



Review

Supportive care after curative treatment for breast cancer (survivorship care): Resource allocations in low- and middle-income countries. A Breast Health Global Initiative 2013 consensus statement[☆]



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ARTICLE INFO

Article history:

Received 11 July 2013

Accepted 23 July 2013

Keywords:

Breast cancer

Supportive care

Survivorship

Low- and middle-income countries

Resource allocations

ABSTRACT

Breast cancer survivors may experience long-term treatment complications, must live with the risk of cancer recurrence, and often experience psychosocial complications that require supportive care services. In low- and middle-income settings, supportive care services are frequently limited, and program development for survivorship care and long-term follow-up has not been well addressed.

As part of the 5th Breast Health Global Initiative (BHGI) Global Summit, an expert panel identified nine key resources recommended for appropriate survivorship care, and developed resource-stratified recommendations to illustrate how health systems can provide supportive care services for breast cancer survivors after curative treatment, using available resources.

Key recommendations include health professional education that focuses on the management of physical and psychosocial long-term treatment complications. Patient education can help survivors transition from a provider-intensive cancer treatment program to a post-treatment provider partnership and self-management program, and should include: education on recognizing disease recurrence or metastases; management of treatment-related sequelae, and psychosocial complications; and the importance of maintaining a healthy lifestyle. Increasing community awareness of survivorship issues was also identified as an important part of supportive care programs. Other recommendations include screening and management of psychosocial distress; management of long-term treatment-related

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complications including lymphedema, fatigue, insomnia, pain, and women's health issues; and monitoring survivors for recurrences or development of second primary malignancies. Where possible, breast cancer survivors should implement healthy lifestyle modifications, including physical activity, and maintain a healthy weight. Health professionals should provide well-documented patient care records that can follow a patient as they transition from active treatment to follow-up care.

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Breast cancer survivors in low- and middle-income countries

Globally, breast cancer 5-year relative survival rates range from 80 to 90% in high-income countries (HICs), to 60% in middle-income countries, to below 40% in low-income countries [1]; in parts of Africa, it may be as low as 12% [2]. These differences have been attributed to disparities in early detection, type of breast cancer, access to treatment, type of treatment, and social and cultural barriers. The concept of cancer survivorship itself as a distinct phase of cancer treatment is relatively new, and awareness of long-term issues affecting cancer survivors is low, especially in low- and middle-income countries (LMICs). Breast cancer patients in LMICs are often younger, and have more advanced and aggressive disease [3]. Radiotherapy for breast conservation and sentinel lymph node biopsy for minimally invasive axillary staging are often unavailable in LMICs [4], leading to more extensive surgical approaches such as mastectomy and axillary lymph node dissection. These are associated with higher rates of long-term complications (body image changes, and loss of arm mobility and lymphedema, respectively). Breast cancer survivors in LMICs may experience greater effects from chemotherapy-induced early menopause, infertility, and impairments in sexual function and body image, and may have an increased risk of recurrence as well as a sense of isolation due to social and cultural conditions. Unfortunately, supportive care services are frequently limited in LMICs; program development for survivorship care and long-term follow-up appropriate for LMICs has not been well addressed.

Supportive care after curative treatment (survivorship care)

Supportive care for breast cancer, including survivorship care, is a distinct aspect of cancer treatment that should be integrated into breast cancer care programs in low- and middle-income countries (LMICs). The Institute of Medicine (IOM) describes survivorship care as encompassing five main areas: 1) surveillance for cancer recurrence or new cancers; 2) management of symptoms that persist after treatment ends; 3) evaluation of risk for, and when possible, prevention of, late-effects of treatment; 4) assessment of psychosocial needs and provision of appropriate support; and 5) counseling of patients on lifestyle modifications for prevention of cancer-related morbidity and mortality, as well as to improve quality of life [5]. As the incidence of breast cancer increases in LMICs, so too will the number of breast cancer survivors, as a result of increased efforts to improve early detection of breast cancer, an increase in breast cancer care programs, and greater availability of effective treatments.

Defining “breast cancer survivors”

For the purposes of this consensus statement, “breast cancer survivors” are defined as patients who have entered the post-treatment phase after initial surgery, with or without chemotherapy and/or radiation (ie, 6 months of curative treatment). Companion Breast Health Global Initiative (BHGI) supportive care

consensus statements cover supportive care during treatment, and supportive and palliative care for metastatic disease.

BHGI global summit and expert panel consensus process

All three BHGI supportive care consensus statements provide recommendations for breast cancer supportive care program implementation in low- and middle-income settings. Methods developed by the Breast Health Global Initiative (BHGI) for the structured creation of evidence-based, 4-tier resource-stratified guidelines and consensus statements (see Table 1) have been previously described [6,7]. A systematic literature review was performed in preparation for the 5th BHGI Global Summit, which was held in association with the International Atomic Energy Association (IAEA) in Vienna, Austria, on October 2, 2012. Supportive care was chosen as a theme for the global summit, as it emphasizes often-overlooked aspects of medical care, which are not always considered directly related to curative intent. The Supportive Care after Curative Treatment (Survivorship Care) Consensus Panel presented on key topics and then performed a consensus analysis through facilitated expert panel discussion in order to draft the core resource-stratified table matrices, which are the primary outcome of the panel examination and deliberation. Companion consensus statements for *Supportive Care during Treatment* [8] and *Supportive*

Table 1

Resource allocation levels: basic, limited, enhanced, and maximal.

Resource Allocation Level*	Description
Basic	Core resources or fundamental services absolutely necessary for any breast health care system to function; basic-level services are typically applied in a single clinical interaction.
Limited	Second-tier resources or services that are intended to produce major improvements in outcome, and are attainable with limited financial means and modest infrastructure; limited-level services may involve single or multiple clinical interactions.
Enhanced	Third-tier resources or services that are optional but important; enhanced-level resources should produce further improvements in outcome and increase the number and quality of therapeutic options and patient choice.
Maximal	High-level resources or services that may be used in some high-income countries, and/or may be recommended by breast care guidelines that do not adapt to resource constraints. They should be considered lower priority than those resources or services listed in the basic, limited, or enhanced categories on the basis of extreme cost and/or impracticality for broad use in resource-limited environments; to be useful, maximal-level resources typically depend on the existence and functionality of all lower-level resources.

* The table stratification scheme implies incrementally increasing resource allocation at the basic, limited, and enhanced levels. Maximal-level resources should not be targeted for implementation in LMICs, even though they may be used in some higher-resource settings.

Table 2
Health systems: health education, community awareness, psychosocial patient-support after curative treatment.

	Basic	Limited	Enhanced	Maximal
Health professional education^a	BCr recurrence, second primary cancer Long-term TX complications Women's health Psychosocial (survivorship) consideration ^c Lifestyle modifications	Psychosocial risk assessments Psychosocial complications of survivorship Sexual health	Psychosocial screening methods	
Patient and family education^b	BCr recurrence or new cancers; symptoms to report Long-term TX complications Appropriate use of CAM Women's health issues Psychosocial issues (survivorship) Lifestyle modifications	Follow-up schedules Adherence to endocrine therapy Sexual health		
Community awareness	Community awareness of BCr survivorship issues			
Psychosocial (survivorship)	Patient and family education ^b Psychosocial (survivorship) consideration ^c Peer support by trained BCr survivors	Psychosocial assessments, including depression Emotional and social support by health professionals	Screening and referral for depression/distress by mental health specialist Psychosocial counseling by mental health specialists Availability of pharmacotherapy Social service counseling for financial, employment and legal issues	Psychiatrist-, psychologist-, or social worker-coordinated care

Note: The table stratification scheme implies incrementally increasing resource allocation at the basic, limited, and enhanced levels. Maximal-level resources should not be targeted for implementation in LMICs, even though they may be used in some higher-resource settings.

Abbreviations: BCr, breast cancer; CAM, complementary and alternative medicine; TX, treatment.

^a The term "health professional" is used to acknowledge the range in medical and other professionals who provide supportive care services in LMICs. When specialists are identified as a required resource, it is assumed that a specialist has a certification for their area of expertise.

^b Patient, family and/or partner education may be the primary intervention for some supportive care services.

^c "Consideration" is a term used in this table to refer to basic patient evaluation through patient-provider interactions, including dialogue, observations, and other appropriate means of evaluation.

and Palliative Care for Metastatic Breast Cancer [9] were developed in parallel during this 2012 Global Summit. Cancer supportive care is an under-researched area of medicine, especially in LMICs. Systematic reviews and meta-analyses are often not available for select topics, or include only studies from HICs. When studies from LMICs are available on a topic, they are provided as additional references.

Key resources needed for survivorship supportive care programs

This section of the consensus statement describes the nine key resources identified for basic breast cancer supportive care after curative treatment (survivorship). A resource-stratified recommendation follows the description of each key resource category, and is also presented in one of the two tables. The resource-stratified tables illustrate how, even at a basic level of resources, a health system can provide comprehensive supportive care services to breast cancer survivors, and plan for incremental program improvements. If a topic is covered in more detail in another companion consensus statement, a link and reference is provided.

Health systems (Table 2)

Health professional education (Table 2, row 1)

Description. Breast cancer supportive care programs are emerging as distinct, specialized fields of medicine that require cross-disciplinary health professional education [10]. The term "health professional" is used to acknowledge the range of medical and other professionals who provide supportive care services in LMICs. When specialists are identified in a recommendation as a required resource, it is assumed that the specialist has a certification for their area of expertise.

Health professional education should address surveillance for breast cancer recurrence and second primary cancers, including patient characteristics and other risk assessments. It should include monitoring for and management of long-term treatment complications, including lymphedema, fatigue, insomnia, and pain, as well as symptom management for long-term treatment-related women's health issues (eg, hormone, menopausal symptoms, sexual health issues). In addition, health professional education should include awareness about the psychosocial complications of survivorship, including depression, emotional distress and changes to social roles, and should include information about available patient support services to manage psychosocial problems. Health professionals should also be instructed about how to educate patients regarding lifestyle modifications that may reduce cancer risks and improve quality of life. Health professionals should be educated about health literacy and cultural sensitivity. (See the companion BHGI consensus statement, *Supportive Care during Treatment* [8], for a more detailed discussion on cultural sensitivity).

1. Panel recommendations. At **basic levels** of resource allocation, health professional education should include education about breast cancer recurrence and second primary cancers, and recognition and management of physical/clinical complications of long-term treatment, including women's health issues (eg, reproductive health, early menopausal symptoms, body image). It should include awareness and recognition of psychosocial complications of treatment, and lifestyle modifications to reduce cancer risk and improve quality of life. At **limited levels**, health professional education should include awareness of patient characteristics associated with increased risk for depression,

Table 3
Survivorship issues: long-term complications, lifestyle modifications, monitoring and documentation following curative treatment.

	Basic	Limited	Enhanced	Maximal
Long-term treatment-related complications	Patient and family education ^b on long-term TX complications Antibiotics for cellulitis or lymphangitis Basic lymphedema supplies	PT, OT, CDT for lymphedema management Fatigue, insomnia management Pain management	Coordinated care by oncology-trained personnel/nursing staff Custom compression garments	Pneumatic pump Perometer
Women's health^a	Patient and family education ^b on early menopause, body image	Patient and family education ^b on sexual health TX of menopausal symptoms: topical agents and simple behavioral strategies	Pharmacotherapy for menopausal symptoms Breast reconstruction for asymmetry Bone-modifying agents	Clinical assessment and tailored intervention for menopausal symptoms and sexual health
Lifestyle modification	Patient education ^b on diet and exercise	Weight management and daily exercise counseling	Exercise program Individualized education by dietitian	Weight management program
Monitoring	Monitor for BCr recurrence, second primary cancers Monitor for long-term TX complications	Monitor for endocrine medication adherence		Genetic testing and counseling Screening for high-risk cancers
Documentation	Patient care record (eg, discharge summary)	Patient treatment summary	Survivorship care plan	

Note: The table stratification scheme implies incrementally increasing resource allocation at the basic, limited, and enhanced levels. Maximal-level resources should not be targeted for implementation in LMICs, even though they may be used in some higher-resource settings.

Abbreviations: BCr, breast cancer; CDT, complete-decongestive therapy; PT, physiotherapy, OT, occupational therapy, TX, treatment.

^a Women's health issues for breast cancer patients include menopause, reproductive health, fertility, body image, and sexual health; educational efforts should include partners, as appropriate.

^b Patient, family and/or partner education may be the primary intervention for some supportive care services.

anxiety or distress, and long-term psychosocial complications. Education should include sexual health issues. At **enhanced levels**, health professional education should include methods for psychosocial screening.

Patient and family education (Table 2, row 2)

Description. Clear and open communication between a patient, their family, and health professionals is an important part of breast cancer supportive care [11]. Patient education can help survivors transition from a provider-intense cancer treatment program to an after-treatment provider partnership and self-management program. Survivorship patient education should help patients and their families understand how to recognize the signs and symptoms of disease recurrence or metastases (eg, cough, shortness of breath, abdominal discomfort, loss of appetite and weight loss) [12], and the importance of attending follow-up appointments and adhering to longer-term endocrine therapy, if prescribed. Education on the management of treatment sequelae, including lymphedema, fatigue and insomnia [8], and pain [9], should be provided. Women's health issues should be addressed, including menopausal symptoms, body image, and sexual health complications. (Reproductive health and fertility concerns are discussed in the companion BHGI consensus statement, *Supportive Care during Treatment* [8]). Partners should be included in sexual health education, when appropriate. Psychosocial complications (eg, depression and emotional distress) and social issues (eg, changing roles at home and work) are important components of supportive care programs that are often overlooked, especially if more intense or urgent physical complications dominate. Healthy lifestyle modifications should be part of survivorship educational programs. For example, remaining physically active, as tolerated, is recommended during treatment [8], and its importance should be reinforced post-treatment, as needed. Guidelines on nutrition and exercise developed in HICs can be adapted, as appropriate, to a particular country or area. Cultural sensitivity and health literacy

should be considered when communicating with patients at all levels of resource allocations. Breast cancer educational strategies should be culturally sensitive and appropriate [13–17]. (See the companion BHGI consensus statement, *Supportive Care during Treatment* [8], for a discussion on cultural sensitivity.)

2. Panel recommendations. At **basic levels** of resource allocation, patient and family education should include discussions on breast cancer recurrence and second primary cancers and symptoms to report. Patient and family education should include discussions on persistent or late-effects of treatment (eg, lymphedema, fatigue, insomnia, pain), symptoms to report, and management strategies, including the appropriate use of complementary and alternative medicine. Women's health issues (early menopause, body image), and psychosocial problems (eg, depression, emotional distress, and changing roles at home and work), and lifestyle modifications (eg, diet and exercise), should be included. At **limited levels**, education should include the importance of follow-up scheduling, adherence to endocrine therapy, and sexual health issues. Patient and family education should be culturally appropriate; partners should be included, as appropriate.

Community awareness (Table 2, row 3)

Description. In LMICs, community education campaigns have successfully raised awareness of breast cancer and the importance of early detection [18]. Similar efforts are needed to educate communities about breast cancer supportive care programs, including survivorship programs [19]. Education of patients, families, and the community has been shown to address and minimize women's potential ambivalence in prioritizing their health, and their fears of diminished femininity and partner's rejection [20–22]. Breast cancer survivorship awareness/outreach should be a component of breast cancer supportive care programs, and should be socially and culturally sensitive [23]. Community advocates can help raise awareness of breast cancer survivorship issues. Programs used successfully to improve awareness of the importance of breast

cancer early detection could be adapted to breast cancer survivor awareness efforts. Partnerships with successful community-based public health awareness programs, such as those for HIV, could be considered.

3. Panel recommendations. At **basic levels** of resource allocation, breast cancer supportive care should include outreach to the community to increase awareness of breast cancer survivorship issues, by working with community advocates and advocacy organizations.

Psychosocial aspects of survivorship (Table 2, row 4)

Description. Psychosocial complications of survivorship are often not addressed, despite reports of depression and distress among breast cancer patients. In LMICs, reports of depressive symptoms among breast cancer patients range from 8 to 60% based on studies from Turkey and Greece [24–26], Korea [27], Portugal and Spain [28], Croatia [29], India [30], and the Czech Republic [31]. Reports from LMICs on anxiety disorders range from 12 to 60% [24–26,28,30]. Screening for and treatment of depression and anxiety may improve quality of life for breast cancer survivors [32]. Depression screening tools developed in HICs have been adapted for use in many LMICs, and include the Hospital Anxiety and Depression Scale (HADS) [25,27,33], the Beck Depression Inventory (BDI) [26,34], and a simplified depressed mood thermometer [28]. Several study outcomes in LMICs suggest that the process of screening for, and identification of depression can reveal associated psychosocial issues [26,29,34–36]. Social disruption, including changing roles at home and work, can lead to psychosocial complications. Treatment for psychosocial problems ranges from peer support to coordinated therapy by psychiatrist or psychologists.

4. Panel recommendations. At **basic levels** of resource allocation, health professionals should consider (through observation, dialogue, and other appropriate means) psychosocial problems of breast cancer survivors, and refer patients to peer support by trained peer volunteers, as appropriate. Patient and family education regarding survivorship issues should be offered. At **limited levels**, psychosocial assessment, including assessment for depression, should be available, with referrals for emotional and social support as indicated. At **enhanced levels**, patients should be screened for depression and psychological distress by mental health specialists and referred for psychosocial counseling as appropriate. Pharmacotherapy for depression and distress, based on available research and clinical practice guidelines (CPGs), should be available. Social services, including employment, financial, and legal counseling, should be available. At **maximal levels**, coordinated mental health care by a psychiatrist, psychologist, or social workers could be considered.

Survivorship issues (Table 3)

Long-term treatment-related complications (Table 3, row 1)

Description. Long-term treatment-related physical/clinical complications include lymphedema, fatigue, insomnia, and pain. Managing lymphedema and shoulder morbidity can be a major concern for breast cancer survivors in LMICs. Patients should be encouraged to self-report upper extremity limb changes. Monitoring for lymphedema can be done using basic circumferential measurements of limb girth (www.armvolume.com) [37], and bioelectric impedance devices [38]. More advanced monitoring strategies, such as perometers, can add sensitivity to limb girth measurement and promote early identification of limb asymmetry [39]. Patient and family education should include teaching simple shoulder movement exercises, and how to incorporate these exercises into daily activities. Limb compression supplies, such as non-custom sleeves [39] or stretch tubing, are often available and may be helpful in controlling lymphedema, whereas physical therapy (PT) or occupational therapy (OT), including the more

intense lymphedema treatment of complex-decongestive therapy (CDT), will require significant expertise to provide. Early introduction of lymphedema therapy, including arm exercises and lymphatic massage, has been associated with a lower incidence of lymphedema, compared to controls [40]. Resistance exercise may reduce symptom exacerbations in survivors with lymphedema [41]. A study in Australia found that women who are informed and knowledgeable about lymphedema risk and management were more likely to adhere to recommended patient-directed lymphedema prevention and management strategies [42]. Patient education should also include self-management for other late-effects of treatment, including fatigue, insomnia and pain. (See the BHGI companion consensus statement, *Supportive Care during Treatment* [8], which covers fatigue, insomnia and pain complications during treatment [8]).

5. Panel recommendations. At **basic levels** of resource allocation, patient and family education about symptom management should be provided. Antibiotics should be available for treating cellulitis or lymphangitis. Basic lymphedema supplies (eg, non-custom sleeves or stretch tubing) should be available to ensure that patients can participate in at-home lymphedema care. At **limited levels**, physical therapy (PT) and occupational therapy (OT), including complete-decongestive therapy (CDT) for lymphedema management should be available. Continued support for symptoms of fatigue, insomnia, and pain should be provided [8]. At **enhanced levels**, custom compression garments should be available. Coordinated care by oncology-trained personnel, such as nursing staff, should be available. At **maximal levels**, pneumatic pumps and perometers (infrared measuring device) could be considered.

Women's health issues (Table 3, row 2)

Description. Breast cancer survivors have unique women's health issues with regards to early menopause, body image, and sexual health. Early menopausal symptoms can be a major long-term treatment effect in LMICs where the majority of women receiving chemotherapy are premenopausal. Health professionals should be able to predict a patient's risk of developing early menopause, based on factors such as patient age, and the type and duration of treatments received; health professionals and patients should be able to recognize symptoms of early menopause [43–45]. Interventions for managing menopausal symptoms include non-hormonal topical treatments for vaginal dryness and behavioral strategies for managing hot flashes. These efforts are especially important for breast cancer care in low-resource settings. Health professionals in LMICs should be aware of sociocultural factors that can influence a woman's knowledge and understanding of menopause [46]. A LMIC study concluded that premenopausal women with breast cancer received insufficient counseling on contraception, early menopause, infertility, fertility preservation, and sexuality [47]. Several studies in HICs have reported that premenopausal women receive insufficient counseling on those issues, despite their interest in receiving such information [47–49]. Clinical assessments and tailored intervention programs for menopausal symptom management have been demonstrated, in HICs, to reduce symptom burden and improve sexual functioning [50]. (See the companion BHGI consensus statement, *Supportive Care during Treatment* [8], for recommendations and discussion on fertility).

Declines in sexual satisfaction and/or the frequency of intercourse have been reported in LMICs after breast cancer treatment [51–53]. Efforts are ongoing to identify the best educational interventions for sexual health [54]. Studies in LMICs have reported women's distress regarding body (breast) changes [51,52,55]. Concerns about body image include feelings of being mutilated, leading to feelings of self-consciousness; reduced satisfaction with sexual life after treatment; and fears of partner rejection [52]. Body

image problems can occur with both mastectomy and breast-conserving therapy [51,52]. A study of South Asian breast cancer survivors in Canada identified body image as an important psychosocial issue when wearing ethnic outfits that outlined the female figure [56]. Health professionals in all settings need to include culturally appropriate information on sexual health in patient-centered interactions with breast cancer survivors, with companion information for sexual partners. “Sexual health” is defined by the World Health Organization (WHO) as “a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity” [57].

6. Panel recommendations. At **basic levels** of resource allocation, patient and family education on women’s health issues (eg, early menopause and body image) should be available. At **limited levels**, treatment of menopausal symptoms with behavioral strategies (eg, efforts to modify or reduce core body temperature) and topical agents (eg, non-hormonal vaginal moisturizers) is recommended. Patient and partner education on sexual health should be available. At **enhanced levels**, pharmacotherapy to manage menopausal symptoms should be available, and could include antidepressants and complementary therapies; these should be administered based on clinical practice guidelines and available research. Breast reconstruction for asymmetry to address body image concerns should be provided, as needed. Bone-modifying agents (eg, bisphosphonates) should be available for women who may be at increased risk for osteopenia and osteoporosis due to premature menopause. At **maximal levels**, clinical assessment and tailored interventions to reduce menopausal symptoms and improve sexual function could be considered.

Lifestyle modifications (Table 3, row 3)

Description. Observational studies in HICs suggest that women who are physically active [58] and maintain a normal weight [59] have lower risk for breast-cancer-specific death and for death from any cause. Guidelines for optimal lifestyles for cancer survivors in HICs, on topics such as physical activity [60] and nutrition [61], can be adapted to LMIC settings. They should be tailored to meet the physical limitations and comorbid conditions of an individual patient, and should be socially, culturally and economically appropriate. For example, strategies to modify ethnically specific foods and make incremental changes in diet should be encouraged. Strategies for optimal nutrition to avoid obesity and weight gain include diets low in fat and refined sugars, and high in fiber, vegetables and fruits. A randomized controlled trial (RCT) of 2437 women with breast cancer found that a low-fat diet reduced risk for recurrence or second primary breast cancer by 24% over a mean 60 months of follow-up [62], whereas another RCT that focused on fruits and vegetables found no effect [63]. A systematic review found that physical activity is associated with reduced breast-cancer-specific and all-cause mortality [58]. Resistive exercise may reduce symptoms of lymphedema [41]. RCTs have shown that short-term structured aerobic exercise programs may improve quality of life in breast cancer survivors [60]. Recommended physical activity (eg, 150 min/week of moderate-to-vigorous physical activity, and resistance exercise at least twice a week) can be modified to accommodate community and cultural habits, and conducted independent of the health care system (eg, at home, with relatives or friends, or in the community). General lifestyle recommendations for breast cancer survivors should follow general healthy living advice associated with chronic disease prevention, as breast cancer survivors are susceptible to chronic diseases (eg, cardiovascular disease), and often die from them. Disease prevention aspects of care should not be ignored due to a history of cancer [64].

7. Panel recommendations. At **basic levels** of resource allocation, patient education should include the associations between lifestyle

factors and breast health, and the importance of nutrition and exercise. At **limited levels**, counseling on the importance of weight management (overweight, underweight) and regular exercise on most days of the week should be offered. At **enhanced levels**, formal exercise programs and individualized education or counseling by a dietitian should be offered. At **maximal levels**, specific weight management programs could be offered.

Monitoring (Table 3, row 4)

Description. Follow-up care of patients after completion of initial treatment is needed to monitor for possible recurrences, long-term side effects of treatments [12], and development of second primary malignancies (eg, breast, cervical, ovarian, and colon) [65], and to optimize overall physical and emotional health [65,66]. Follow-up frequency and intensity should reflect underlying patient risk factors [12,66]. Intervals between visits, length of follow-up period, providers responsible for follow-up, and investigations performed at each follow-up visit should be based on individual patient profiles [67]. However, the expert panel agreed that a review of systems and physical examination would likely detect the majority of recurrences; routine blood and radiologic studies are not recommended, as they have not been proven to have an impact on survival. Monitoring and follow-up care should be patient-specific [67], and provide patients with information about those responsible for their post-treatment care [68]. Women with ER-positive breast cancer should be monitored for adherence to endocrine therapy, because side effects (vaginal discharge, arthralgia and hot flashes) may cause women to stop using the medication, in the absence of reinforcement and/or non-hormonal supportive care interventions [69].

8. Panel recommendations. At **basic levels** of resource allocation, monitoring for cancer recurrence or second primary cancers with review of systems and physical examination should be part of follow-up care. At **limited levels**, monitoring for adherence to endocrine therapy should be provided. At **maximal levels**, genetic counseling and screening for high-risk cancers should be considered.

Documentation (Table 3, row 5)

Description. Breast cancer care is multidisciplinary and thus requires the use of shared patient care records. As survivors transition from oncology-focused care to primary care or community-based care, a detailed diagnosis and treatment summary should follow the patient, and include primary tumor biology, stage of disease, and sequence of given treatments. Recent literature reviews found that many primary care providers did not receive adequate documentation regarding a patient’s diagnosis and treatment when the patient transitioned to their care [70,71]. Both physicians [72] and patients [56,73,74] in HICs have identified treatment summaries as helpful and preferred information resources [68]. Simple patient care documentation strategies include hospital discharge reports or outpatient treatment summaries. More advanced documentation can include treatment summaries and survivorship plans.

9. Panel recommendations. At **basic levels** of resource allocation, health professionals should provide well-documented patient care records that can follow a patient as they transition from active treatment to follow-up care. At **limited levels**, treatment summaries should be provided to patients to share with their providers. At **enhanced levels**, survivorship plans could be considered.

Special concerns and emerging issues in LMICs

Fear of cancer – patient’s own risk assessment

Studies in LMICs have documented breast cancer patients’ fears and concerns about how the diagnosis of breast cancer, as well as

breast cancer treatments, may impact their lives [20,75]. Breast cancer patients taking endocrine therapy may have fear of recurrence related to extended treatment protocols, though others may feel protected by extended adjuvant therapy [76]. As more breast cancer patients in LMICs become survivors, fear of cancer recurrence may emerge as an area of concern, especially in younger survivors. Studies in HICs have documented breast cancer survivors' fear of cancer recurrence [77,78]. A systematic review found associations between fear of cancer recurrence and physical symptoms, treatment type, low optimism, family stressors, and fewer significant persons as support [79]. Other reviews found that younger breast cancer survivors are more likely to report fear of recurrence [79], and are more likely to experience more intense fears [48,80], as well as to report worries about health, social roles, womanhood, death and parenting [81]. More research is needed to determine the cutoff for clinically significant fear of recurrence [82].

Advanced documentation

Survivorship care plans are formal documents that include: scheduled follow-up visits; documentation of required investigations, such as yearly mammograms; and information about who will be responsible for these aspects of post-treatment care [68]. Based on recommendations from the Institute of Medicine (IOM) [5], survivorship plans are being evaluated as a tool to help patients and providers communicate and track follow-up care and concerns. Two studies provide models for how survivorship care plans can be adapted for LMICs, including plans to help manage late-effects of treatment and promote healthy living [68], and to define patient preference for content and format of survivorship care plans based on patient demographics [73]. A review article provides details on implementing treatment summaries as part of survivorship plans [68]. Templates of treatment summaries are available on the ASCO website (www.asco.org), and have been adapted for electronic use by Journey Forward (www.journeyforward.org). Finding a brief and concise format for survivorship plans is needed for implementation in low-resource settings.

Advanced lymphedema care

In cases where more pronounced functional loss or pain associated with lymphedema requires additional rehabilitation medicine expertise or care coordination, consultation with a physiatrist can be helpful to assist with medical management of lymphedema (as well as other physical or cognitive impairments), and provides an interdisciplinary approach to coordination of care. Pneumatic compression pumps, recommended only at a maximal level of resource allocation, are relatively expensive and may not be effective when used as an isolated treatment [83]. More research is needed regarding advance treatments; other advance treatments include laser therapy [84], kinesiotaping [85], and liposuction [86].

Cardiotoxicity

Adjuvant chemotherapy and/or radiation therapy, as well as HER2/*neu* targeted therapies, may cause late cardiotoxicity (eg, cardiomyopathy, coronary ischemia, thromboembolism, arrhythmias and conduction abnormalities, and valvular and pericardial disease) in up to 33% of patients [87]. Pre-existing cardiovascular conditions may compound adverse effects of cardiotoxic treatments. There are no current guidelines to address ongoing cardiac surveillance for breast cancer patients, but it has been the subject of a recent review [87]. (See the companion BHGI consensus statement, *Supportive Care during Treatment* [8], which covers treatment-related toxicities.)

Sexual health

Health systems should acknowledge sexual health as a valid health indicator. Awareness of the incidence of sexual health issues, and the associated causes of sexual dysfunction, should be part of health professional education. Reports from LMICs of declines in sexual satisfaction and/or the frequency of intercourse range from 20% to 80% [51–53]. LMIC studies also indicate that low sexual desire and dyspareunia are common symptoms experienced by breast cancer patients [51,52,55]. Reasons for disturbed sexual function may include low self-esteem, hair loss, abrupt menopause, vaginal dryness, partner's difficulty understanding one's feelings, and body image problems [88–90]. Upper limb dysfunction (eg, as a result of lymphedema) may interfere with sexual functioning [91]. Discussions of sexual health may be taboo in some cultures [92]; however, it is important for health professionals to acknowledge and discuss a patient's sexual health concerns. Health professionals should be prepared to discuss: body changes after surgery; chemotherapy-induced menopausal changes and strategies to maintain vaginal health (eg, use of vaginal moisturizers and lubricants, pelvic floor exercises); and reduced sexual desire that may occur during treatment and the first year of recovery [93]. Psycho-educational interventions for sexual dysfunction include skill-based training (such as problem-solving), communication skills, counseling, hypnosis, and specific sex therapies delivered to individual patients, patients and their partners, and groups of patients [94]. Interventions shown to produce stronger effects tend to be couple-focused, and include treatment components that: 1) educate both partners about the woman's diagnosis and treatments; 2) promote couples' mutual coping and support processes; and 3) include specific sexual therapy techniques to address sexual and body image concerns [93].

Depression and distress screening

Screening for depression and emotional distress is a component of cancer care guidelines in HICs [95] and some LMICs [96,97]. (See the companion BHGI consensus statement, *Supportive Care during Treatment* [8], for more details.) The expert panel had mixed opinions regarding the resource allocation level for screening of depression, with final consensus that formal screening should be required at an enhanced level of resource allocation. For psychological distress, there does not seem to be conclusive evidence for the overall effectiveness of screening methods [98,99]. However, screening does seem to improve patient-provider communication, and can be a mechanism for prompting referrals to peer support or to mental health professionals. The panel did agree that consideration of depression and emotional distress (which can occur as part of patient-provider interactions and observations) should be part of routine supportive care at a basic level of resource allocation, and that it is an area that needs much improvement. For example, a report on Slovak breast cancer survivors identified psychosocial support as an urgent need in this LMIC [100]. A report from Spain concluded that follow-up care for breast cancer survivors should address emotional, psychological and/or social effects of treatment sequelae (eg, effects of lymphedema, early menopause, and infertility; fear of recurrence; and changes in family relationships and employment) [101].

Advanced psychosocial interventions

Interventions studied in HICs include educational/informational programs [102], bio-behavioral programs [103], problem-solving and behavioral activation [104], mindfulness [105], and supportive

expressive therapies [106]. Adjuvant pharmacotherapy may be useful for some patients.

Employment and work-related issues

Delays in returning to work are associated with more advanced disease at diagnosis, axillary lymph node involvement, and HER2/neu-positive tumors [107]; lack of support from employers [108]; and other medical, demographic and socioeconomic factors [109]. In HICs, 80% of breast cancer patients returned to work [109–111], although the rate was lower for some subpopulations, such as low-income Latina women in the USA [110]. Work-related issues in LMICs have not been well documented.

Alcohol and tobacco use

Studies on alcohol and tobacco use in HICs may not be directly translatable to LMICs. Alcohol use in HICs is associated with both increased risk of primary breast cancer [112] and risk of recurrence in postmenopausal women [113]; however, the association between alcohol use and breast cancer prognosis is unclear. Tobacco use is associated with several diseases for which breast cancer survivors are at increased risk, such as cardiovascular disease [114]; however, observational studies have not shown a consistent relationship between tobacco use and survival or recurrence [115].

Genetic testing

US Preventive Task Force guidelines recommend genetic screening for women at high risk for familial breast cancer syndrome [12,44]. In addition to the financial burden of testing, identifying women in LMICs with a genetic predisposition for breast cancer may carry cultural and social stigmas. The panel recommended genetic counseling at maximal levels of resource allocation. However, this does not negate its importance for breast cancer survivors who have a family history of early onset breast and/or ovarian cancer, or for those diagnosed at a very young age without a strong family history. Genetic counseling can provide opportunities for these women to reduce risks of second cancers. For example, survivors who test positive for *BRCA1/2* may wish to receive risk-reducing surgery (prophylactic mastectomy, bilateral salpingo-oophorectomy). Family members may also benefit by receiving heightened breast cancer surveillance, chemoprevention, or risk-reducing surgery. Although genetic testing to identify cancer risk may elevate some patients' or families' fears, consideration of cultural and social acceptance of genetic testing and inheritable traits is important as it helps inform future health decisions.

Discussion

The most effective way to expand survivorship care in LMICs is through the involvement of primary care networks and community-based programs. We hope that by having shared tools, such as this consensus statement and the resource-stratified tables, breast cancer health professionals can engage in a global conversation and encourage efforts to implement and improve supportive care programs in LMICs for breast cancer survivors.

Recommendations included in this consensus report are part of the continuum of care that begins with diagnosis, and continues throughout the remainder of a woman's life. Survivorship care is intended to maximize health and well-being, while using tailored strategies to monitor for recurrence and late-effects of treatments. Many women will have an uneventful recovery from their treatments, while others may experience serious physical or psychosocial sequelae. Health professionals and others must be prepared

to educate women and their families about the most common issues they are likely to experience, and to address each woman's specific problems, in order to enhance recovery, improve functioning, and maximize adherence to recommended treatments.

Panelists

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Conflict of interest statement

BOA received consulting compensation from GE Healthcare and Navidea Biopharmaceuticals; EDA received Consulting/Speaking compensation from Pertong Roche; JRG received grant/research support from Amgen, Genentech, Novartis, and Roche. All other authors and panel members reported no conflict of interest.

Acknowledgements

BHGI received (2012 Global Summit) grants and contributions from Fred Hutchinson Cancer Research Center, Susan G Komen for the Cure® (Contract ID: INT-3063.0/Tracking No: 221664), International Atomic Energy Agency Programme of Action for Cancer Therapy, National Cancer Institute, The Lancet Oncology, Elsevier, American Society of Clinical Oncology, Sheikh Mohammed Hussein Al-Amoudi Center of Excellence in Breast Cancer, Pan American Health Organization, European Society of Medical Oncology, European School of Oncology, Open Society Foundations, LIVE-STRONG, and an unrestricted educational grant from Sanofi.

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