



# Optimisation of the continuum of supportive and palliative care for patients with breast cancer in low-income and middle-income countries: executive summary of the Breast Health Global Initiative, 2014

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Supportive care and palliative care are now recognised as critical components of global cancer control programmes. Many aspects of supportive and palliative care services are already available in some low-income and middle-income countries. Full integration of supportive and palliative care into breast cancer programmes requires a systematic, resource-stratified approach. The Breast Health Global Initiative convened three expert panels to develop resource allocation recommendations for supportive and palliative care programmes in low-income and middle-income countries. Each panel focused on a specific phase of breast cancer care: during treatment, after treatment with curative intent (survivorship), and after diagnosis with metastatic disease. The panel consensus statements were published in October, 2013. This Executive Summary combines the three panels' recommendations into a single comprehensive document covering breast cancer care from diagnosis through curative treatment into survivorship, and metastatic disease and end-of-life care. The recommendations cover physical symptom management, pain management, monitoring and documentation, psychosocial and spiritual aspects of care, health professional education, and patient, family, and caregiver education.

## Introduction

The Breast Health Global Initiative (BHGI) published three consensus statements in October, 2013 that focused on resource allocations for supportive and palliative care for patients with breast cancer in low-income and middle-income countries.<sup>1-3</sup> Combined, these consensus statements covered supportive and palliative care for breast cancer during treatment, after treatment for long-term complications, and for patients with metastatic disease. This set of expert consensus recommendations on supportive and palliative care supplements and completes the earlier published BHGI resource-stratified recommendations for early detection, diagnosis, and treatment of patients with breast cancer in low-income and middle-income countries.<sup>4</sup> The resource-stratified recommendations for breast cancer provide a model for similar supportive and palliative care initiatives that address the management of other common treatable malignancies in low-income and middle-income countries.

At the same time that the BHGI's expert panels were developing the supportive and palliative care recommendations for breast cancer, WHO<sup>5,6</sup> and the US Institute of Medicine (IOM)<sup>7</sup> were reviewing and updating their recommendations on palliative care. Both WHO<sup>5,6</sup> and the IOM<sup>7</sup> expanded their definitions of palliative care to acknowledge the importance of early palliation and the need for supportive care services. However, neither group directly addressed supportive care during cancer treatments (for short-term or long-term complications). The BHGI consensus panel recommendations cover the often-overlooked topics of supportive care for treatment-related complications

(during treatment and after treatment with curative intent), palliative care that includes early palliation starting at diagnosis, and more traditional palliation associated with end-of-life care.

## Background and definitions

Much of the research and policy work in supportive and palliative care has been done under the broad umbrella of cancer care; however, many studies specific to breast cancer care are available. Both general and specific studies have informed the consensus panels' resource allocation recommendations.<sup>1-3</sup>

## Palliative care

WHO and the Worldwide Palliative Care Alliance (WPCA) estimate that, every year, 20 million people worldwide need palliative care (based on 1-year survival prognosis), and 80% of those in need live in low-income and middle-income countries.<sup>8</sup> The regional variations in the need for palliative care range from an estimated 19·6% in African regions to 41·5% in western Pacific regions.<sup>8</sup> WHO and WPCA further estimate that another 20 million people are in need of early palliation.<sup>8</sup> The American Cancer Society and the Center to Advance Palliative Care published a position statement that palliative care is "appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment".<sup>9</sup> The WHO and WPCA report provides clarification on their understandings of palliative care: it applies to chronic, life-threatening, and life-limiting disorders; it should be available early in, and throughout, the course of the illness; and it can be provided in a wide

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	During treatment: treatment-related complications	After treatment: long-term complications	Site-specific metastatic disease complications
<b>Basic (level 1)</b>			
Analgesics, co-analgesics	..	..	Bone (co-analgesics), brain, liver, skin
Antibiotics	Haematological, infections (broad spectrum)	Long-term complications (cellulitis or lymphangitis)	Skin (broad spectrum)
Anticholinergics	..	..	Bowel obstruction
Anticonvulsants	..	..	Seizures, pain
Antidiarrhoeal drugs	Chemotherapy-induced diarrhoea	..	
Antiemetics	Chemotherapy-induced nausea and vomiting	..	Chemotherapy-induced nausea and vomiting, bowel obstruction, brain, liver
Antihistamines	..	..	..
Antipsychotics	..	..	..
Anxiolytics	..	..	..
Charcoal (activated)	..	..	Skin
Laxatives (non-stimulating)	Constipation	..	Constipation
Metronidazole	..	..	Fungating skin lesions
Morphine (oral and parenteral) and other opioids	Musculoskeletal, nervous system, non-specific pain	..	Pain, dyspnoea
NSAIDs	..	..	Pain (especially bone)
Non-morphine pain medicines*	Musculoskeletal, nervous system, non-specific pain	Pain management*	..
Opioids for breathlessness	..	..	Lung
Pain management (basic)*	(See panel)	(See panel)	(See panel)
Steroids	..	..	Bowel obstruction, bone, brain, liver, lung
Stool softeners	Constipation	..	Constipation
Topical agents	Nervous system (peripheral neuropathy support)	..	..
<b>Limited (level 2)</b>			
5HT <sub>3</sub> blockers	Gastrointestinal	..	..
Antacids	Gastrointestinal	..	..
Antifungals	Haematological, Infection	..	..
Anxiety medicines	Gastrointestinal	..	..
DMSO	Skin	..	..
H <sub>2</sub> antagonists	Gastrointestinal	..	..
Mucositis topical agents	Gastrointestinal	..	..
Non-morphine opioids	..	..	Bowel obstruction
Other pain medicines*	Musculoskeletal, nervous system, pain management	..	..
Silver nitrate	..	..	Skin
Stimulant laxatives	Gastrointestinal	..	..
Topical agents	Skin (steroid or zinc-containing creams)	Women's health (menopausal symptoms)	..
<b>Enhanced (level 3)</b>			
Anesthetics for nerve blockage	Nervous system	..	..
Antidepressants	Psychosocial†	..	..

(Table 1 continues on next page)

range of settings such as a patient's home, care facility, hospital inpatient unit, or outpatient care service.<sup>8</sup> The IOM report outlines key palliative care goals “to prevent and relieve suffering and to improve quality of life for people facing complex illness”.<sup>7</sup> According to WHO, “many of the services and interventions for providing palliative care are already within the reach of countries, including those in low-income and middle-income range.”<sup>6</sup>

### Supportive care

As the understanding of the scope of palliative care expands beyond end-of-life care, the definition of supportive care might become less clear. Many organisations struggle to define and differentiate supportive care and palliative care.<sup>10</sup> A systematic review of the literature noted that published definitions of palliative care and supportive care both addressed symptom control and quality of life, and both were applicable in the early stages of disease.<sup>11</sup> Supportive care was most often used for patients in active treatment, including cancer survivors, and less often included interdisciplinary care; palliative care was more likely to include interdisciplinary care, volunteer support, and bereavement counselling.<sup>11</sup>

For the aim of the BHGI resource-stratified recommendations, supportive care includes the assessment and management of short-term and long-term treatment-related complications. As such, supportive care is the logical companion of palliative care; palliative care focuses on disease-related complications, including site-specific metastatic disease complications. Short-term treatment complications include the toxic side-effects of chemotherapy and radiation therapy, and complications of surgery and endocrine therapy. Long-term treatment complications include lymphoedema, fatigue, and non-specific pain, and might also include long-term organ-specific toxicities (eg, cardiotoxicity), dependent on the specific chemotherapy regimen given. For survivors of breast cancer, supportive care is often overlooked, but is a crucial component of quality cancer care. A study of patients with breast cancer noted that 51% of patients reported unmet medical care needs, and 88% reported at least one medical symptom 5 months to 5 years after treatment.<sup>12</sup> As more treatment options (both curative intent and life-prolonging) become available for patients with breast cancer, the need for supportive care services will continue to increase.

WHO's resolution, “Strengthening of palliative care as a component of integrated treatment throughout the life course”,<sup>5</sup> passed unanimously and affirms that palliative care improves quality of life for patients with cancer (including patients with breast cancer) and their families, and reduces use of health-care systems, including treatment in hospitals. WHO's earlier resolution emphasised the need for interdisciplinary care and the need for both palliative care providers and

supportive care providers within a community.<sup>6</sup> The resolution noted that “the delivery of quality palliative care is most likely to be realized where strong networks exist between professional palliative care providers, support care providers (including spiritual support and counselling, as needed), volunteers and affected families, as well as between the community and acute and aged [elder] care providers.”<sup>6</sup> Together, supportive care and palliative care services, irrespective of how each is defined by a particular health system or organisation, are important components of breast cancer programmes, in all countries, including in low-income and middle-income countries. Both supportive and palliative care require appropriate resource allocations, and consideration of the cultural context of the population served.

### Survivorship care

In the 2013 consensus statement resource-stratified recommendations, breast cancer survivors were defined as patients who had entered the post-treatment phase after 6 months of curative treatment (ie, surgery, chemotherapy, and radiation therapy).<sup>2</sup> This definition might differ from other research or policy uses of the term survivor, including the timeframe used by WHO in discussion of palliation (ie, 1-year survival prognosis), and the widely used 5 year survival statistic. This treatment-centred definition allowed BHGI panel members to focus on three distinct phases of clinical breast cancer care: during treatment, after treatment with curative intent, and metastatic disease.

### Pain management

According to WHO, more than 5 million patients with cancer every year have moderate-to-severe pain due to insufficient access to pain medicines.<sup>13</sup> Breast cancer pain includes treatment-related pain (eg, post-surgery pain and lymphoedema pain), non-specific pain related to long-term complications, and site-specific metastatic-disease-related pain (eg, bone pain and bowel obstruction).<sup>1-3</sup> In low-income and middle-income countries, pain management is affected by low morphine consumption compared with high-income countries. For example, morphine consumption in Canada was reported to be 87·46 mg per person-year, compared with 0·0032 mg per person-year in Nigeria.<sup>13</sup> Lack of availability and appropriate use of internationally controlled substances for relief of pain continues to be a difficulty in many low-income and middle-income countries.<sup>5</sup> Although formularies in most regions now conform to the WHO recommendations, overregulation of morphine distribution still restricts access.<sup>14,15</sup> The BHGI consensus panels regard breast cancer pain management to be a special concern in low-income and middle-income countries because of regulatory and health system limitations on access to opioids (eg, absence of infrastructure, resources, or coordination of care).

	During treatment: treatment-related complications	After treatment: long-term complications	Site-specific metastatic disease complications
(Continued from previous page)			
Bone-modifying agents	Musculoskeletal	Women's health	Bone
Calcium alginate	..	..	Skin
Fentanyl patch	..	..	End-of-life pain management*
Growth factors; granulocyte growth factors	Haematological	..	..
Iron therapy	Haematological	..	..
NK-1 antagonists	Gastrointestinal	..	..
Opioid pumps	..	..	End-of-life pain management*
Methadone	..	..	End-of-life pain management*
Other non-morphine opioids	Musculoskeletal	..	..
Opioid analgesics	Gastrointestinal (mucositis support)	..	..
PPIs	Gastrointestinal	..	..
Pharmacotherapy†	Psychosocial (depression)	Women's health (menopausal symptoms), psychosocial (depression or distress)	Psychosocial (antidepressants)
Radioisotopes	..	..	Bone

Adapted with permission from the 2013 BHGI consensus statements supportive care during treatment for breast cancer,<sup>2</sup> supportive care after curative treatment for breast cancer (survivorship care),<sup>2</sup> and supportive and palliative care for metastatic breast cancer.<sup>3</sup> The basic, limited, and enhanced 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 and enhanced levels. Maximal level resource allocations are not presented in this table. \*Pain management should follow the WHO pain ladder recommendations; see panel for detailed pain recommendations. †Pharmacotherapy for menopausal symptoms should follow clinical practice guidelines based on available resources. ..=potentially applicable during other phases of care for patients with appropriate medical indications. DMSO=dimethyl sulfoxide. 5HT<sub>3</sub> blockers=5-hydroxytryptamine blockers. NSAIDs=non-steroidal anti-inflammatory drugs. NK-1=neurokinin-1. PPIs=proton pump inhibitors.

**Table 1: Checklist of supportive and palliative care drugs for physical symptom management of patients with breast cancer at basic, limited, and enhanced levels of resource allocations**

### Psychosocial and spiritual aspects of care

Patients with breast cancer often have unmet psychosocial and spiritual needs. These needs might differ on the basis of a patient's cancer prognosis and phase of care (during treatment, after curative treatment, after diagnosis of advanced disease, or at end-of-life).<sup>16</sup> Psychosocial and spiritual needs might also differ on the basis of cultural and community norms. All resource allocations should be developed and implemented with consideration of the cultural context of the target population.<sup>1-3</sup>

Incorporation of psychosocial and spiritual components of care into routine cancer care delivery needs an interdisciplinary approach, and can be challenging if training, guidelines, and reimbursement strategies are not well established.<sup>7</sup> Particular psychosocial issues associated with breast cancer include depression, anxiety, and concerns about social stigma, body image, or changes in social roles.<sup>1-3</sup> Studies suggest that spirituality can have a role in helping women cope with breast cancer in low-income and middle-income countries.<sup>17-20</sup>

	During treatment: treatment-related complications	After treatment: long-term complications	Site-specific metastatic disease complications
<b>Basic (level 1)</b>			
Anxiety symptom management	Gastrointestinal	..	..
Basic physical activity (eg, aerobic, ROM)	Musculoskeletal	..	..
Basic lymphoedema supplies	..	Long-term treatment complications (lymphoedema)	..
Mucositis support (eg, ice chips)	Gastrointestinal	..	..
Nasogastric tube	..	..	Bowel obstruction
Oral and intravenous hydration and electrolyte replacement	Gastrointestinal	..	..
Oxygen therapy for hypoxic patients	..	..	Lung
Patient and family education*	(See table 6)	(See table 6)	(See table 6)
Simple dressings and skin barriers	..	..	Skin
Thoracentesis	..	..	Lung
Assessment instruments†	Gastrointestinal (consideration of parasitic and bacterial infection)	..	Skin (wound and skin assessment), bone (spinal cord compression and fractures)
<b>Limited (level 2)</b>			
Behaviour strategies (simple)	..	Women's health (menopausal symptoms)	..
Counselling	Gastrointestinal (dietitian), haematological (infectious disease for febrile neutropenia), skin (coordinated patient care)	Lifestyle modification (weight management and daily exercise)	..
Coordinated patient care	Skin	..	..
Fatigue, insomnia management	..	Long-term complications	..
Menopausal symptom management	Women's health (management of menopausal symptoms)	Women's health (simple behavioural strategies)	..
Pain management (non-drug therapies)	..	Long-term complications	..
Patient and family education*	(See table 6)	(See table 6)	(See table 6)
Platelet transfusion	Haematological	..	..
Pleurodesis, thoracotomy, VATS	..	..	Lung
Physical therapy, occupational therapy	Musculoskeletal physical therapy (lymphoedema, shoulder mobility, pain), nervous system (functional limitations)	Long-term treatment complications (lymphoedema): physical therapy, occupational therapy, and complete-decongestive therapy	Pain management (physical therapy and occupational therapy; functional limitations and pain)
Radiotherapy	..	..	Bone, brain (whole brain), lung, skin, end-of-life pain management
Red blood cell transfusion	Haematological	..	..

(Table 2 continues on next page)

**Resource allocations for supportive and palliative care**

Previous BHGI consensus recommendations focused on early detection, diagnosis, and treatment of early-stage and advanced-stage breast cancer in low-income and middle-income countries,<sup>4</sup> but they did not directly address supportive care and palliative care. The 2013 BHGI consensus recommendations now fill this gap. This overview combines recommendations from the three BHGI expert panels: the During Treatment Panel, the Survivorship Panel, and the Metastatic Disease Panel. Recommendations were stratified into four resource levels: basic (level 1), limited (level 2), enhanced (level 3), and maximal (level 4) health system resources. Basic resources are fundamental services that are absolutely necessary for any breast health-care system to function; basic-level services are usually applied in a one-off clinical interaction.<sup>1</sup> Limited resources are attainable with restricted financial means and modest infrastructure. Enhanced resources “are optional but important”, and improve options and outcomes.<sup>1</sup> The maximal resource allocations are lower-priority, higher-cost options, and are generally not recommended in low or limited resource settings.<sup>1</sup>

This resource stratification approach recognises that within any one country, whether classified by the World Bank as low, lower-middle, middle, or high income, or by WHO as low, medium, or high, variations in the resources available to local breast cancer control programmes are likely. The BHGI resource-stratified framework was developed to allow policy makers to see a resource-stratified pathway for breast cancer care that can start at a basic level of resources across the continuum of care (early detection, diagnosis, treatment, and palliative care) and move along the pathway (from basic to limited and from limited to enhanced) in unison, as resources become available. Policy makers are encouraged to develop their own breast cancer control pathway that is informed by best practice guidelines, consensus statements, and research relevant to their populations, with consideration of the cultural context of their service population.

**Development of consensus statements**

Translation of guidelines and research into practice is challenging,<sup>21</sup> and translation of resource-neutral research and guidelines developed in high-income countries to low-resource settings provides an additional challenge. Research in low-income countries and middle-income countries is increasing, as shown by the 5222 citations in the BHGI-INCTR Library Catalogue for Breast Cancer Control.<sup>22</sup> However, systematic reviews and meta-analyses are often not available or only include high-income country studies.<sup>2</sup> When high-level evidence is not available, consensus expert opinion or judgment can help inform policy and practice until such evidence becomes available. Consensus statements rely on available evidence and the consensus of identified

experts. Each of the three panels identified by BHGI included at least 12 subject-matter experts, chosen for their expertise in breast cancer disease management and their experience and knowledge of supportive and palliative care practices in high-income countries and low-income and middle-income countries. The panels were co-chaired by an expert from a high-income country and an expert from a low-income and middle-income country. The 3 day open-session panel deliberations were attended by 129 experts and advocates, from 41 countries.

### Consensus panel recommendations for resource allocations: addressing the continuum of care

Health system supportive and palliative care resources should be available to manage short-term treatment-related side-effects (during treatment), long-term treatment-related side-effects (after treatment with curative intent), and metastatic disease. The three consensus panels each focused on resource allocations for their assigned phase of care, while at the same time recognising that breast cancer care is a continuum that includes breast health awareness, diagnosis, treatment, and palliative care components. The panels identified common resource allocation categories across the continuum of care that, if provided, could help avoid fragmentation of care. This Review combines these three panels' recommendations with the common categories identified: physical symptom management (medicines, procedures, patient interventions, and specialty services), pain management, monitoring and documentation, psychosocial and spiritual aspects of care, health professional education, and patient and family education. The Metastatic Disease Panel also identified care models for palliative care resource allocations.

#### Physical symptom management

##### *During treatment*

The During Treatment Panel concluded that health system resources for supportive care should be available to manage treatment-related toxicities (eg, musculoskeletal, gastrointestinal, skin, nervous system, and haematological toxicities), surgical complications (eg, surgical pain and lymphoedema), and women's health complications (eg, early menopausal symptoms).<sup>1</sup> Recommendations for physical symptom management include resources allocations for medicines (table 1), procedures, patient interventions, and specialty services (table 2). A key recommendation was that health professionals should know, before recommending a treatment plan, what supportive care resources are available. The During Treatment Panel concluded, "During treatment planning, the availability of resources to manage the toxic effects of chemotherapy and radiotherapy, and/or manage the complications of surgery and endocrine therapy, must be considered. When resources to manage side-effects are unavailable or limited, effective chemotherapy with less

	During treatment: treatment-related complications	After treatment: long-term complications	Site-specific metastatic disease complications
(Continued from previous page)			
Surgery	Skin (debridement surgery)	..	Bone (spinal cord compression, fracture, and obstruction), skin (debridement)
Assessment instruments†	..	..	Bone (routine assessment for spinal cord compression and fractures)
<b>Enhanced (level 3)</b>			
Air mattress, egg crate mattress	..	..	Skin
Biliary stents	..	..	Liver
Central line access or management	Skin	..	..
Consultation	Gastrointestinal (individualised or dietitian), skin (dermatology), nervous system (neurologist for pain and cognitive issues)	Lifestyle modification (exercise programme and dietitian consultation)	..
Coordinated patient care	..	Long-term complications (oncology-trained personnel and nursing staff)	..
Custom compression garments	..	Long-term complications (lymphoedema)	..
Embolisation	..	..	Liver
More sophisticated dressing material	..	..	Skin
Percutaneous drainage	..	..	Liver
Radiotherapy	..	..	Brain (stereotactic)
Stoma or wound therapy	..	..	Skin
Surgery	..	Breast reconstruction for asymmetry	Brain
Venting gastric tube	..	..	Bowel obstruction
Assessments†	Bone assessment for at-risk patients	..	..

Adapted with permission from the 2013 BHGI consensus statements, supportive care during treatment for breast cancer;<sup>2</sup> supportive care after curative treatment for breast cancer (survivorship care);<sup>3</sup> and supportive and palliative care for metastatic breast cancer.<sup>4</sup> The basic, limited, and enhanced 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 and enhanced levels. Maximal level resource allocations are not presented in this table. \*Patient and family education is often a primary patient service need in low-income and middle-income countries (table 6). †Several assessments were identified by panels as needing additional health system resources beyond routine patient monitoring (table 3). ROM=range of motion. VATS=video-assisted thoracic surgery. ..=potentially applicable during other phases of care for patients with appropriate medical indications.

**Table 2: Checklist of procedures, patient interventions, and specialty services for supportive and palliative care physical symptom management of patients with breast cancer at basic, limited, and enhanced levels of resource allocations**

severe toxicities should be the treatment recommendation."<sup>1</sup> This patient-centred approach to care is endorsed by the IOM<sup>7</sup> and WHO<sup>5</sup> as a health system goal.

##### *After treatment with curative intent (survivorship)*

The Survivorship Panel identified the management of physical long-term treatment complications as a crucial component of breast cancer care. This treatment often



includes management of musculoskeletal complications (eg, lymphoedema), women's health issues (eg, early menopausal symptoms), and symptoms of fatigue, insomnia, and non-specific pain.<sup>2</sup> Recommendations for physical symptom management include resource allocations for medicines (table 1) and procedures, patient interventions, and specialty services (table 2). The panel identified patient education on lifestyle modifications (to reduce cancer risk and improve quality of life) as part of supportive care for breast cancer survivors. To support the continuum of care, patient care plans and survivorship care plans should include details of a patient's treatment protocol so that potential, specific treatment-related complications, including organ-specific toxicities, are considered.

#### Metastatic disease

The Metastatic Disease Panel identified resource allocations for the management of site-specific metastases or complications (eg, bone, bowel, brain, liver, lung, and skin).<sup>3</sup> Recommendations for physical symptom management include resources allocations for medicines (table 1) and procedures, patient interventions, and specialty services (table 2). For example, health system resources should be available to manage complications of metastatic disease (eg, bowel obstruction), provide procedures to relieve complications of advanced disease (eg, thoracentesis), and ensure appropriate use of specialty equipment or supplies (eg, wound dressings).

#### Panel: Pain management for patients with breast cancer at basic, limited, enhanced, and maximal levels of resource allocations

##### Basic (level 1)

Pain consideration (simple assessment)  
Pain drugs, including morphine (basic)  
Management of pain-related physical symptoms  
Surgical pain management  
Complementary and alternative medicine and non-drug pain management

##### Limited (level 2)

Other pain drugs  
Radiotherapy (single and multifraction)  
Physical therapy and occupational therapy for functional limitations or pain management

##### Enhanced (level 3)

Pain screening  
Pain care plan  
Opioid pumps, methadone, and fentanyl patch  
Consultation with specialist in pain therapy  
Surgery (cord compression, fracture, and obstruction)

##### Maximal (level 4)

Locoregional anaesthesia, spinal analgesia

Pain management should follow the WHO pain ladder recommendations. Adapted with permission from the 2013 BHGI consensus statement, supportive and palliative care for metastatic breast cancer.<sup>2</sup> 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.

#### Pain management

Pain management was identified as a crucial component of breast cancer care by all three panels. The Metastatic Disease Panel addressed the general principles of pain management; each panel considered pain management issues specific to their topic area, such as treatment-related (including surgical) pain, lymphoedema, non-specific pain after treatment, or pain related to disease advancement. General pain recommendations include resource allocations for pain assessment and reassessment and appropriate pain therapy based on the level and type of pain (panel). The panels referred to existing guidelines relevant to breast cancer pain management, including the European Society for Medical Oncology (ESMO) clinical practice guideline,<sup>23</sup> National Comprehensive Cancer Network (NCCN) adult pain guidelines,<sup>24</sup> WHO pain ladder,<sup>25</sup> and the International Association for the Study of Pain (IASP) Guide to Pain Management in Low-resource Settings.<sup>26</sup> The Metastatic Disease Panel identified simple, effective assessment methods such as the Numeric Rating Scale, the Visual Analogue Scale, and the Verbal Descriptor Scale.<sup>3</sup> Pain assessment instruments have been successfully adapted to low-income and middle-income country settings.<sup>27–30</sup>

#### Monitoring and documentation

All three panels noted the need for resource allocation for monitoring and documentation. The During Treatment Panel identified monitoring for treatment-related toxicities as an essential resource, with additional monitoring, such as blood chemistry, liver and renal function, and cardiovascular assessment, as appropriate for the type of treatment offered. The Survivorship Panel identified monitoring for cancer recurrence or second primary cancers as part of routine follow-up care after treatment. The Metastatic Disease Panel identified confirmation testing for patients with symptoms that suggest disease metastases. All three panels agreed that resources to ensure documentation should be available from the time of diagnosis, and documentation should include a patient care record that can be shared with the patient's care team. As more sophisticated patient monitoring systems become available, treatment summaries, survivorship plans, and advance care planning should be available (table 3).

#### Psychosocial and spiritual wellbeing

Psychosocial and spiritual aspects of breast cancer care are often overlooked. Psychosocial care includes identification of patients in need of psychosocial support and referring patients to available community or specialty services. Assessment (and reassessment) of a patient's psychosocial needs should be part of routine patient–clinician communications.<sup>6</sup> Assessment strategies at a basic level of resources (level 1) might include consideration, a term used in table 4 to refer to

	During treatment	After curative treatment	Metastatic disease
Basic (level 1)	Physical exam, complete blood count, potassium and sodium, urea, bilirubin and transaminase, and chest radiograph when needed, urinalysis, and microbiology; check for early lymphoedema, nausea and vomiting, constipation and diarrhoea, fatigue and insomnia, and pain	Monitor for breast cancer recurrence and second primary cancers; monitor for long-term treatment complications; documentation: patient care record (eg, discharge summary)	Confirmation tests for metastasis in symptomatic patients
Limited (level 2)	Other blood chemistry and liver function tests; renal function assessment; non-imaging cardiovascular assessment	Monitor for endocrine medication adherence; documentation: patient treatment summary	..
Enhanced (level 3)	Extensive laboratory support and bone density tests	Documentation: survivorship care plan	..
Maximal (level 4)	..	Genetic testing and counselling; screening for high-risk cancers	..

Adapted with permission from the 2013 BHGI consensus statements, supportive care during treatment for breast cancer;<sup>1</sup> supportive care after curative treatment for breast cancer (survivorship care);<sup>2</sup> and supportive and palliative care for metastatic breast cancer.<sup>3</sup> 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.

**Table 3: Monitoring and documentation for patients with breast cancer during treatment, after curative treatment, and for metastatic disease at basic, limited, enhanced, and maximal levels of resource allocations**

	During treatment	After curative treatment	Metastatic disease
Basic (level 1)	Patient and family education (treatment-related); psychosocial consideration*; peer support by trained volunteers; spiritual consideration*; spiritual support: community-based	Patient and family education (survivorship); psychosocial consideration*; peer support by trained breast cancer survivors	Patient, family, and caregiver education; psychosocial (end-of-life) consideration*; psychosocial support: community-based; bereavement support: community-based; spiritual consideration*; spiritual support: community-based
Limited (level 2)	Psychosocial assessment, including depression; patient and family support groups; psychosocial support by health professionals	Psychosocial assessments, including depression; emotional and social support by health professionals	Patient, family, and caregiver education; emotional and spiritual aspects of death and dying; advanced care planning
Enhanced (level 3)	Screening and referrals for depression and distress by mental health specialist; psychosocial counselling by mental health specialist; prescription drugs for depression	Screening and referral for depression and distress by mental health specialist; psychosocial counselling by mental health specialist; availability of pharmacotherapy; social service counselling for financial, employment, and legal issues	Screening and referrals for depression and distress by mental health specialist; psychosocial counselling by mental health specialist; antidepressants; social services for financial, legal, and family matters; clinic-associated or hospital-associated spiritual support; hospital or hospice spiritual reflection and meditation space
Maximal (level 4)	Psychiatrist-coordinated, psychologist-coordinated, or social-worker-coordinated mental health care	Psychiatrist-coordinated, psychologist-coordinated, or social-worker-coordinated mental health care	Psychiatrist-coordinated, psychologist-coordinated, or social-worker-coordinated mental health care

Adapted with permission from the 2013 BHGI consensus statements, supportive care during treatment for breast cancer;<sup>1</sup> supportive care after curative treatment for breast cancer (survivorship care);<sup>2</sup> and supportive and palliative care for metastatic breast cancer.<sup>3</sup> 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.

\*Consideration is a term used in this table to refer to basic patient assessment through patient-provider interactions, including dialogue, observations, and other appropriate means of assessment.

**Table 4: Psychosocial and spiritual aspects of breast cancer care during treatment, after curative treatment and for metastatic disease at basic, limited, enhanced, and maximal levels of resource allocations**

basic patient assessment through patient-provider interactions, including dialogue, observations, and other appropriate means of assessment. Table 4 provides a guide to development of these aspects of psychosocial and spiritual care in a stepwise fashion, beginning with patient education and community resources at a basic level of resource allocation, and moving to an enhanced level of services that includes social workers and mental health professional counselling, formal assessments, and prescription drugs for depression. Psychosocial issues might vary during different phases of breast

cancer. For example, during treatment, patients with breast cancer might experience emotional distress related to their changing roles at home and work, whereas patients diagnosed with metastatic disease might struggle with fears of death and dying and related spiritual issues (table 4). The form of psychosocial support will vary on the basis of available resources, expertise, and sociocultural practices; for example, peer support can be offered at a basic level, whereas at an enhanced level, the goal would be to offer formal counselling by a mental health professional.

	During treatment	After curative treatment	Metastatic disease
Basic (level 1)	Appropriate use of clinical practice guidelines; women's health issues; psychosocial consideration*; spiritual consideration*; health literacy, cultural literacy, and communication skills	Breast cancer recurrence and second primary cancers; long-term treatment complications; women's health; psychosocial (survivorship) consideration*; lifestyle modifications	Appropriate use of clinical practice guidelines; awareness of complementary and alternative medicine used by patients; palliative care pain assessment and management; side-effects of pain drugs; skin complications; psychosocial (end-of-life); spiritual (end-of-life); health and cultural literacy; communication skills
Limited (level 2)	Women's health issues (sexual health); psychosocial effect of breast cancer/treatment (individual and community)	Psychosocial risk assessments; psychosocial complications of survivorship; sexual health	Appropriate referral to specialists; pain syndromes and referral strategies; emotional and spiritual aspects of death and dying
Enhanced (level 3)	Psychosocial screening methods	Psychosocial screening methods	Palliative care training for nursing staff; in-service palliative care updates

Adapted with permission from Elsevier from the 2013 BHGI consensus statements, supportive care during treatment for breast cancer;<sup>1</sup> supportive care after curative treatment for breast cancer (survivorship care);<sup>2</sup> and supportive and palliative care for metastatic breast cancer.<sup>3</sup>The basic, limited, and enhanced 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. \*Consideration is a term used in this table to refer to basic patient assessment through patient-provider interactions, including dialogue, observations, and other appropriate means of assessment.

**Table 5: Health professional education for breast cancer care during treatment, after curative treatment, and for metastatic disease at basic, limited, and enhanced levels of resource allocations**

	During treatment	After curative treatment	Metastatic disease
Basic (level 1)	Treatment-related toxicities and other treatment side-effects; fatigue, insomnia; reproductive health, fertility and body image; psychosocial issues; spiritual issues	Breast cancer recurrence or new cancers: symptoms to report; long-term treatment complications; appropriate use of complementary and alternative medicine; women's health issues; psychosocial issues (survivorship); lifestyle modifications; community awareness of survivorship issues	Late-disease risks, complications of advanced disease, and palliative care treatment; pain self-management; skin care; psychosocial issues (end-of-life); spiritual issues (end-of-life)
Limited (level 2)	Sexual health; psychosocial effect of breast cancer and treatment	Follow-up schedules; adherence to endocrine therapy; sexual health	Emotional and spiritual aspects of death and dying; advanced care planning

Adapted with permission from the 2013 BHGI consensus statements, supportive care during treatment for breast cancer;<sup>1</sup> supportive care after curative treatment for breast cancer (survivorship care);<sup>2</sup> and supportive and palliative care for metastatic breast cancer.<sup>3</sup>The basic, limited, and enhanced 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.

**Table 6: Patient and family breast cancer education during treatment, after curative treatment, and for metastatic disease at basic and limited levels of resource allocations**

**Education**

*Health-professional education*

A properly trained health-care workforce with competency in supportive and palliative care is hugely needed in low-income and middle-income settings.<sup>6</sup> All three panels identified health-professional education in supportive and palliative care issues as a crucial, and usually underserved, need in low-income and middle-income countries. Health-professional education should include a clear understanding of available supportive care resources to manage treatment-related complications and how to triage a patient to the best available care based on a patient's diagnosis and prognosis, patient and family preferences, and available resources. Health-professional education and training should include evidence-based pain management strategies (including

pain assessment and reassessment, and effective pain treatment, including morphine administration) and strategies in psychosocial and spiritual assessment and referral (table 5). Training in communication skills and cultural sensitivity should also be provided.

*Patient education*

All three panels agreed that the goal of patient-centred breast cancer care requires that patients are well informed about their disorder and the resources are available to them to manage their disease in a culturally appropriate manner.

Patient and family education is a primary basic level intervention delivered through effective patient-provider communications.<sup>31,32</sup> The consensus panels identified patient education topics specific to each phase of care: during treatment, after treatment, and patients with



metastatic disease (table 6). Development of common educational communication strategies across the continuum of care can maximise the effectiveness of cancer education.<sup>31</sup>

During treatment, patients with breast cancer should understand how to recognise and report treatment-related toxicities, understand how treatments might affect reproductive health and body image, and be aware of psychosocial and spiritual issues that might arise during treatment. After treatment with curative intent, patient education should focus on persistent or late effects of treatment (eg, lymphoedema, fatigue, insomnia, and non-specific pain). Patients should know what symptoms to report to their health-care team and effective self-management strategies. For patients diagnosed with metastatic disease, patient education should focus on complications of advanced disease and available palliative care strategies and their benefits and risks (table 6).

#### Palliative care models

The BHGI consensus panel recommendations concur with the WPCA,<sup>8</sup> WHO,<sup>5,6</sup> and IOM<sup>7</sup> statements that there are several appropriate palliative care settings. The Metastatic Disease Panel recommended that when limited (level 2) resources are available, care models should begin with home-based care that includes community or family support. As more health-system resources become available, new care settings should be considered, such as outpatient and hospital-based care (table 7).

#### Discussion

International support for supportive and palliative care programmes, delivered in a culturally appropriate manner, continues to increase.<sup>5-9</sup> Clinical trials continue to show the benefit of early palliative care in the management of advanced cancer, including improved symptom control, quality of life, and survival.<sup>33-35</sup> Although palliative care programmes are still new to national health-care systems in low-income and middle-income countries, many countries are hard at work developing capacity and establishing localised and national programmes. The WHO and WPCA report<sup>8</sup> on global palliative care programme development, which reviewed 234 countries, reported that 8.6% of countries had advanced mainstream integration of palliative care programmes, 10.7% had preliminary mainstream integration, 7.3% had localised general programme development, 31.6% had localised isolated programme development, 10% were engaged in capacity building, and 32% of countries had no palliative care programme. Most BHGI Global Summit expert panel members and participants resided, or have practised in, countries engaged in palliative care programme development, adding practical experience to the evidence-based discussions. The BHGI resource-stratified recom-

Care models	
Basic (level 1)	Patient-centred decision-making; clinician communication with patient and family (eg, conferences); trained palliative care volunteers; home-based with community or family support; hospital-based with community or family support;
Limited (level 2)	Home-based with trained palliative care nursing support; hospital-based with trained palliative care nursing support; outpatient with trained health professional support; palliative care consulting services (referrals); multidisciplinary team approach*
Enhanced (level 3)	Home-based with clinic and hospital backup; outpatient clinics with trained palliative care physicians; inpatient palliative care unit; palliative care training centre; quality assurance system; interdisciplinary team approach*
Maximal (level 4)	Palliative care specialist services

Adapted with permission from the 2013 BHGI consensus statement, supportive and palliative care for metastatic breast cancer.<sup>3</sup> 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. \*Multidisciplinary team approach refers to a patient-care model that includes experts from different disciplines, whereas an interdisciplinary team approach requires a more integrated and coordinated approach to patient care, where experts from different disciplines establish shared patient-care goals.

**Table 7: Palliative care models for patients with breast cancer at basic, limited, enhanced, and maximal levels of resource allocations**

mendations include both supportive care and palliative care, and acknowledge that these two crucial cancer-care components might overlap and are often overlooked during health-system resource allocations.

Choice of the categories for the groupings of health-care resource allocations was not perfect. For example, in the individual consensus statements, women's health issues was called out as a separate category, whereas in this combined presentation, those specific women's health resources were placed within the broader categories of physical symptom management, psychosocial and spiritual aspects of care, health-professional education, and patient and family education. This method in no way suggests that women's health issues are not an important aspect of breast cancer care, but is simply an alternative way to classify resource allocations into broad groups. In the same way, lifestyle modification resource allocations, identified by the After Curative Treatment Panel and presented as a separate resource allocation category, were incorporated into the broad categories for this Review.

Our focus on clinically related topics did not allow us to address other important health-related supportive care and quality-of-life public health issues such as nutrition, sanitation, and safe living conditions. The need for these public health supportive services in low-resource settings might be a barrier to quality health care. Additionally, women's rights issues and social justice issues that might

### Search strategy and selection criteria

For the summit planning process and subsequent summit manuscript preparation we searched for articles published in English between Jan 1, 2001, and Dec 31, 2012, with the search term "supportive care and quality of life in low and middle-income countries". A larger BHGI library database created in 2010 was also available, called BHGI-INCTR Library Catalogue for Breast Cancer Control that contains 5222 citations related to breast cancer care in low-income and middle-income countries. A report that describes the database was published in 2011.<sup>21</sup> More than 44 guidelines related to supportive care, treatment related-complications, palliative care, and quality of life were reviewed. Each panel contributed additionally from their individual libraries.

To create this executive summary, we updated our search in PubMed, Web of Science, and Ovid for articles published in English between July 1, 2012, and May 30, 2014, with the major topic search terms "breast neoplasms", "breast health", "developing countries", "low and middle-income countries", and "international breast health" and with minor topic search terms "quality of life", "supportive care", "palliative care", "hospice care", "assisted living facilities", "survivorship", "survival", "survivors", "socioeconomic factors", "mortality", "women's health services", "diet therapy", "breast diseases", "side-effects", "adverse effects", "patient care", "end-of-life", "terminal care", "secondary cancer prevention", "post-treatment care", "psychological", "pain management", "pain relief", "rehabilitation", "cancer care", "cancer care facilities", "emotional support", and "secondary prevention".

restrict a woman in seeking care were not directly addressed. The consensus recommendations also did not address men with breast cancer. Male breast cancer cases make up less than 1% of the breast cancer case worldwide.<sup>36</sup>

Patient-centred care might be a difficult concept in some cultures where cultural norms, such as protection of an ill family member from news of poor prognosis, conflict with a patient's right to know and informed consent. In these situations, patient educational interventions need to be developed in a culturally sensitive manner.

The issue of competency checks related to educational efforts was not directly addressed during the panel discussions and is assumed to be part of any quality educational programme, whether for health professionals or patients. Additional resources might be needed to provide quality assurance for supportive and palliative care.

The resource-allocation table matrices provide a method for policy makers to use when assessing their breast cancer control resource needs. Identification of necessary resources based on clinical evidence and empirical findings is only one step in a complex, multifactorial process. Additional efforts are needed to address how resources should be accessed and how they

are best implemented in a local setting at the individual patient level. WHO recommends a general cancer control planning strategy that asks three questions: where are we now, where do we want to be, and how do we get there?<sup>37</sup> The WHO palliative care resolution deliberations presented a call to action for health providers: it is "the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured".<sup>5</sup> We hope this compilation of expert panel resource-stratified recommendations can contribute to the development or expansion of breast cancer supportive care and palliative care programmes in low-income and middle-income countries.

### Contributors

The first draft of this Review was written by SRD, in consultation with BOA, JFC, and PAG and based on the collaborative efforts of the Breast Health Global Initiative Global (BHGI) Summit Co-chairs (JRG and RC-R) and BHGI Global Summit Co-chairs (PAG, C-HY, FC, NB, JFC, and HD). All authors contributed their expertise in development, analysis, and interpretation of the original data, reviewed, edited, and approved the content of the report.

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BOA received consulting compensation from GE Healthcare, AstraZeneca, and Navidea Biopharmaceuticals. JRG received grant and research support from Amgen, Genentech, Novartis, and Roche. JFC received consulting, grant, and research support from Procetus, grant and research support from Amgen, and was on the data safety and monitoring committee for KangLaiTe. NB received consulting, speaking, and teaching compensation from Roche. All other authors declare no competing interests.

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