

**BREAST  
CANCER  
INITIATIVE 2.5**  
Making breast health a global priority



**SURVIVORSHIP CARE**

# Survivorship Care after Curative Treatment for Breast Cancer

Knowledge Summary



## INTRODUCTION

Breast cancer survivors are patients who have entered the posttreatment phase after the successful completion of breast cancer therapy with curative intent; longer-term endocrine therapy and/or targeted therapy may continue during survivorship care. Globally, breast cancer survival rates are increasing, creating a new generation of survivors in need of ongoing care and counseling. Evidence suggests that a significant number of people with a cancer diagnosis have unmet informational, psychosocial and physical needs which can be effectively addressed through survivorship care interventions.

Survivorship care services include treatment of long-term complications, surveillance for cancer recurrence, and counseling on prevention strategies, such as lifestyle modifications. Other issues include early menopause, body image concerns, sexual health and psychosocial issues related to breast cancer and its treatment. Long-term treatment-related complications include lymphedema and other upper limb dysfunctions, pain, fatigue, insomnia and bone health concerns. Increased risk of cardiovascular complications occurs with some cancer treatments [see Table 1].

Common challenges associated with survivorship care include fragmentation of services when a patient transitions from active oncology treatment to posttreatment follow up care. Breast cancer survivors can have unique treatment-related complications, including lymphedema (tissue swelling caused by the build-up of excess lymph fluid) and reproductive health, body image and sexual health concerns. Delivering high-quality survivorship and supportive care can enhance patients' long-term health by managing concerns related to cancer treatment and survivorship. It is essential that health professionals be able to recognize, diagnose and treat long-term complications of breast cancer treatment, including psychosocial issues that require intervention or referral for support services. In low-resource settings, the challenges for survivors can be significant: recurrence rates are higher, treatment modalities cause greater morbidity and the psychosocial effects of cancer and its treatment can be profound. Return to daily work and family life can be complicated and cancer survivors deserve informed, quality health care during this transition.

## KEY SUMMARY

### Breast Cancer Survivors

- Patients who receive curative treatment for early stage breast cancer should have their needs assessed with appropriate follow up care after treatment [often referred to as survivorship care].
- Breast cancer survivors make up a growing percentage of breast cancer patients in low- and middle-income countries [LMICs]. In high-income countries [HICs], almost 90% of all women diagnosed with breast cancer are alive 5 years

after diagnosis.

- Breast cancer treatment is a long-term process and women who complete treatment remain at risk of recurrence, long-term treatment-related toxicities and long-term psychosocial issues related to breast cancer and its treatment.

### Core components of survivorship care after curative treatment

- Essential components of follow up care for breast cancer patients after curative treatment include monitoring for breast cancer recurrence, managing long-term treatment-related complications and providing psychosocial care specific to survivor issues.
- Well established referral systems, communication and coordination of care are essential to help patients transition from oncology care to follow up care.
- Information about survivorship support should be included in awareness and education programs for health professionals, patients, families and caregivers.
- Treatments can affect reproductive health and other women's health issues. The psychosocial impact of treatment should be anticipated and addressed.

### Health system and workforce capacity

- A survivorship care team should ideally consist of physicians, nurses, social workers, psychologists, spiritual counselors, volunteers, traditional healers and religious leaders, with close communication and links to pharmacists. If palliative care is provided by community volunteers or family members, training should be provided.
- Ensure health care providers are properly trained in the assessment and management of long-term treatment-related toxicities and long-term psychosocial aspects of care for breast cancer survivors, including the use of culturally sensitive patient-provider communications.
- Engage survivors and community representatives to ensure health care providers are trained in culturally sensitive patient-clinician communication skills that focus on patient-centered care.
- Emphasize the advantages of survivorship services after treatment, in addition to information about detection and diagnosis of breast cancer and available treatments, in community awareness and patient and family education programs.

### Resource-stratified pathways across the continuum of care

- Follow a defined resource-stratified pathway to allow for coordinated incremental program improvement across the continuum of care based on outcome goals, identified barriers and needs and available resources.



## POINTS FOR POLICYMAKERS:

### OVERVIEW

#### Preplanning

- Identify data sources for estimating survivorship needs.
- Identify stakeholders, key decision-makers and champions.
- Identify who will lead in strengthening the survivorship care program.

#### Planning Step 1: Where are we now?

##### *Investigate and assess*

- Conduct a self-assessment using standardized tools. Toolkits are available to assess and support survivorship care program development.
- Identify structural, sociocultural, personal and financial barriers to accessing survivorship care.
- Assessments should determine who is providing services (e.g., family members, community volunteers, health workers), as well as the population covered by existing services.
- Identify deficiencies in supportive care services, such as access to pain medication [e.g., <http://www.who.int/cancer/palliative/painladder/en/>].

#### Planning Step 2: Where do we want to be?

##### *Set objectives and priorities*

- Ensure women have access to survivorship support care and services.
- Train health professionals in survivorship care.
- Establish clear protocols for routine surveillance for recurrence or second primary breast cancer for survivors, as well as counseling services for psychosocial issues.
- Improve awareness among health systems, communities and patients and their families regarding the supportive care needs of breast cancer patients after curative treatment.

#### Planning Step 3: How do we get there?

##### *Implement and evaluate*

- Establish a resource-stratified approach to survivorship care for breast cancer survivors as part of long-term breast cancer program planning. Some of the required resources for survivorship care (e.g., monitoring, patient education) may already exist or can be implemented at low cost.
- Implement quality assurance measures and monitor and track supportive care services.

## WHAT WE KNOW

**Lymphedema:** Lymphedema is a long-term risk of breast cancer surgery, with different levels of severity associated with different types of surgical procedures [i.e., axillary lymph node dissection versus sentinel node biopsy]. The frequency of lymphedema after axillary node dissection can range from 10–50%. This condition can significantly reduce a woman's quality of life and the management of lymphedema is an essential component of follow up care. Tracking the incidence of lymphedema and its level of severity can help inform quality improvement of breast cancer treatment. Free online assessment tools are available, and more-advanced tools can be purchased. The effects of lymphedema can be minimized through patient education and training in limb exercises, range of motion activities, weight lifting, use of compression garments and effective weight management. Patient counseling should include instruction on incorrect or unsafe exercises that can exacerbate lymphedema. Short-term pharmacologic therapies may relieve some lymphedema-related symptoms, but long-term pharmacologic therapies [e.g., anticoagulants, diuretics, antibiotics] are not known to reduce the onset or progression of lymphedema. Patients and health professionals should be advised to avoid injury to or constriction of the affected limb [e.g., advised about the appropriate placement of intravenous catheters and blood pressure cuffs]. The primary treatment of lymphedema, initiated at early onset, includes compression garments, complete decongestive therapy, surgical therapy and manual lymphatic drainage [often done with the assistance of physical and occupational therapists], based on available resources [see Table 1]. Other upper limb dysfunction includes decreased shoulder range of motion and pain. Limited shoulder range of motion after surgery affects at least two-thirds of breast cancer patients. Management includes early intervention with exercise [see Table 1].

**Postmastectomy pain syndrome:** Postmastectomy pain syndrome [PMPS] is a chronic neuropathic disorder caused by direct nerve injury or the formation of a traumatic neuroma either during or after breast surgery, possibly exacerbated by local radiation treatments and neurotoxic chemotherapies. Symptoms commonly include pain and tingling in the chest wall, axilla and arm. It varies in severity and may affect about 20–30% of all women following breast surgery. It is called PMPS because it was first described in mastectomy patients, but it may occur after lumpectomy or other breast surgical procedures as well. Treatment options are limited but include pharmacotherapy, regional nerve blocks and alternative therapies. Antiepileptic and antidepressant medications may be more effective than opioid analgesics; opioids may not be effective against neuropathic or phantom pain.

**Menopausal symptoms:** Symptoms such as vasomotor symptoms and vaginal dryness can significantly affect long-term quality of life. Chemotherapy can cause menopausal symptoms in premenopausal women and hormonal therapy can cause menopausal symptoms in all women, regardless of menopausal status. Women in all resource settings have reported that they received inadequate counseling on menopausal symptoms, contraception, sexuality and fertility

preservation. Women also report treatment-related distress regarding body changes, including a sense of mutilation, feelings of self-consciousness, reduced satisfaction with sexual life and fears of partner rejection. Twenty years after treatment, almost 30% of women reported sexual problems. Health professionals should be trained in women's health topics and culturally appropriate provider-patient communication strategies. Breast cancer care requires a discussion of sensitive women's health topics, including menopausal symptoms, and health professionals should be aware of sociocultural differences in a woman's understanding of these issues, as well as her potential preference for female health professionals. Patient counseling should be part of supportive care services at all resource levels [see Table 1].

**Other complications:** Fatigue, insomnia and nonspecific pain are often reported by breast cancer survivors after treatment. Deficits in emotional, cognitive and social functioning have also been reported up to one year after treatment and may persist over years in some patients. Therefore, care for breast cancer survivors should include monitoring for these long-term treatment-related health and quality of life complications.

**Psychosocial aspects of care:** Breast cancer patients commonly report emotional distress, which can develop into both psychological and physical health complaints. Fear of recurrence has been associated with physical and psychological symptoms. Women may have difficulty reentering the workplace or reintegrating into their family and community after breast cancer treatment. Breast cancer survivors may have psychosocial concerns related to reproductive issues or sexual health that need to be addressed. Family stressors and a low level of optimism are more likely to occur if a woman has a small or minimal social support system or if policies are not in place to protect employment.

**Bone health:** Aging, menopause and some systemic therapies, such as antiestrogen treatments and chemotherapy are associated with an increased risk of bone loss and possibly fractures. Pathologic fractures are associated with a recurrence of breast cancer. Interventions to promote bone health include calcium and vitamin D supplementation and patient education on lifestyle modifications [e.g., reduced consumption of alcohol, tobacco cessation and increase in exercise]. In high-resource settings, bisphosphonates or monoclonal antibodies can be used to increase bone density. If resources for prophylactic treatment for bone health in high-risk women are available, baseline screening of bone density should be provided. The WHO Fracture Assessment Tool can be used to assess a patient's osteoporotic fracture risk, with or without bone mineral density measurements.

**Sexual health:** Sexual health issues can contribute to psychological distress. Breast cancer survivors can experience a significant decline in sexual satisfaction, dyspareunia [difficult or painful sexual intercourse] and low sexual desire related to low self-esteem, hair loss, menopausal symptoms, difficulty with a partner's understanding and body image concerns. Discussion of sexual health may be a difficult topic to introduce in some





settings; however, health professionals must consider this part of their medical professional duty and establish a culturally appropriate method to acknowledge and consider sexual health concerns. Sexual health interventions should include partners, if appropriate, to increase understanding of the complications associated with a breast cancer diagnosis and treatment and to promote mutual coping and provide a shared understanding of strategies to address sexual and body image concerns. As more resources become available, specialists in sexual health should be available to provide counseling and couple-focused therapy [see Table 1].

**Cardiovascular health:** Cardiovascular health should be assessed and closely monitored, particularly in high-risk patients. Some patients may develop long-term cardiovascular complications related to the type of treatment received. For example, cardiotoxicity can be a side effect of adjuvant chemotherapy (e.g., anthracyclines, such as doxorubicin or epirubicin), targeted therapy (e.g., trastuzumab), or radiation therapy. Preexisting cardiovascular conditions may compound the adverse effects of breast cancer treatments. There are no guidelines to address cardiac status after treatment; however, health systems should provide an assessment of cardiovascular health during follow up visits.

**Lifestyle modifications:** Certain strategies may reduce breast cancer recurrence and improve overall health. Breast cancer survivors are at increased risk of developing contra-

lateral breast cancer, other cancers or other chronic diseases. Survivorship care should include cancer prevention and chronic disease prevention interventions. Women who remain physically active and are able to maintain a normal weight have lower risks of breast cancer-specific death and death from any cause. General lifestyle recommendations for breast cancer survivors are the same as for general healthy living. Physical activity provides an overall improvement in health status and may be associated with a decrease in breast cancer recurrence. Women should be counseled to avoid alcohol consumption, a recognized risk factor for breast cancer [see Table 1].

**Risk of recurrence:** Risk of breast cancer recurrence varies by disease stage as well as the extent of surgery and whether or not radiation and systemic therapy was provided. Recurrences can occur locally (in the breast or chest wall), regionally (in the lymph nodes in the chest region) or at distant sites (bones, liver, lung, brain, skin and other sites). Locoregional recurrence can be managed with potentially curative surgical resection (with or without radiation) or additional systemic therapy. Routine laboratory evaluations and radiologic studies other than mammography (e.g., liver function tests, serum tumor markers, chest or abdominopelvic imaging, serum alkaline phosphatase and PET scan) are not recommended because they have not been shown to have an impact on survival. Breast cancer quality controls should include data on breast cancer recurrence rates.



## WHAT WORKS

**Coordination of care:** The goal of breast cancer survivorship care is to prioritize effective communication and coordination of care as well as cost-conscious care, across the continuum of care without fragmentation, recognizing the interplay between cancer survivorship, surveillance, psychosocial factors, long-term treatment-related toxicities and comorbid conditions. This can be facilitated by shared transition or survivorship plans. Importantly, specific training in breast cancer survivorship should be provided at the primary care level [see Table 2]. Where specific services for survivorship care are not available, the most effective venue for introducing these services is through primary care networks and other community-based programs or survivor support groups. Monitoring for long-term treatment-related complications should be part of routine follow up care for breast cancer patients.

**Health professional education and training:** Most breast cancer patients transition back to primary care after curative treatment; however, the continuation of specific breast cancer care is still required. Patients should be monitored by health care providers for cancer recurrence, second primary cancers and long-term treatment-related toxicities, including lymphedema, fatigue, pain, early menopausal symptoms, sexual health issues and psychosocial issues. Health care providers should be trained to advise patients about lifestyle behaviors that could reduce the risk of breast cancer recurrence and

improve overall quality of life, such as weight management, exercise, and avoidance of alcohol consumption. Health literacy and cultural sensitivity are important concepts that should be integrated into all provider training and health services, as well as communication skills to aid in discussion of sensitive topics [see Table 2].

**Recurrence monitoring protocols:** Protocols for monitoring breast cancer recurrence should be part of routine follow up care. Protocols should include the type of follow up [e.g., review of systems, frequency of follow up] and the provider with whom to follow up [e.g., primary care provider or oncology specialist]. The American Society of Clinical Oncology recommends a follow up schedule of every 3-6 months for the first three years after primary therapy, then every 6-12 months for the next two years, and then annually. All breast cancer patients are at risk for locoregional recurrence, development of distant disease or second primary malignancies. Routine monitoring should include a review of systems, physical exams, and surveillance mammography [if available]; non-routine tests should be performed as indicated by a patient's clinical history and available resources. A comprehensive physical exam should include: breast, chest wall and regional lymph node examination, musculoskeletal evaluation for range of motion and lymphedema, cardiopulmonary examination, abdominal exam, neurologic examination and a gynecologic exam. A review of symptoms should check for symptoms of metastatic disease as well as



long-term treatment-related toxicities [e.g., cognitive function, weight status and bone health]. If a patient has been prescribed endocrine therapy, side effects should be monitored and the importance of adherence should be discussed with the patient. Women who have had reconstructive surgery should be monitored by physical exam. Mammography can be considered but has limited utility with breast prostheses. Breast MRI does not have a known benefit and should not be performed in the absence of a clear indication [see Table 1].

**Documentation protocols:** Coordination of care for breast cancer survivors includes transitioning patients from oncology care to primary care; therefore, it is important that an accurate and complete patient history is available. The primary care provider and patient must be fully informed of the detailed diagnosis [e.g., primary tumor biology, stage of disease, tumor receptor status] and treatment history, including the type of treatments [e.g., surgery, systemic therapy, radiotherapy and symptom management during treatment] and the sequence of treatments. A patient's risk of recurrence and treatment-related complications should be assessed. Introducing a survivorship care plan can help standardize care, reduce duplication of care and ensure follow up care is comprehensive. Survivorship plans should identify the clinician responsibility for specific aspects of posttreatment care and the recommended frequency of follow up visits. Survivorship plans should be updated to include new test results and patient concerns. Examples of treatment summaries are available online [e.g., [www.asco.org](http://www.asco.org) and [www.journeyforward.org](http://www.journeyforward.org)].

**Patient and family education:** Effective communication between health professionals and patients and their families establishes the framework for optimal care. Health education should be integrated throughout care, patients must be counseled and involved in the planning of their transition of care and interventions must be designed to improve breast cancer survivor outcomes. Breast cancer survivors need to understand the signs and symptoms of breast cancer recurrence or metastases to be active participants in their own care. Active participation can improve adherence to follow up visits and recommended ongoing treatments. Effective patient-clinician communication can help identify long-term treatment-related side-effects, such as fatigue, insomnia, pain and psychosocial issues. Informational interventions can be conveyed through direct patient-clinician discussions or counseling, printed material, videos or online website content [see Table 2].

**Survivor support groups:** Breast cancer survivors are a valuable resource and essential partners and advocates in promoting awareness about breast cancer survivorship. Providers can play a role by engaging with breast cancer support groups and informing patients about such groups. Survivor groups can serve as a powerful source for emotional and physical support. Peer guidance from survivors can convey hope and address

quality of life issues. In addition, increased visibility of survivors in society can help change beliefs about cancer survivorship and encourage women with breast health concerns to seek care [see Table 2].

**Psychosocial support:** Psychosocial support should be provided within the health system through effective patient-clinician communication and referrals to community services. Protocols for breast cancer follow up after curative treatment should include evaluation for and treatment of identified psychological distress and psychosocial issues [see Table 2]. Screening tools are available that can identify women at high risk for psychological distress, including depression and anxiety, and can be administered as part of routine follow up visits or by mental health specialists, if available [see Table 2]. As more resources become available, professional psychosocial services [involving psychiatrists, psychologists and social workers] should be provided to assist breast cancer survivors with psychological distress, sexual health and other psychosocial concerns.

**Pain control after curative treatment:** Breast cancer patients can experience nonspecific or specific pain after curative treatment. Pain assessment should be part of routine follow up care. Inadequate pain control can contribute to psychological distress and should be viewed as a priority. The WHO Cancer Pain Ladder [[www.who.int/cancer/palliative/painladder/en/](http://www.who.int/cancer/palliative/painladder/en/)] should be used as a reference tool. Access to pain medications is considered a global health priority.

**Genetic testing:** Patients who have a strong family history of breast cancer and/or are diagnosed at a young age may be candidates for genetic testing, if available. It is estimated that approximately 5% of breast cancer patients carry a mutation known to be associated with an increased risk of breast cancer. Women with *BRCA1* or *BRCA2* gene mutations may be eligible for prophylactic surgery [breast and/or ovarian]. Counseling for high-risk survivors with a strong family history of breast cancer and women with a known *BRCA1* or *BRCA2* mutation should be provided in the absence of genetic testing to help reduce risks of second cancers. Prevention strategies for concerned family members with known high-risk genetic mutations include surveillance, chemoprevention and prophylactic surgery.

**Employment rights:** For many employed breast cancer patients, returning to work improves quality of life and physical and mental health. Delays in returning to work have been associated with a lack of support from employers, more advanced disease at diagnosis or other medical or socioeconomic factors. Health systems should partner with community social services, support groups and employers to help protect employment rights and facilitate the return to work for breast cancer patients who desire to do so.

## PLANNING STEP 1: WHERE ARE WE NOW?

### *Investigate and assess*

#### **Assess number of patients in need of breast cancer care after curative treatment**

- Examine data on breast cancer incidence and stage of disease at presentation to help estimate the number of patients who will likely need supportive care after curative treatment.

#### **Assess the existing survivorship services**

- Identify and review existing protocols for survivorship care and coordination of care. Review where supportive care services are being provided and who is providing them. Many applicable basic services are likely in place within a health system, including the ability to monitor for cancer recurrence and the treatment of long-term complications, even if a specific survivorship program does not exist.
- Consider the appropriate cultural and social context of the target population. Engage survivors in understanding the social and cultural norms and the types of psychosocial and sexual health interventions needed.
- Assess health care services that may currently exist within the health system for the management of common treatment-related toxicities.
- Include family and other caregivers in survivorship care planning. Educational and support services should be available to caregivers.
- Assessments should determine who is providing services (e.g., family members, community volunteers, health workers) as well as the population covered by existing services.
- Assessment tools have been developed to identify treatment-related physical and psychosocial complications. These tools can be used to improve patient-provider communication, strengthen referral systems and inform future health system supportive care expansion.

#### **Assess patient access and barriers to survivorship care**

- Identify structural, sociocultural, personal and financial barriers to accessing survivorship care.
- Structural barriers may include legislative barriers, a lack of protocols for survivorship care, a lack of coordination of care, especially during the transition from oncology to primary care, a lack of trained health professionals and a general lack of awareness of the continued need for care for breast cancer patients after curative treatment.
- Consider focus groups with patients to understand sociocultural barriers to accessing survivorship services.
- Assess outreach to rural or hard-to-reach communities and marginalized populations.
- Engage community leaders in program development to help ensure activities are implemented in a manner relevant to the community.

- Investigate workplace attitudes, policies and practices regarding health care and employment protection. Barriers to care may be more extreme in low-resource settings and associated with cultural or psychosocial aspects of care related women's health issues (including sexual health).

#### **Assess health system capacity**

- Coordination of care is crucial. Effective survivorship care requires the coordinated involvement of patients, their families, community support services and health providers and may require additional health professional training.
- Assessing and managing psychosocial complications during treatment may require targeted training of existing health professionals and partnering with community services.
- Assess current referral systems from treatment to survivorship care.

#### **Assess monitoring and evaluation capacity**

- Review monitoring of treatment-related complications as a routine part of breast cancer care, including monitoring for psychosocial complications, such as reproductive or sexual health issues; surgical complications, such as lymphedema; systemic therapy complications, such as musculoskeletal, gastrointestinal, nervous system, hematologic and skin and nail toxicities and pain management.
- Quality assurance programs should be in place to reduce treatment-related complications of surgical procedures, radiotherapy and systemic therapy.
- Assessment tools can assist health care providers in identifying treatment-related toxicities, surveillance strategies for recurrence and coordination of care between providers.

## PLANNING STEP 2: WHERE DO WE WANT TO BE?

### *Set objectives and priorities*

#### **Define target population and approach**

- Use available data on cancer incidence and demographic data to determine the services most needed for survivorship support.
- All patients receiving treatment for breast cancer are at risk for treatment-related toxicities and may have unmet needs, including pain management.
- Survivorship care requirements for long-term treatment-related complications will vary based on the type of treatment received. Health systems should match the type of care services provided to the available treatment options.
- Younger survivors may need to confront reproductive health issues, such as fertility. Body image and sexual health concerns may be long-term treatment-related complications for survivors that can be addressed through patient education and counseling.



### **Identify community and health system partnerships**

- Breast cancer survivors and advocates should be included as key contributors in supportive care planning and implementation. Advocacy groups can provide a range of support, from promotion of programs to direct provision of supportive services.
- Identify opportunities for engaging and educating primary care providers in components of survivorship care.

### **Identify gaps and barriers**

- Identify gaps in the health system to integrate and coordinate care for breast cancer patients after curative treatment, including routine follow up surveillance for cancer recurrence and for long-term treatment-related complications.
- Identify attitudes and misconceptions about cancer and survivorship care services and pain management. Barriers often include political, regulatory, medical and societal barriers, and thus require political support.
- Coordinate survivorship care services with other care services along a resource-stratified pathway to avoid deficits in essential supportive care services.

### **Set achievable objectives**

- Establishing clear protocols for routine surveillance of breast cancer recurrence or second primary breast cancers in survivors will help inform health professionals and patients about the health system's expectation for continued care for breast cancer patients.
- Managing long-term complications of breast cancer improves quality of life and provides hope to the community at large that women can recover from breast cancer and have a quality of life similar to their age-matched peers.
- Access to pain medication and management of psychosocial distress are ethical issues and should be considered health priorities for every health system.
- Educate health professionals through guideline development and continuing education programs.
- Raising the public profile of survivorship care can help inform populations about available services and promote it as an important community and health system priority.

### **Set priorities and establish feasibility of programs**

- Emphasize integration of services, expansion of existing services, surveillance for recurrence, long-term treatment-related complications and psychosocial distress.
- Reintegration of breast cancer patients into their family, community or workplace after curative treatment should be a priority for survivorship programs.
- Implement demonstration projects with measurable outcomes.
- Follow a resource-stratified approach for program development.

## **PLANNING STEP 3: HOW DO WE GET THERE?**

*Implement and evaluate*

### **Establish financial support and partnerships**

- An interdisciplinary and multisector approach can optimize the response to survivorship care needs in a community and should include support from health policymakers, patient advocates, community and spiritual leaders and health care providers.
- Partner with medical institutions to integrate training into existing programs.
- Advocacy groups can provide a range of support from promotion of programs to direct provision of supportive services. Breast cancer survivors and advocates should be included as key contributors to supportive care planning and implementation.
- Partnerships with employers and community social services can help breast cancer survivors reenter the workplace and community.

### **Implement and disseminate**

- Expand existing educational programs to include breast cancer survivorship care education.
- Include information about survivorship services for patients after treatment and expectations for quality of life in all breast cancer awareness interventions.
- Clarify and monitor the referral system for patients transitioning between providers and follow up.
- Actively engage, support and promote survivorship groups.

### **Monitor and evaluate**

- Monitor all breast cancer patients after curative treatment for recurrence and treatment-related complications, including lymphedema, reproductive or sexual health issues, psychological distress or psychosocial issues and pain management.
- Data on breast cancer recurrence and treatment-related complications should be collected to inform future program direction and breast cancer treatment quality control programs.

## CONCLUSION

Breast cancer patients who receive curative treatment can achieve a quality of life equivalent to their peers. Survivorship care is an integral aspect of successful cancer care. It must be patient/family oriented and consider culturally appropriate interventions. Coordination of care is a key issue as patients transition from oncology focused care to primary care. To ensure effective services, a health system must be able to coordinate care through standardization of protocols and a multidisciplinary team approach. Documentation of a patient's diagnosis, treatment history and comorbidities must be available, including patient risk for complications such as lymphedema. Patient-clinician communication must include consideration of psychosocial issues related to breast cancer treatment. Basic services should emphasize patient education, monitoring of recurrence and complications and clinical surveillance. When more health service resources become available, screening tools for psychological distress should be added, as well as referrals to mental health specialists. As health capacity increases, dietitians, physical therapists and occupational therapists should be included in clinical services. Successful survivorship care requires health system commitment to offer women who are emerging from one of life's greatest challenges the best services possible.

**Table 1. Resource allocations for breast cancer survivor care:**

	Basic	Limited	Enhanced	Maximal
Long-term treatment-related complications	Patient and family education <sup>a</sup> on long-term treatment (Tx) complications <sup>b</sup> Antibiotics for cellulitis or lymphangitis Basic lymphedema supplies	Physical therapy (PT), occupational therapy (OT), complete-decongestive therapy (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 issues <sup>c</sup>	Patient and family education: early menopause, body image	Patient and partner education: 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 <sup>a</sup> on diet and exercise	Weight management and daily exercise counseling	Exercise program Individualized education by dietitian	Weight management program
Monitoring	Monitor for breast cancer recurrence, second primary cancers Monitor for long-term complications	Monitor for endocrine medication adherence		Genetic testing and counseling Screening for high-risk cancers
Documentation	Patient care record (e.g., discharge summary)	Patient treatment summary	Survivorship care plan	

<sup>a</sup> Patient and family education may be the primary intervention for some supportive care services.

<sup>b</sup> Long-term treatment related complications include lymphedema, menopausal symptoms, reproductive health, sexual health fatigue, insomnia, non-specific pain, postmastectomy pain syndrome, bone health, psychosocial issues, cardio toxicities, etc. Pain management should follow the World Health Organization Pain Ladder recommendations.

<sup>c</sup> Women's health issues for breast cancer patients include menopause, body image, reproductive health, including fertility, and sexual health; educational efforts should include partners.

NOTE: The Basic, Limited, Enhanced and Maximal table stratification scheme implies incrementally increasing resource allocation; for example, if a resource is listed at a Basic level it is expected to be available also at Limited, Enhanced and Maximal levels.

Source: the 2013 BHGI consensus statements, "Supportive care after curative treatment for breast cancer" with permission from Elsevier.

**Table 2. Resource allocations for breast cancer survivor care: health professional education, patient education, community awareness and psychosocial aspects**

	Basic	Limited	Enhanced	Maximal
Health professional education <sup>a</sup>	Breast cancer recurrence, second primary cancer Long-term treatment complications <sup>c</sup> Women's health issues <sup>d</sup> Psychosocial [survivorship] consideration <sup>e</sup> Lifestyle modifications Health literacy, cultural literacy, communication skills	Psychosocial risk assessments Psychosocial complications of survivorship Sexual health	Psychosocial screening methods	
Patient education <sup>b</sup>	Breast cancer recurrence, or new cancers: symptoms to reports Long-term treatment complications <sup>c</sup> Appropriate use of CAM Women's health issues Psychosocial [survivorship] consideration <sup>d</sup> Lifestyle modifications	Follow up schedules Adherence to endocrine therapy Sexual health		
Community awareness	Community awareness of breast cancer survivorship issues			
Psychosocial aspects	Patient and family education [survivorship] Psychosocial [survivorship] consideration <sup>e</sup> Peer support by trained Breast cancer survivors	Psychosocial assessment, including depression Emotional and social support by health professionals	Screening and referrals for depression/distress by mental health specialist Psychosocial counseling by mental health specialist Availability of pharmacotherapy Social service counseling for financial, employment and legal issues	Psychiatrist-, psychologist-, or social-worker-coordinated mental health care

Abbreviations: **CAM**, complementary and alternative medicine.

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

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

<sup>c</sup> Long-term treatment related complications include lymphedema, menopausal symptoms, reproductive health, sexual health, fatigue, insomnia, nonspecific pain, postmastectomy pain syndrome, bone health, psychosocial issues, cardio toxicities, etc. Pain management should follow the World Health Organization Pain Ladder recommendations.

<sup>d</sup> Women's health issues for breast cancer patients include menopause, body image, reproductive health, including fertility and sexual health; educational efforts should include partners.

<sup>e</sup> 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.

NOTE: The Basic, Limited, Enhanced and Maximal table stratification scheme implies incrementally increasing resource allocation; for example, if a resource is listed at a Basic level it is expected to be available also at Limited, Enhanced and Maximal levels.

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