

“HK Breast Cancer Registry: Evidence for Improving Cancer Control and Treatment”

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Hong Kong Breast Cancer Picture

Breast cancer is an increasing health burden in Hong Kong.

- Breast cancer forms 12.7% of all cancers diagnosed.
- It makes up 26.4% of all cancers in women: it is the number one cancer affecting women in Hong Kong.
- 9 new cases are diagnosed each day.
- In 2011, there were 3,419 recorded incidences of new cases of breast cancer.
- There is a 1 in 17 lifetime risk of invasive breast cancer for women in Hong Kong.

Cancer Registries: A Background

Why do we need breast cancer registry? Cancer registries are the eyes and ears of cancer control around the world. The UICC World Cancer Declaration in 2006 called for an increase in number of countries with cancer registries. Currently, cancer registries cover 1/6 of the world's population.

There are three types of cancer registries:

- Cancer registries: population-based and produce statistics on incidence and mortality of all cancers in a given population.
- Cancer specific registries: maintain data on particular type of cancer with lifetime follow up
- Health care institution registries: report to a central Cancer Registry.

Hong Kong Breast Cancer Registry (HKBCR)

The HKBCR is a non-governmental initiative, established and operated by the Hong Kong Breast Cancer Foundation (HKBCF) since 2007. It is the first of its kind in Hong Kong and is the most comprehensive breast cancer-specific data collection and monitoring system which records risk exposures, disease patterns, treatment trends and outcomes, and the physical and psychosocial impact of cancers. Since its inception, it has collected more than 13,000 cases and publishes its data analysis in annual reports and bulletins.

The mission of HKBCR is as follows:

- Provide vital data, analysis and insights for medical professionals, policy makers, HKBCF, and the wider public, to advocate and design plans for more effective cancer control
- Help bring about changes in public policies and medical practice for improved breast healthcare in Hong Kong
- Set a model for other cancer specific registries to guide cancer control plans in Hong Kong

The objectives of HKBCR is as follows:

- Analyze the causes and risk factors of local breast cancer
- Identify disease and treatment trends in the local context
- Evaluate the impact of breast screening in early detection
- Advocate and support people-oriented public healthcare policies
- Develop and improve the standard of care for breast cancer patients

The HKBCR is led by a steering committee consisting of medical professionals including surgeons, oncologists, and pathologists, public health specialists, patient representatives, legal expert and IT professional.

This is an opt-in registry which means that patients have to complete consent forms in order for the Registry to obtain the data regarding their cancer. The HKBCR works in collaboration with local hospital clusters to invite patients to join this initiative.

For each case, around 300 data items are collected. These data set indicators were designed by the working group under BCR steering committee. The information given is valuable in terms of helping to identify preventive measures and values of early detection, keep track of disease characteristics and treatment trends, understand the physical and psychosocial impacts of breast cancer on the patient, and analyse the clinical outcomes of breast cancer through patient status follow-up.

At the time of publishing its #Hong Kong Breast Cancer Registry Report No. 6+, the HKBCR has accumulated a total of 12,345 cases since its establishment. Cases are spread out through the whole territory, and the registry is working towards a larger representation. Currently, there is a 70-30 split in cases coming from public and private healthcare institutions. Overall, HKBCR currently has 40% coverage of all the new breast cancer cases obtained by the Hong Kong Cancer Registry. Currently, the HKBCR provides the foremost comprehensive picture of breast cancer in Hong Kong.

Data collected by the Hong Kong Breast Cancer Registry

1. Demographics, Risk Factors and Health Background and Breast Screening Habits

This basic demographic and lifestyle information enables the HKBCF to identify common risk factors and enables a macro view of the breast cancer picture in Hong Kong.

2. Clinical Presentation, Cancer Characteristics, Treatment Methods and Patient Status

Information regarding clinical presentation, cancer characteristics and treatment methods enable local clinicians to compare standard practices with the rest of the world and identify the most accurate diagnostic tests available. HKBCR also tries to follow-up with patients to track recurrences and survival data.

3. Physical and Psychosocial Impacts after Treatment

By asking core questions about the physical, mental and emotional wellbeing of patients, we are able to understand how well they cope with the disease and thereby provide adequate care and support.

Breast Cancer HK Online (BCRA Online)

HKBCR has started an online resource for medical professionals which may be accessed online at brcaonline.hkbcf.org. Breast Cancer HK Online is an online platform that further enhances access to the BCR data. Registered medical professionals are able to use this programme and the valuable data collected to generate reports according to their tailored parameters. Breast Cancer HK Online aims to assist medical professionals in their clinical assessments and decisions through access to information on local disease development and treatment trends.

Key findings from Hong Kong Breast Cancer Registry

1. Breast cancer picture in Hong Kong is different from the west. Hong Kong's median age for breast cancer diagnosis is 7-8 years younger compared to countries in the West^[1-3] (Table 1). A significant majority of breast cancer incidences are self-detected in Hong Kong compared to countries like the US, where self-detected incidences are the minority^[4,5] (Table 2). The common cancer stage at diagnosis is stage II, and the statistics showed that the distribution of cancer stage at diagnosis in Hong Kong was different from that in western countries such as Canada, where population-based breast screening programmes are implemented. In countries such as Canada, stage 0 to I breast cancer prevail^[4,6] (Figure 1).

Table 1 The median and distribution of age at diagnosis among breast cancer patients in Hong Kong, United States, and Australia

	Hong Kong	United States	Australia
Median age at diagnosis	54 (2011)	61 (2006-2010)	62 (2009)
Age group of diagnosis			
<20	0%	0%	0%
20-29	1%	1%	1%
30-39	7%	4%	5%
40-49	29%	19%	17%

50-59	29%	27%	25%
60-69	18%	23%	26%
70-79	9%	18%	15%
80+	7%	8%	11%

Table 2 The first detection method of breast cancer among Hong Kong and United States patients.

	Hong Kong	United States
Self-detected	85%	18%
Screen-detected	9%	43%
Other screening methods, such as breast self-exam, clinical breast exam	6%	39%

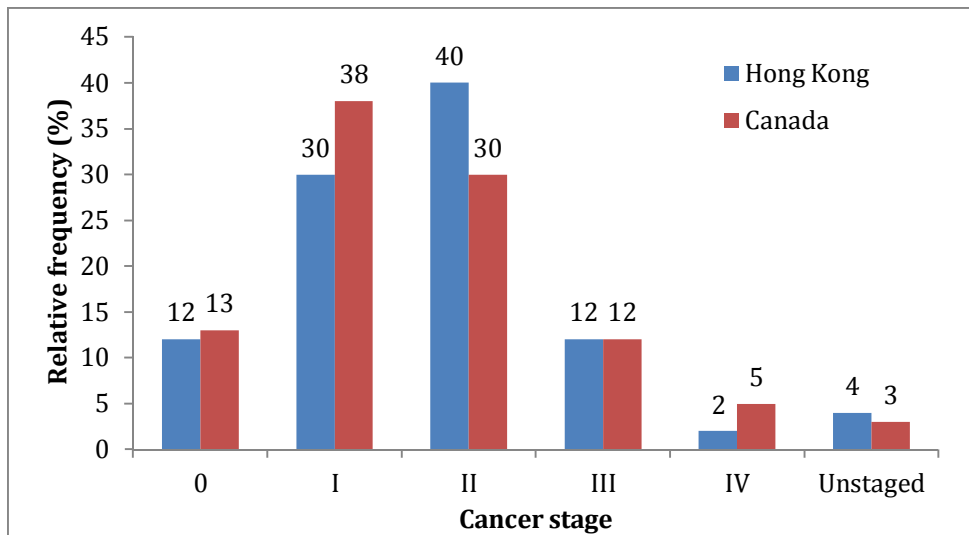


Figure 1 The stage distribution of breast cancer patients in Hong Kong and Canada.

- Patients are different in public vs. private medical sector, where patients from the public medical sector have larger tumours^[7] and later cancer stage at diagnosis^[7] (Table 3). Higher proportions of patients from the public sector received mastectomy, but less of them received reconstruction (Table 3), when compared to patients from private medical sector^[7]. Besides, patients from Hong Kong Island were found to have highest screening habits (Table 4), and advanced cancer stage was more frequently found in low income districts^[8].

Table 3 Distribution of tumour size, cancer stage, and type of surgery of patients and proportions of patients receiving reconstruction among three medical service groups

Tumour size (cm)	Private	Private/Public	Public
<2cm	51.1%	56.1%	44.0%
≥2cm	48.9%	43.9%	56.0%
Cancer stage			
Stage 0	13.6%	9.8%	5.7%
Stage I or II (early-stage)	70.8%	77.3%	73.6%
Stage III or IV (late-stage)	13.2%	11.8%	18.2%
Unstaged	2.4%	1.1%	2.5%
Type of surgery			
Breast-conserving surgery	66.6%	52.0%	34.2%
Mastectomy	33.4%	48.0%	65.8%
Reconstruction done	17.9%	18.8%	15.0%

Table 4 Rate of having regular breast screening habits among patients in Hong Kong Island, Kowloon or the New Territories

	Hong Kong Island	Kowloon	New Territories
Breast self-examination	22.5%	18.4%	20.8%
Clinical breast examination	63.3%	39.2%	43.6%

Mammography screening	44.6% (1 in 2)	23.6% (1 in 4)	21.7 (1 in 4)
Ultrasound screening	37.5%	20.6%	18.9%

3. Studies on the difference between self- and screen-detected breast cancers found that the latter has smaller tumour size, earlier stage distribution, less nodal involvement, less mastectomy rate and less use of chemotherapy^[9] (Table 5).

Table 5 Differences in pathological characteristics (tumour size and nodal status) and treatments received between self- and screen-detected breast cancer patients.

	Self-detected	Screen-detected	P value
Tumour size	2.3cm	1.3cm	<0.001*
Node positive	42%	21%	<0.001*
Mastectomy	67%	46%	<0.001*
Chemotherapy	66%	25%	<0.001*

*significant difference as $p < 0.05$

4. Patients who had self or total delay for more than 3 months were more likely to have larger and node-positive tumours and more stage III to IV cancer. Self delay is more significant than care delay. Non-clerical / labours workers (vs. housewives), or widowed patients (vs. unmarried patients), or patients with history of benign breast disease (vs. patients without history of benign breast disease) were more likely to self delay for 3 or more months. Therefore, breast health education should emphasize on alerting public to signs of breast cancer, and advising women to seek medical consultation in less than 3 months on discovery of abnormality. In addition, bottle neck in diagnostics should be addressed to avoid delay in medical treatment^[10].

Conclusion

Overall, the experiences of the HK Breast Cancer Registry proves the value of the information collected by such registries, the analyses of which is then used to inform a holistic approach towards cancer prevention, control and care. There is yet more knowledge to be uncovered in the HK Breast Cancer Registry, it is a treasure trove of information which can guide local cancer prevention, control and treatment.

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