

Report from the SE Asia Breast Cancer Symposium

SEABCS 2021

BACKGROUND

Breast cancer is the leading cause of cancer related deaths for women in SE Asia. In 2020 in the ASEAN countries alone there were approximately 159,000 breast cancer cases and 59,000 breast cancer related deaths reported¹. In the majority of Asian countries classified as low- and middle-income, women typically present with breast cancer at a younger age (50) and an advanced stage (3 and 4) compared to their western counterparts² and more than 75 % of those with cancer in the region experience death or financial catastrophe within one year of diagnosis³. There are many factors that contribute to the late diagnosis and poor survival rates in the region including the lack of locally available screening and treatment facilities, low health literacy, financial burden and stigma. There is an urgent need for more resources to aid early detection and policies aimed to provide adequate financial protection from the costs of cancer in the region.⁴

HISTORY OF SEABCS

Since 2016 this annual event has convened up to 1,200 global and regional experts in the field of breast cancer including clinicians, policy makers, cancer patients, patient advocates and caregivers, representing more than 22 countries to share the latest advances and techniques for both early and late-stage interventions with a strong focus on improving capacity around breast cancer early detection, treatment, support and advocacy. The symposium has acted as a catalyst for the development of an informal-regional coalition for women's cancers in the region.

Past agendas have included topics such as; advances in treatment, clinician capacity building, strengthening and expanding advocacy efforts, best practice sharing among clinicians and support groups, the importance of collecting and publishing evidence-based data, regional coalition building, peer-to-peer support training, advanced breast cancer, advocacy and how it relates to civil society and policy makers, including best practices for working with governments to affect positive policy change. The countries that have hosted the Symposium to date are: 2016 Viet Nam, 2017 Myanmar, 2018

¹ GLOBOCAN, 2021

² IMPROVING BREAST CANCER OUTCOMES IN ASIA

Ch Yip, Consultant Breast Surgeon, Ramsay Sime Darby Health Care, Kuala Lumpur, Malaysia, Clinical Professor, Universiti Tunku Abdul Rahman, Kuala Lumpur, Malaysia and Visiting Consultant, University of Malaya, Kuala Lumpur, Malaysia Cancer Control Cancer Care in Emerging Health Systems, 2018.

³ ACTION Study Group, Kimman M, Jan S, et al. Catastrophic health expenditure and 12-month mortality associated with cancer in Southeast Asia: results from a longitudinal study in eight countries. BMC Med. 2015;13:190. Published 2015 Aug 18. doi:10.1186/s12916-015-0433-1

⁴ ACTION Study Group, Kimman M, Jan S, et al. Catastrophic health expenditure and 12-month mortality associated with cancer in Southeast Asia: results from a longitudinal study in eight countries. BMC Med. 2015;13:190. Published 2015 Aug 18. doi:10.1186/s12916-015-0433-1

Malaysia, 2019 Thailand, 2020 Postponed due to COVID 19, 2021 Indonesia - Virtual, 2022 Philippines.

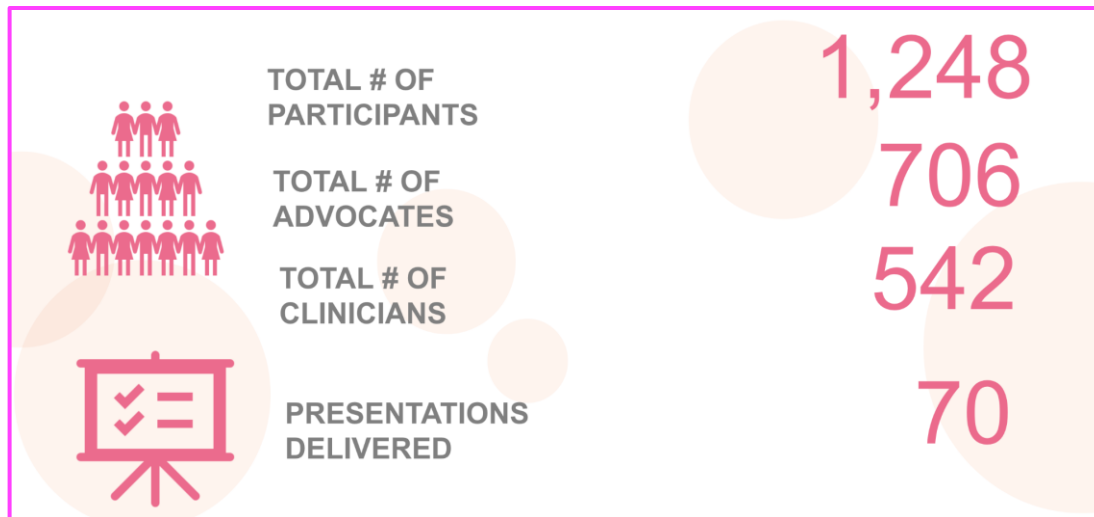
SEABCS 2021

The **5th South East Asia Breast Cancer Symposium 2021 Indonesia**, July 31 - August 1, 2021, *“Putting Patients at the Heart of Breast Cancer Control”*, proved to be the most successful symposium in the event's 5-year history. Hosted by the Indonesian Breast Cancer Foundation, this was the **first** virtual SEABCS. Access was **free** for all **cancer survivors, care partners and advocates** and as no travel costs were required, a virtual platform offered more equitable access to the meeting. This increased

<p>2016 Hue City, Vietnam</p> <p>The premiere 3-day event attracted over 250 attendees representing 16 countries and provided participants with continued medical education, experience sharing, patient advocacy and survivorship components along with networking opportunities.</p>		<p>2018 Kuching, Malaysia</p> <p>With the theme of “Patient-Centered Care” and over 350 attendees from 17 countries participating. Patient navigation, peer to peer support, oncology nursing strengthening and patient/clinician communication were among the topics explored.</p>	
	<p>2017 Yangon, Myanmar</p> <p>“Comprehensive Cancer Care Continuum: Knowledge into Practice”, drew over 500 attendees from 16 countries. The symposium explored challenges & opportunities in breast cancer around early detection, optimal care delivery, supportive survivorship programs and quality of life.</p>		<p>2019 Bangkok, Thailand</p> <p>This 2-day event carried the theme of “Patient and Provider Empowerment” and more than 225 attendees representing 14 countries participated in panel discussions and workshops.</p>

participation from previous years by more than **70%**. The same held true for clinician participation, for a small fee of between \$10 - \$30 USD, clinicians could join in the two days events and receive a CME certificate. Again, we saw a substantial increase in clinician attendees from past meetings. We also had a record number of countries participating with a total of **22**. This year saw the first **ASCO** endorsed symposium and the first ASCO joint session. The **70** presentations made by clinicians, government representatives, policy makers and patient advocates covered; *effective policy shaping, key regional learnings from COVID-19, communications, multidisciplinary care and management, improving early detection and timely treatment, equitable and sustainable approaches to achieve impact, along with clinical presentations in the areas of radiology and surgery.*

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COVID-19 AND BREAST CANCER

The COVID-19 pandemic has increased unemployment and catastrophic economic strain in many Southeast Asian countries, which may force cancer patients to choose between providing for their families or paying for their treatments.⁵ The pandemic has required countries who presented at SEABCS to adapt in almost every way, including in the area of breast cancer care. COVID-19 has caused delays in all aspects of breast cancer care, from screening and diagnosis, to treatment and survivorship throughout the region. Various efforts have been made to overcome this problem including vaccination programs for health care professionals, breast cancer patients, families and society at large. In many countries, vaccination guidelines have been published which are specific to cancer patients, some with a focus on breast cancer patients.

COVID-19 increased the use of social media to safely deliver information about breast cancer throughout the region. Two successful strategies shared were by Indonesia and Vietnam. Indonesia was able to optimize the use of telemedicine, when appropriate conditions (access to smartphones and connectivity) were in place, while in VietNam they were able to decentralize the delivery of chemotherapy to cancer patients. They improved capacity for delivering chemotherapy at local hospitals via the provision of telemedicine education and oversight of regional primary health care providers by oncology specialists located at central oncology centers.

Recommendations were made to increase the use of telemedicine for both patients and healthcare providers. Although, it was noted that telemedicine may not address the challenges of patients from lower socio-economic groups as they may not have video call capacity or sufficient data connectivity. It was suggested that social media and eBooks might be a valuable

⁵ Kong YC, Sakti VV, Sullivan R, Bhoo-Pathy N. Cancer and COVID-19: economic impact on households in Southeast Asia. *Ecanermedicalscience*. 2020;14:1134. Published 2020 Nov 3. doi:10.3332/eca ncer.2020.1134

tool to improve health literacy and awareness about breast cancer, however, education is not enough without timely and affordable access to services.

There was a call for improved education of primary health care providers in the signs and symptoms of breast cancer as well as their knowledge of treatment and the referral pathway. To improve access to services and timely treatment, breast cancer services should be decentralized and service users should be incorporated into development/deployment of these services. Lastly, coordinated collaboration is needed across all stakeholders; governments, health care professionals, NGOs, private sectors and civil society to assist with breast cancer care, especially in the era of the COVID-19 pandemic.

TREATMENT AND SUPPORTIVE CARE

BUILDING CAPACITY FOR PATIENTS SUPPORT GROUPS (PSG) TO BE ABLE TO IMPACT POLICY EFFECTIVELY

There is a need to recognize the importance of implementing policies for women's cancers, a priority for shaping cancer prevention and control. This can provide new opportunities to shift our communities to more of a prevention and early detection mindset. Lessons can be learned from active engagement with successful initiatives led by the NCD community and integrating relevant information and links to direct services. Equity, integrity, and improvement of the healthcare quality should be key terms when looking at shaping policy. Until those in positions of power value the health and wellbeing of every girl and woman as equal to that of men, and until they act on this commitment, this seemingly achievable goal will never be attained.

PSGs in SE Asia have great potential to extend the voice and needs of breast cancer patients and their families. PSGs may consist of survivors, families/care partners, and enthusiasts/activists. In the process of shaping the policy of breast cancer control, the voice of patients should not be 'assumed', but should be captured and incorporated. When addressing policy, a consistent and focused agenda is key. While it often takes more time than anticipated, organizations should not lose focus, but keep driving forward. Having solid community support and a strong public presence are two essentials that can help PSGs gain political support from decision makers. These groups can benefit from continuous capacity building and partnership with relevant stakeholders.

PSGs are strongly advised to have data/evidence-based fact sheets ready at all times and be ready to push their agenda forward when opportunities arise. It is also important to think outside the box, use public support and influential resources to drive your message to policy makers. Groups are encouraged to consider alternative ways to drive their message, such as partnering with celebrities, politicians, digital influencers and the media to help build and drive their narrative. These combined activities can improve their capability to propel their agenda more swiftly, and effectively strengthen their voice.

EARLY DETECTION CONNECTED TO TIMELY TREATMENT

Most obstacles to early detection and timely treatment of breast cancer in the region are the lack of awareness about risk factors and prevention coupled with the fear and misunderstanding of mammography screening. Further barriers include: fragmented services, financial burden, lack of awareness regarding the importance of early detection, insufficient diagnosis and care management options and the side effects of treatment. Downstaging breast cancer can be implemented more aggressively by strengthening early detection methods, as one way of improving survival in the long term. Strengthening the early detection of breast cancer needs to be implemented at the referral system level with early detection services and funding combined with a clear pathway to treatment.

A shift to a new paradigm of integrated care and patient centered is a model that appreciates experience and values. Patient needs are integral for the development of a health system which can answer the complex health challenges that arise. It is critical to provide education to patients and allow them to voice their concerns and wishes. An effective model is to provide navigation throughout the healthcare system while ensuring the provision of adequate emotional support resources for patients and their care partners. There are many benefits to empowering patients in this way including increased satisfaction with the medical system, increased adherence to their treatment plan and improved clinical outcomes.

ENSURING ACCESS TO EFFECTIVE AND QUALITY BREAST CANCER CARE AND TREATMENT, VIA MULTIDISCIPLINARY MANAGEMENT AND IMPROVED COMMUNICATION SKILLS

There is great need for healthcare professionals to be adequately trained in effective communication skills to ensure a satisfactory consultation with their patients in general, but communication is particularly important in the area of advanced breast cancer (ABC).

Communication skills training for healthcare professionals can greatly improve the relationship between them and their ABC patients. From preparing a message, to choosing appropriate language and considering tonal and nonverbal communication, there are many factors that need to be considered to ensure the communication experience is a positive and productive one. The [ABC Global Alliance](#) collaborates and shares resources and knowledge worldwide to improve the patient experience, including communication tools for healthcare providers.

It is also of great importance to deliver health literacy guidance and communication tools to patients in order to build their confidence when consulting their doctors. It is important to empower patients to be able to ask questions in order to obtain all the answers and information they need.

Despite several initiatives, more needs to be done on communication skills for breast cancer patients in low- and middle-income countries in SE Asia. Each country should examine how much emphasis is given to communication skills training modules for medical and nursing students as well as how to measure the clinician's proficiency in these skills. Patient organizations can work towards participating in training via theoretical and practical

communication skills including role-plays for medical and nursing students. Much more needs to be done to develop health literacy for the public in the Southeast Asian region so that the common person can understand about diseases, prevention, early detection, and timely medical treatment.

DIAGNOSTIC IMAGING

Risk assessment including breast density should be implemented using technology information systems to achieve more coverage for early detection. Research should be developed among radiologists in Indonesia which could be screening or diagnostic imaging, including image guided biopsy. To achieve higher accuracy in biopsy, radiologists should overcome challenges in small lesions and manage complications as well. Cost effective analyses should be implemented and quality assurance in breast MRI should be well maintained within the radiology department.



MULTIDISCIPLINARY CARE

This ASCO sponsored session focused on the need to implement a multidisciplinary approach to breast cancer care to achieve best treatment outcome for breast cancer patients. Guidelines and clinical pathways should be developed and be implemented in cancer management to increase the quality of treatment. Post-treatment follow-up, especially surrounding patient needs, should be assessed in supportive and survivorship care as well. ASCO has a wide range of activities to support capacity building among health care professionals, therefore it is

recommended to oncologists to join ASCO as a member to build capacity and improve cancer care delivery.

GLOBAL INITIATIVES

There are global initiatives that can have a positive impact on local conditions. A significant challenge of breast cancer in the region is that the high incidence and prevalence of death from breast cancer often fall on the shoulders of low- and middle-income countries. Accessible and affordable screening and early diagnosis programs along with primary prevention, the introductions of healthy habits to lower the risk of breast cancer, are essential in shifting this dynamic.

The objective of the WHO's Global Breast Cancer initiative (GBCI) is to lower the death caused by breast cancer in the world by 2.5% per year, from 2020 until 2040. There are three pillars to achieve this, health promotion for early detection, timely breast cancer diagnosis and comprehensive breast cancer management. Healthcare systems should be tasked with providing appropriate resources for early detection, diagnosis and treatment. To be effective, breast cancer early detection should be followed up with effective and timely treatment and supportive care. GBCI has the potential to be a catalyst of change by developing the relevant approach on cancer in women and women's health along the continuum of life.

The Union for International Cancer Control's Breast Cancer Program looks to assist regional partners to accelerate the improvement of breast cancer management. The program highlights the breast cancer focus through building capacity for cancer organizations and community networks. The initiative provides global scale meeting platforms and aims to strengthen and improve bonding among breast cancer communities through a remotely delivered mentoring program for patient groups.

CONCLUSIONS

Equity, integrity, and improvement of the healthcare quality should be something everyone in the region should be striving for. Sustainable programs promoting breast health awareness, breast cancer early detection and early diagnosis, breast cancer comprehensive and timely treatments, along with supportive care throughout the continuum should be implemented in all levels of health care centers by health care professionals in coordination with advocacy groups. Multidisciplinary care should be the standard.

Many studies have demonstrated cost-saving in the treatment of cancer through the implementation of early detection and screening methods. In that regard, breast cancer screening and treatment services should be decentralized to improve access to and use of these services.

What is rarely acknowledged is the disproportionate impact of cancer on the lives and livelihoods of women, and the downstream impacts this creates for societies. More studies are needed to assess the financial burden of both medical and non-medical costs of a cancer diagnosis. Additionally, studies similar to the ACTION studies should be undertaken periodically, at least every 10 years to provide comprehensive data for the region. Countries should mobilize resources for such “evaluation” studies on the perspectives of health care and the patients.

Mutual commitment and responsibility from all stakeholders is important to ensuring the success of breast cancer prevention and control through health promotion, screening, early detection and standardized treatment. These efforts will significantly decrease new cancer incidents while increasing the survival rate of breast cancer patients. The success of breast cancer prevention and control are closely related to the participation of the community, including the role of advocacy organizations. A strong collaboration among breast cancer organizations in SE Asian Countries may help to strengthen the effort to reduce the prevalence of advanced breast cancer cases in the region, with the hopes of reaching the 2040 WHO target goal.

The establishment of a regional SE Asian Breast Cancer Coalition or Task Force of clinicians, advocates, patients, care partners, advocates, policy makers, academics could be a valuable tool in building capacity across the region.

KEY TAKEAWAYS

- Build capacity for PSG to operate effectively
- Early detection must be connected to timely treatment
- Early detection services should be coupled with funding and a clear treatment pathway
- Ensure access to effective and quality breast cancer care and treatment, via MDT and improvement of communication skills
- Guidelines and clinical pathways for multidisciplinary cancer management should be implemented
- We must leverage the work of global initiatives for local benefit
- The use of telemedicine, social media and eBooks should be linked with access to services
- Some breast cancer services could be decentralized to increase access, as shown with chemotherapy units in VietNam during COVID
- Service users should be incorporated into development/deployment of services
- Coordinated collaboration is needed across all stakeholders
- Countries should mobilize resources for evaluation studies
- Strong collaboration among breast cancer organizations in SE Asian Countries is needed to help strengthen these efforts