

Dr. R.L Spittel Oration : A breast cancer registry to improve quality and reduce disparities in breast cancer care – lessons learnt

S. Seneviratne

Department of Surgery, Faculty of Medicine, Colombo, Sri Lanka

President and the members of the council of the College of Surgeons of Sri Lanka, family members of Dr. R.L Spittel, my most respected teachers, colleagues, friends, ladies and gentlemen.

First, I wish to thank the president and the council of the College of Surgeons for giving me the opportunity to deliver the Dr. R.L Spittel oration for the year 2016. I consider it a great honour and a privilege bestowed upon me to honour a great Sri Lankan surgeon of yesteryear.

Dr. Richard Lionel Spittel FRCS, CMG, CBE was born in 1881 in Tangalle. He graduated from Colombo Medical Faculty with MBBS in 1905. Subsequently he moved to England where he completed fellowship of the Royal College of Surgeons of England in 1909. Dr. Spittel returned to Sri Lanka the following year to assume duties as the 3rd Surgeon at General Hospital, Colombo.

Dr. Spittel was a pioneering Surgeon. He performed wonders in an era when medical facilities in Ceylon were rather primitive and speed as well as accuracy were essential prerequisites for a good surgeon. Dr. Spittel was the first to perform a skin graft in Sri Lanka and was the first to perform a blood transfusion using his own blood.

Dr. Spittel was a surgeon with many skills. Apart from being a scholar and a teacher, he was a naturalist and a great writer. Dr. Spittel had an innate love towards anthropology and jungles of Ceylon and its native inhabitants, the Veddahs. He was one of the foremost personalities to recognize the need to record the customs of Veddahs.

Over a period of four decades Dr. Spittel published many books on historical aspects of Sri Lanka and Veddahs. Some of the well-known books include Wild Ceylon (1924) Savage Sanctuary (1941) Vanished Trails (1950) Where the White Sambhur Roams (1951) and Wild White Boy (1958).

Dr. Spittel died in 1969. His life was beautifully summarized in the obituary notice published in the British Medical journal

Correspondence: S. Seneviratne
E-mail: sanjeewa_sa@yahoo.com
DOI: <http://10.4038/sljs.v34i4.8316>



the same year. I quote *“though steeped in western culture, [he] went off the beaten tracks of clubs and tennis courts into the wilderness where Ceylonese customs, traditions, arts and crafts were studied and revealed to the world”* I unquote.

What Dr. Spittel strived for during his lifetime is reminiscent of the topic I have selected for my oration today. Similar to Dr. Spittel's exploration of Ceylonese wilderness, during my oration today, I will try to emphasise the need to explore the epidemiology and outcomes of breast cancer in our country, to identify how it differs from the west in order to understand how we can improve outcomes for women with breast cancer.

Breast cancer is the commonest cancer among women in this world. The world incidence of breast cancer (i.e. the number of women diagnosed with breast cancer) is nearly three times the next in the list, colorectal cancer. It is also the biggest cancer killer among women. Sri Lanka is no different. According to WHO estimates approximately 4000 Sri Lankan women are diagnosed with breast cancer and almost a third of this number succumb to breast cancer each year [1].

The highest incidences of breast cancer are observed in developed countries including the USA, England, Australia and New Zealand. Comparatively in developing countries like Sri Lanka breast cancer incidence has been much lower. According to WHO estimates, in developed countries breast cancer incidence has steadily increased from 1970s to turn of the millennium. Since then it has plateaued and over last 5 to 10 years has been declining gradually. In contrast, rates of breast cancer in developing countries including Sri Lanka are still rising steadily.

More striking are the differences in patterns of death from breast cancer in developed and developing countries. Even while the incidence of breast cancer was increasing, breast cancer mortality was declining steadily in the developed world. In contrast, in developing countries mortality rates have been increasing steadily in parallel with incidence, thereby narrowing the mortality gap between developed and developing countries. At the current rate, within the next decade we are likely to surpass the mortality rates of

from diagnosis through treatment was performed. Some of the more important findings that originated out of the analyses are discussed below.

5 years. Adherence with adjuvant endocrine therapy was analysed based on prescription data of each individual patient from national pharmaceutical database. It was found that

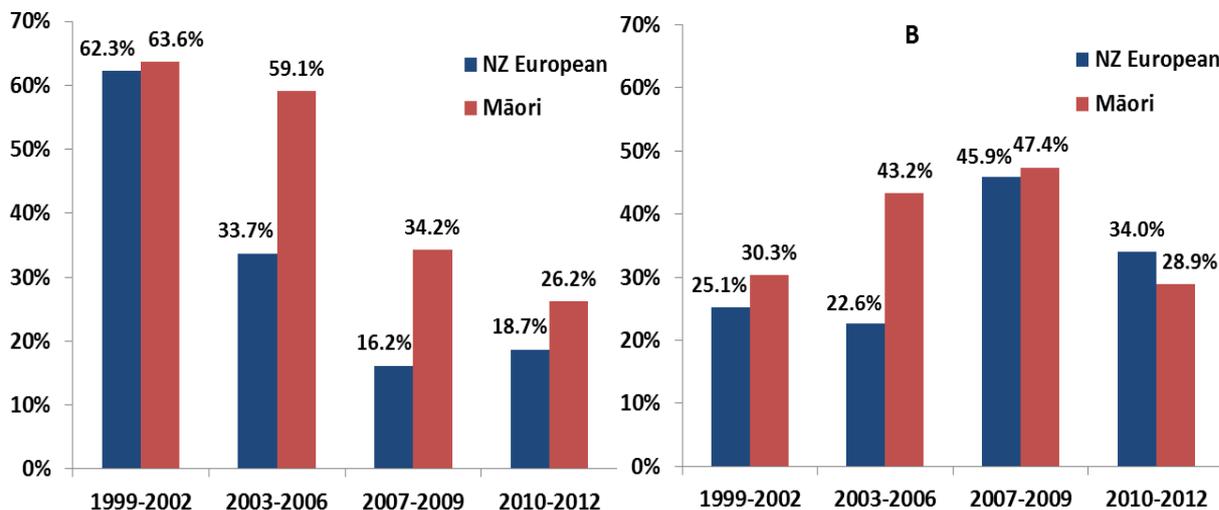


Figure 1 Time trends in delay in adjuvant chemotherapy longer than 60 days (Panel A) and adjuvant radiation therapy longer than 90 days (Panel B) for invasive breast cancer in Waikato, New Zealand 1999–2012

Timeliness in providing surgical care and adjuvant therapy and how these have changed over the study period found that timeliness in providing care has improved significantly over the study period. However, for some women namely ethnic minority Maori women and women of lower socioeconomic groups continue to experience longer delays to undergo surgery and to receive adjuvant chemotherapy [4, 5]. Although adjuvant endocrine therapy for breast cancer is a highly effective mode of treatment, it is well known that many women do not take these medications as prescribed for

over 40% women had not completed the five year course of endocrine medication while a quarter had stopped it before the end of the first year [6].

Impacts of breast cancer screening on breast cancer outcomes and, how disparities in screening contributes to poor outcomes among Maori, rural and women of poor socioeconomic backgrounds were also studied [7]. Figure 2 shows the impact of socioeconomic status on 10 years breast cancer survival. There were major differences in

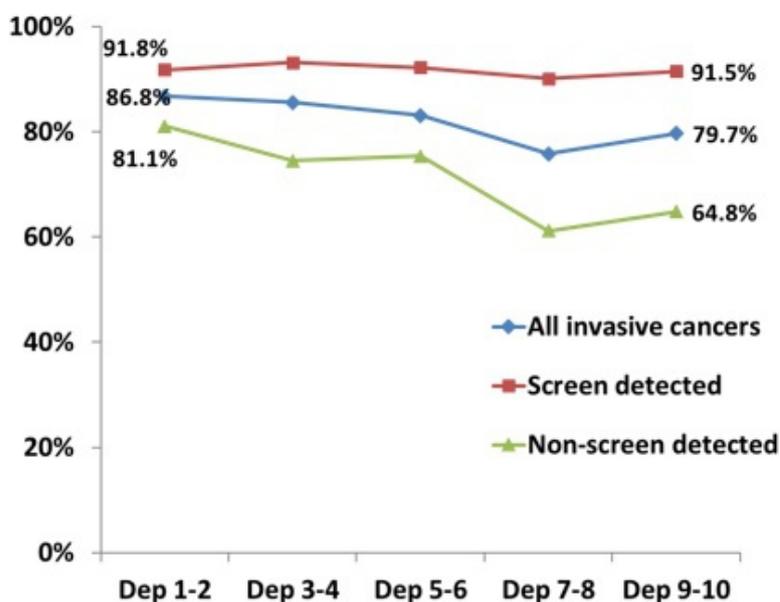


Figure 2 Ten-year breast cancer specific survival rates by socioeconomic deprivation based on Kaplan-Meier survival curves (Dep 1-2 – Least deprived, Dep 9-10 – Most deprived) for screening age women in Waikato, New Zealand 1999–2012

developed countries.

There are many reasons for worsening mortality rates in developing countries. First, in this part of the world many breast cancers are diagnosed late. In comparison, in developed countries a majority of cancers are diagnosed early; either when they are very small palpable lumps or are impalpable as seen with mammographic screen detected cancers.

Quality, timeliness and accessibility of cancer treatment have also been contributory to this disparity. In resource limited countries like Sri Lanka, patients have to wait for a longer time to receive cancer treatment and sometimes effective latest cancer treatments might not be freely available due to cost. Furthermore, resources are not equally distributed among all regions or hospitals in our country. This obviously would lead to a sub-optimal cancer care and thereby outcome disparities by geography, socioeconomic status or ethnicity.

According to data published by the National Cancer Control Programme (NCCP) of Sri Lanka, 2401 female breast cancers have been recorded in Sri Lanka in 2010, which is lower than the GLOBOCAN estimate for the same year [1, 2]. Of those, over a third have been diagnosed at an advanced stage. Furthermore, for about 40% of breast cancers, staging data are unavailable. At least some of these unstaged cancers could be advanced at diagnosis where women would not undergo surgery and hence the actual proportion of advanced cancers are likely to be even greater.

Based on above information it is evident that there are many areas of breast cancer care that are quite obscure. For instance, there is limited data on incidence and stage at diagnosis of breast cancer in Sri Lanka. Further, we have hardly any data on how breast cancers are diagnosed, treated or followed up in Sri Lanka or their outcomes. As such, we know very little on possible disparities in cancer care by geography, ethnicity or socioeconomic status. It is important that we understand these areas in order to plan and implement measures to improve cancer outcomes in our country. Not only that, without such data we will not know how effective the measures that we implement, nor their cost effectiveness.

In the next segment of my talk, I will discuss the findings from a doctoral research project I carried out in New Zealand at the University of Auckland, where breast cancer outcomes and reasons for outcome disparities in New Zealand (NZ) were studied.

New Zealand is a country with a total population of 4.5 million. The majority about two thirds are of European origin and others are almost equally distributed among Indigenous Maori, Pacific Islanders and Asians. The health system is primarily a publicly funded although there is a

thriving private sector much like Sri Lanka. They have one of the best health information systems in the world. Through a national health index (NHI) number which is unique to each individual, life time health data for each individual could be linked with many other national health and non-health related data sets.

Breast cancer is a major public health problem in NZ. They have the 9th highest breast cancer incidence rate in the world. Further, mortality rate from breast cancer is 20% higher than neighbouring Australia which is a cause for great concern. There were some reports indicating major disparities in breast cancer outcomes by geography, socioeconomic status and geography in NZ. For instance, according to NZ National Cancer Registry (NZCR) data, Maori have a 60% higher breast cancer mortality rate than the European population and a similar though less pronounced disparity is seen between women of low and high socioeconomic groups.

Before this research project was started, there were many unanswered questions. First, why are NZ women having poor outcomes overall, and why are there so many disparities, for instance by ethnicity, geography or socioeconomic status. Secondly, what is the quantitative contribution of these factors towards breast cancer outcome disparities and finally what actions are needed to overcome these issues were also not known.

To answer these questions, a comprehensive set of data covering the full breast cancer care pathway from a population based cohort of women with breast cancer was needed. This was done through one of the four regional breast cancer registries that are functioning in New Zealand. The selected Waikato Breast Cancer Registry (WBCR) was the most comprehensive out of four regional registries. This region included a total population of approximately 400,000 which included a mix of different ethnic, socioeconomic and geographic regions.

The WBCR established in 1999 included data for all breast cancers in the region from 1999 and included over 3000 cases. A major effort was required to get the data up to the quality that was required for proposed analyses. For many cases, this required accessing the original patient records, hard or soft copies to fill in the blanks and to confirm the accuracy of data. At the end, with much difficulty a dataset was prepared that included all breast cancers diagnosed within this region over a period of 15 years.

The first analysis that was done was to compare this dataset with the national registry, the NZCR. This study found that national registry was 99% complete for registrations, but further details, for example cancer staging were missing or inaccurate for a significant proportion of women [3]. A comprehensive analysis of the dataset to identify the quality of breast cancer care and timeliness in providing such care

survival for breast cancer by socioeconomic groups for symptomatic cancer which was over 15%, but no differences were observed for screen detected cancer. This further highlighted the importance of screening as a possible tool which could be utilized to reduce cancer disparities among populations.

Ethnic differences in breast cancer biology was also studied, which has been a major topic of interest in the USA. However unlike in the USA, no major or significant differences in either tumour aggressiveness or expression of tumour receptors were observed in New Zealand [8].

Finally, this dataset was used to model how different disparities are brought about and how much each of these factors are contributing towards the observed disparities [9]. It was noted that almost all the disparities were due to modifiable factors. It was evident that, if equal quality of healthcare is provided all women have the potential to achieve equal and optimum cancer outcomes, which currently are experienced only by the rich, urban European populations.

These study findings were brought to the attention of stakeholders involved with breast cancer care to improve the quality of breast cancer care and to reduce disparities. First, the NZ Ministry of Health introduced several initiatives to improve the quality and timeliness of care which were highlighted in this study. One important area was the recruitment of specialized cancer care nurses to help women navigate the complex cancer care pathway. On the research front, these findings attracted much needed research funds to trial new strategies to improve breast cancer outcomes and to reduce disparities. Currently our research team is involved with two major interventional studies with funding from the NZ Health Research Council to identify the most effective ways to improve breast cancer outcomes and to reduce disparities.

In the next segment I will discuss how a similar breast cancer registry established locally could potentially help us accomplish the same in our country.

Establishing a registry is not expected to be an easy task. Many challenges are recognized which range from data source identification, collection of data from identified sources, funding, trained man power and maintaining confidentiality of collected data. Some of these are more relevant to the local context. For instance, as we do not have proper medical record keeping systems nor electronic records and hence data retrieval will be a major issue. Novel and innovative strategies will have to be identified and implemented in order to overcome these issues.

For example, it may be possible to obtain help from the different professional colleges of relevant specialities who are

involved with the management of breast cancer in the country. Through these college members it will be possible to identify and implement ways to ensure a steady process for identification of patients and collection of cancer data.

In addition, Ministry of Health, NCCP, hospitals where breast cancers are treated, Well Woman and related clinics manned by Medical Officers of Health, Public Health Sisters and Midwives could also be potential resources to obtain breast cancer data. Will have to be included in this process to ensure the long term functioning of the registry. Funding for functioning and long-term sustenance of the registry would be an important issue that will have to be addressed.

During the last year since my return to Sri Lanka we have done the ground work to identify challenges in establishing a registry in the local setup and to find ways to overcome these challenges. Prospective data identification and collection protocols have established and a database in Microsoft access format has been created to enter breast cancer data. However, a lot more work is needed before these data collection processes and can become fully functional.

Breast cancer is already a major public health problem in Sri Lanka and is likely to get worse in the future. We need to implement actions in many fronts to tackle this problem effectively in order to minimize the burden of breast cancer in our country. While improving and upgrading the quality of diagnostic, cancer treatment and pathology services remain the priority areas to improve breast cancer outcomes, a breast cancer registry would provide invaluable information on the effectiveness of these interventions. Many challenges are expected but we are hopeful that we can overcome these challenges with perseverance and by working together with other stakeholders to make it a reality.

The work I have presented here would not have been a possibility without the support of many people. I have named a few here and apologize for not thanking others individually. First I want to thank my supervisors at the University of Auckland Prof. Ross Lawrenson and A/Prof Ian Campbell for guiding me and for motivating me to complete my doctoral project successfully in a timely manner.

I also wish to thank Prof. Nandadeva Samarasekera, my mentor and head of the department for pursuing me to read for a PhD from the day I was recruited to the department. My colleagues at department of surgery have always been a great strength and their continuous support and motivation have been a great help. I also wish to thank my parents and in-laws for their continuous support. Last but not least, my wife Sumudu for being a caring wife and helping me throughout while herself was busy with her work.

Thank you ladies and gentlemen for your kind attention and have a pleasant evening.

All authors disclose no conflict of interest. The study was conducted in accordance with the ethical standards of the relevant institutional or national ethics committee and the Helsinki Declaration of 1975, as revised in 2000.

References

1. Ferlay J, Soerjomataram I, Ervik M, Dikshit R, Eser S, Mathers C, Rebelo M, Parkin D, Forman D, Bray F. GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide Lyon, France: International Agency for Research on Cancer; 2013. Available from: <http://globocan.iarc.fr>.
2. National Cancer Control Programme Sri Lanka. Cancer Incidence Data, Sri Lanka 2010. *Ministry of Health*, 2016.
3. Seneviratne S, Campbell I, Scott N, Shirley R, Peni T, Lawrenson R. Accuracy and completeness of the New Zealand Cancer Registry for staging of invasive breast cancer. *Cancer epidemiology*. 2014;38(5):638-44. <https://doi.org/10.1016/j.canep.2014.06.008>
4. Seneviratne S, Campbell I, Scott N, Coles C, Lawrenson R. Treatment delay for Māori women with breast cancer in New Zealand. *Ethnicity & health*. 2015;20(2):178-93. <https://doi.org/10.1080/13557858.2014.895976>
5. Seneviratne S, Campbell I, Scott N, Kuper-Hommel M, Round G, Lawrenson R. Ethnic differences in timely adjuvant chemotherapy and radiation therapy for breast cancer in New Zealand: a cohort study. *BMC Cancer*. 2014;14(1):839. <https://doi.org/10.1186/1471-2407-14-839>
6. Seneviratne S, Campbell I, Scott N, Kuper-Hommel M, Kim B, Pillai A, Lawrenson R. Adherence to adjuvant endocrine therapy: Is it a factor for ethnic differences in breast cancer outcomes in New Zealand? *The Breast*. 2015;24(1):62-7. <https://doi.org/10.1016/j.breast.2014.11.011>
7. Seneviratne S, Campbell I, Scott N, Shirley R, Lawrenson R. Impact of mammographic screening on ethnic and socioeconomic inequities in breast cancer stage at diagnosis and survival in New Zealand: a cohort study. *BMC public health*. 2015;15(1):46. <https://doi.org/10.1186/s12889-015-1383-4>
8. Seneviratne S, Lawrenson R, Scott N, Kim B, Shirley R, Campbell I. Breast Cancer Biology and Ethnic Disparities in Breast Cancer Mortality in New Zealand: A Cohort Study. *PLOS one*. 2015;10(4):e0123523. <https://doi.org/10.1371/journal.pone.0123523>
9. Seneviratne S, Campbell I, Scott N, Shirley R, Peni T, Lawrenson R. Ethnic differences in breast cancer survival in New Zealand: contributions of differences in screening, treatment, tumor biology, demographics and comorbidities. *Cancer Causes & Control*. 2015;26(12):1813-24. <https://doi.org/10.1007/s10552-015-0674-5>