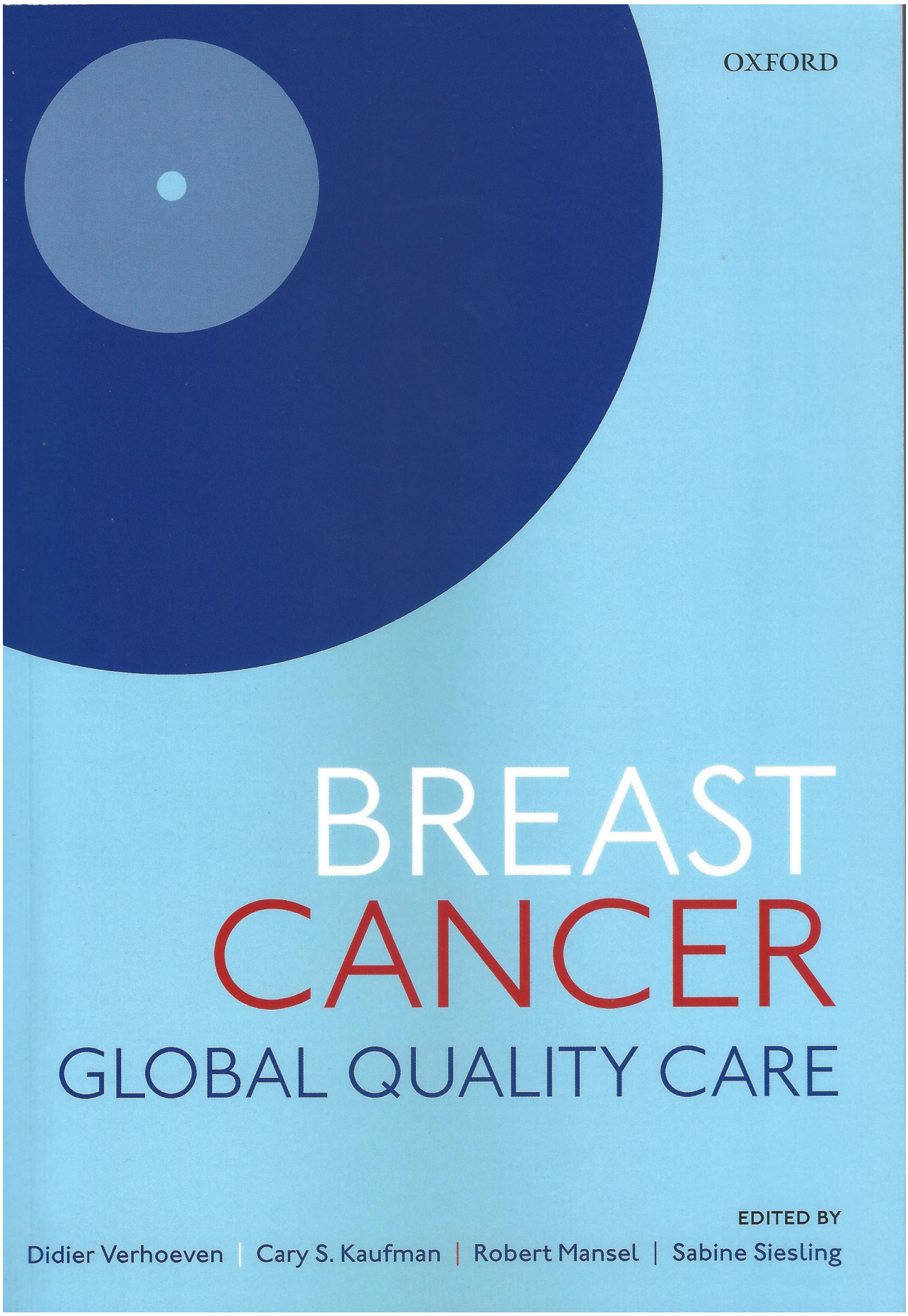
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BREAST
CANCER
GLOBAL QUALITY CARE
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Perspective from India

Improving Breast Health Care

Raghu Ram Pillarisetti

Introduction

The incidence of breast cancer in India has been rising steadily over the past decade. With 155, 000 new cases being diagnosed in 2018, the incidence of breast cancer has overtaken cervical cancer to become the commonest cancer affecting women (1). Some 75,000 women succumb to the disease every year—for every two women newly diagnosed with breast cancer, one dies (2).

There are several worrying trends in the country:

- Rising incidence in young women—as opposed to the west, where the vast majority present aged >50 years, most breast cancers present in younger women (peak incidence: 40–50 years).
- More than 60% present in advanced stages due to lack of awareness and absence of an organized population-based screening programme.
- Higher incidence of triple-negative breast cancers (27%) when compared to the west, with consequent poor prognosis in this subgroup (3).
- The 5-year survival rate is around 60% as opposed to more than 80% in the west.
- India currently spends only 1.2% of its GDP on publicly funded health care. This is considerably less than most other comparable countries.

There is a huge discrepancy in the availability, quality, and reporting of breast imaging and pathology across the country. The vast majority of breast cancers is managed by general surgeons rather than by surgical oncologists. Breast surgery is not a distinct subspecialty in the country, and only a small fraction of women presenting with breast cancer are assessed by a comprehensive multidisciplinary team. There is very little effort directed towards empowering people about the importance of early detection of breast cancer, and counselling patients is not considered to be an important component of breast cancer care. Breast-conserving surgery is not routinely offered, and axillary radiotherapy is routinely given to many patients due to inadequate axillary surgery. Due to the enormous costs, many do not complete their course of chemotherapy. Most patients who are Her2 positive simply cannot afford trastuzumab. While few cancer centres offer care comparing with the best centres across the world, by and large, cancer

care in India is a 'lottery' with some getting excellent care, while most do not. That there is huge variation in the survival of patients with breast cancer across the country is an understatement.

Cancer displays a significant socioeconomic gradient in India. Out-of-pocket expenditure is among the highest in any ailments. The out-of-pocket spending on in-patient care in private clinics is about three times that of public facilities. Treatment of about 40% of cancer hospitalizations is financed mainly through borrowings, sale of assets, and contributions from friends and relatives. Figure 35.1 shows the percentage of cancer patient households reporting distressed financing by wealth quintiles in public and private sector treatment. Although important differences are observed, a lot of households in all categories report distress (4).

Four aims were created to improve the delivery of breast healthcare in India:

1. Establish a dedicated centre for breast health.
2. Establish a breast cancer foundation.
3. Implement a population-based breast cancer screening programme reaching out to the underprivileged community.
4. Establish breast surgery as a subspecialty in India.

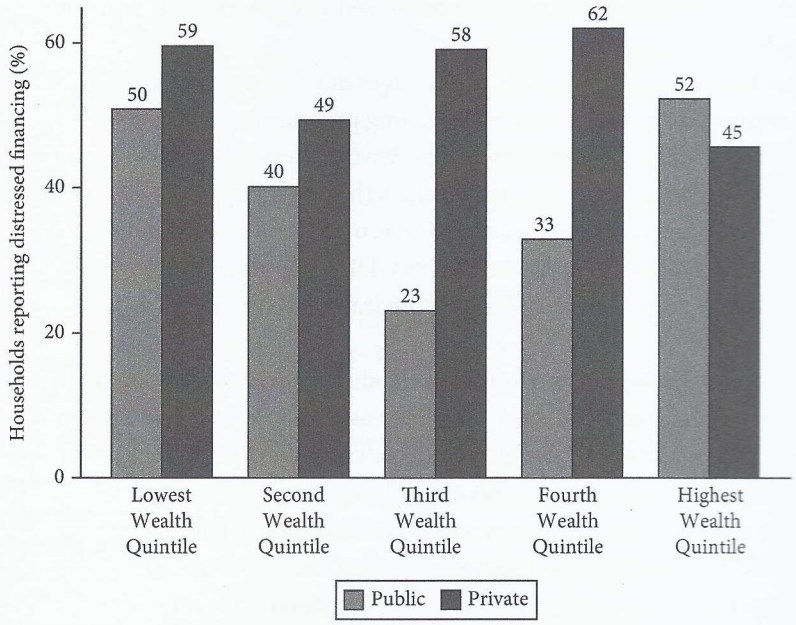

Figure 35.1 Percentage of cancer patient households reporting use of distressed financing as a major source, by wealth quintiles and public and private sector treatments, India, 2014.

Reproduced from Rajpal S, Kumar A, Joe W. 'Economic burden of cancer in India: Evidence from cross-sectional nationally representative household survey, 2014'. PLoS One. Volume 13, Issue 2: e0193320. Copyright: © 2018 Rajpal et al. DOI: 10.1371/journal.pone.0193320. Available under the Creative Commons Attribution 4.0 International License. http://creativecommons.org/licenses/by/4.0/

Three out of these four aims have been completed, and the path for the fourth one has been paved.

A Dedicated Centre for Breast Health

South Asia's first free-standing, purpose-built, comprehensive Breast Health Centre was conceived and designed in Hyderabad (2007). Krishna Institute of Medical Sciences (KIMS)–Ushalakshmi Centre for Breast Diseases was established under the auspices of KIMS hospitals, one of the largest corporate hospital groups in South India (5). It was designed and based on the best aspects of the Royal Marsden, Cardiff, and Nottingham, breast centres in the UK. KIMS–Ushalakshmi Centre for Breast Diseases is a unique set-up in India, where clinical assessment, breast imaging, breast biopsy, and counselling are all done in a purpose-built unit that is dedicated to the management of all types of breast disease, both benign and malignant, by a committed multidisciplinary team. This landmark initiative has brought about a revolutionary change— the 'breast centre' concept in the Indian subcontinent.

One of the essential roles in delivering a state-of-the-art breast health service is a good breast radiologist. Breast radiology services were in their infancy, in India. The consultant radiologist at KIMS Hospitals in Hyderabad travelled to the UK to obtain training at St George's Breast Screening Centre in London. A breast radiologist and members of her team at the Jarvis Screening Centre in Guildford (UK) came to India to train the radiographer and to quality-assure the first 950 screening mammograms. Mobile screening began in 2007 in Hyderabad. It was the first initiative of its kind in India. In 2012, a national organization, The Breast Imaging Society of India, was formed, inspiring many radiologists across India to take up breast radiology as a career.

Establish a Breast Cancer Foundation

The Ushalakshmi Breast Cancer Foundation was established in 2007 (6). Working closely with Breast Cancer Care UK, Britain's only UK-wide charity providing breast care, the Foundation printed and distributed some 100,000 information booklets that provide information about every aspect of breast health in English and the local regional language (Telugu). The author developed the world's first mobile phone breast app (Figure 35.2). This novel digital application provides information about every aspect of breast cancer and benign disease in 12 languages. The aim of the app is to counsel, guide, and educate women across the nation about various aspects of breast health.

The Foundation championed a one-of-a-kind, large-scale breast cancer awareness drive across the southern Indian states of Telangana and Andhra Pradesh. A number of unique and innovative events have been organized in urban and rural regions with many celebrity breast cancer survivors from India and abroad lending their support to

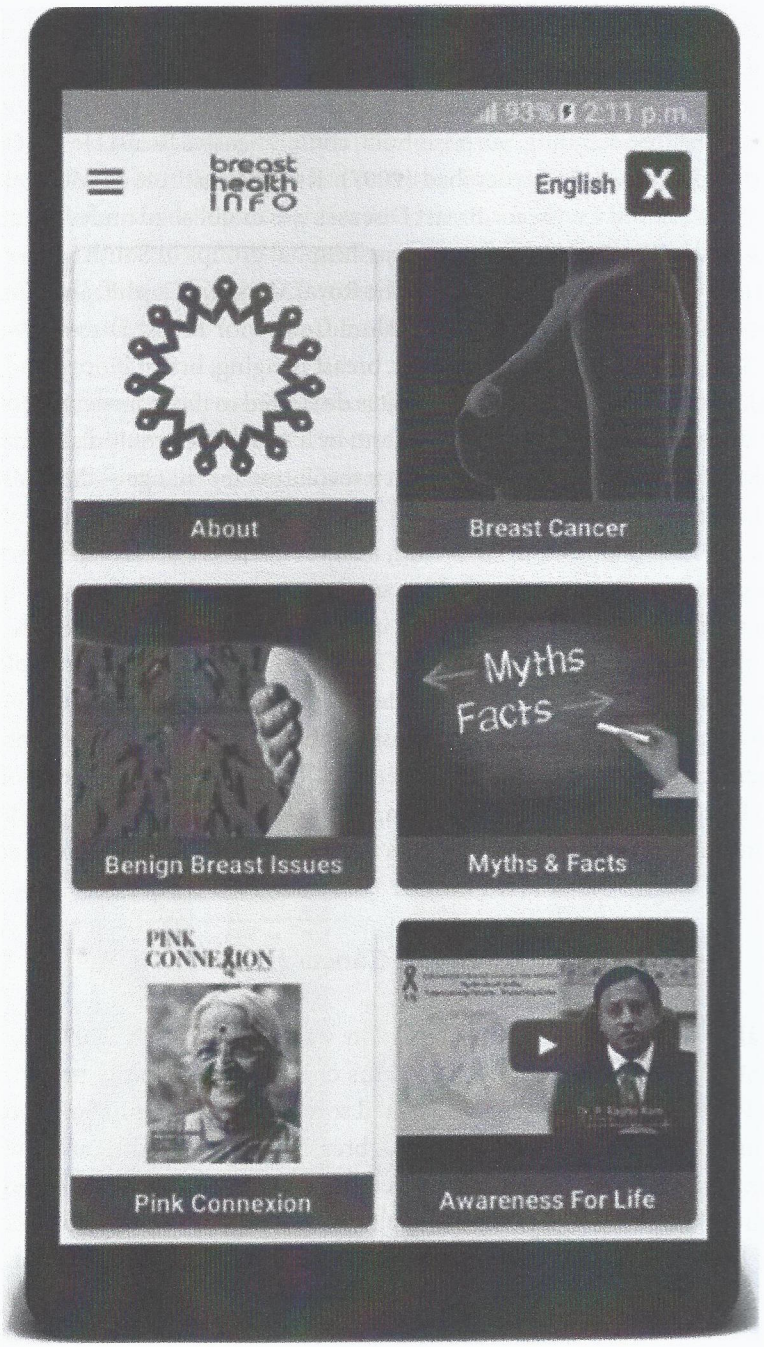

Figure 35.2 The world's first mobile phone breast app.

this worthy cause. Over the past decade, the campaign has addressed more than 1,000 organizations across India and abroad, has appeared in several television programmes, and has been featured in more than 100 full-page articles in major newspapers and magazines.

Implement a Population-Based Breast Cancer Screening Programme Reaching out to the Underprivileged Community

Due to the absence of a nationwide population-based screening programme, more than 60% of breast cancers present in advanced stages in India. Mammography is not a viable option for population-based screening in India. The reasons are the enormous costs, early age at diagnosis (<50 years), huge variation in mammographic reporting, and issues relating to quality assurance. However, there is considerable evidence regarding the efficacy of clinical breast examination (CBE) in detecting small breast cancers when performed by trained healthcare workers in the community setting.

Between 2012 and 2016, some 200,000 underprivileged women between the ages of 35 and 65 years across 4,000 villages in 15 districts of Telangana and Andhra Pradesh were screened for early signs of breast cancer with CBE. The programme used the services of 3,750 healthcare workers, employed by the government, who were trained under the auspices of the Foundation to perform CBE. Cancers detected through this initiative are treated free of charge through the State Government-funded Aarogyasri scheme. In 2017, The Ministry of Health, Government of India incorporated clinical breast examination into the National Cancer Screening Guidelines. Since 2018, the national cancer screening programme for breast, cervical, and oral cavity has been rolled out across the nation. In the fullness of time, this landmark screening programme would hopefully make a significant impact on ensuring early detection and reducing the burden of advanced cancers in the country.

Establish Breast Surgery as a Subspecialty in India

Breast surgery is not a recognized subspecialty in India. Moreover, until 2011, there was no dedicated Surgical Society in India focused exclusively upon issues surrounding breast disease. Recognizing the need for a paradigm shift in delivery of breast health care in India, the Association of Breast Surgeons of India (ABSI) was formed in 2011, the first and only organization in South Asia representing general surgeons, surgical oncologists, and plastic surgeons treating patients with breast disease. The Association has been established along similar lines to those of the Association of Breast Surgeons in the UK and the American Society of Breast Surgeons. The formation of ABSI is in many ways the first step towards developing breast surgery as a distinct subspecialty in India (7).

A nationwide ABSI Training Module was developed as a structured breast surgical training programme in many cities and towns across India to instruct trainees and surgeons in every aspect of breast health in a simple, easy-to-understand format. An ABSI Overseas Fellowship Programme was established to enable breast surgical trainees from India to obtain 'hands on' one-year oncoplastic surgical training in preselected centres of excellence in the UK. Since 2016, three trainees from India completed subspecialty training in the UK. They have since returned to India and are practising the art and science of breast surgery in the country.

Key Messages

- The rising incidence and mortality coupled with age shift and late stage of presentation is a cause for great concern.
- Breast cancer advocacy can transform breast cancer from a 'taboo' issue to a more commonly discussed one.
- There is a need for a paradigm shift in the management of breast cancer and indeed breast health care in India.
- The concepts of breast cancer advocacy, breast centre, breast specialists, and the subspecialty of breast surgery are all bound to improve the delivery of breast healthcare in India in forthcoming years.

References

1. Asthana S et al. Breast and cervical cancer risk in India: an update. *Ind. J Public Health* 2014;58:5–10.
2. Global Comparison of Breast Cancer. Available from: http://www.breastcancerindia.net/statistics/stat_global.html
3. Dikshit R et al. Cancer mortality in India: a nationally representative survey. *Lancet* 2012;379:1807–1816.
4. Rajpal S et al. Economic burden of cancer in India: evidence from cross-sectional nationally representative household survey, 2014. *PLoS One* 2018:13(2):e0193320.
5. KIMS–Ushalakshmi Centre for Breast Diseases. Available from: http://www.breastcancerindia.org/
6. Ushalakshmi Breast Cancer Foundation. Available from: http://ubf.org.in/
7. ABSI—The Association of Breast Surgeons of India. Available from: http://www.absi.in/