to finance their activities, and are funded through governmental contributions and nongovernmental organizations' donations. This translates into two issues: first, the programs' lack of sustainability and risk of discontinuity, and second, vulnerability to patient saturation because of limited human and material resources.

Advocacy groups play an essential role in ensuring that all YWBC have information on and access to state-of-the-art early detection, diagnosis, and treatment of breast cancer and have made a huge impact on the establishment of initiatives for YWBC [19]. In LMICs their impact has, however, been limited, largely because of lack of funding, resources, and advocacy expertise. Additionally, since public health services are often inadequate in LMICs, advocacy groups find themselves filling a void and navigating patients to existing services rather than striving to shape policy.

Finally, in spite of current advances on YWBC care, most oncology training programs still do not emphasize their special needs, leading to oncologists not adequately addressing them [1¹²]. Therefore, attention to important supportive care and survivorship issues are repeatedly found to be deficient in the treatment of YWBC [2–5].

POSSIBLE FUTURE ACTIONS

Practice guidelines and algorithms, such as the First International Consensus Guidelines for Breast Cancer in Young Women [20¹³] and the consensus statement on Supportive Care During Treatment for Breast Cancer [18¹⁴], should be disseminated and available for their widespread use. This will allow standard clinical and supportive care for all YWBC, even in oncologic centers where no specific programs exist. Cancer centers should formally commit to these standard clinical practices by financing, at least partially, dedicated services and existing programs for YWBC, guaranteeing their continuity.

Since in many cancer institutions specialized supportive care services, such as fertility, sexuality and genetics consultations, are not available, partnerships between local centers should be encouraged. Interinstitutional and international collaborations should take place to make the most of available resources, to avoid repeating efforts, and to promote fund sharing. Well established programs should serve as mentors and examples for the less developed

settings in LMICs. Also, collaborations should be promoted within countries that lack established YWBC programs so as to expand the currently covered population. Finally, efforts should be directed to producing materials and resources in the most widely spoken languages worldwide, other than English, as to aid YWBC located in countries where programs for this population are not currently established.

Acknowledgements

We gratefully acknowledge the contributions we received from program directors, managers, and navigators on information about their programs, as well as renowned clinicians on the report about the initiatives undertaken in their cancer centers dedicated to YWBC.

Financial support and sponsorship

None.

Conflicts of interest

There are no conflicts of interest.

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Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

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This review illustrates that breast cancer among Latin American women is a growing burden throughout the region. The findings of this study reveal that there is scarce information regarding this matter in Latin American countries. Also, there are no specific clinical or educational programs that focus on this population. A call to action is deserved for better care of this emergent challenge.

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