Cancer Epidemiology 38 (2014) 638–644

Contents lists available at ScienceDirect

Cancer Epidemiology

The International Journal of Cancer Epidemiology, Detection, and Prevention

journal homepage: www.cancerepidemiology.net

Accuracy and completeness of the New Zealand Cancer Registry for staging of invasive breast cancer

Sanjeewa Seneviratne [a,*], Ian Campbell [a], Nina Scott [b], Rachel Shirley [c], Tamati Peni [c], Ross Lawrenson [a]

[a] Waikato Clinical School, University of Auckland, New Zealand
[b] Māori Health Services, Waikato District Health Board, Hamilton, New Zealand
[c] Waikato Breast Cancer Trust, Waikato Hospital, Hamilton, New Zealand

ARTICLE INFO

Article history:
Received 7 April 2014
Received in revised form 17 June 2014
Accepted 24 June 2014
Available online 16 July 2014

Keywords:
Breast cancer
Cancer registry
Stage
Unstaged

ABSTRACT

Purpose: Population based cancer registries are an invaluable resource for monitoring incidence and mortality for many types of cancer. Research and healthcare decisions based on cancer registry data rely on the case completeness and accuracy of recorded data. This study was aimed at assessing completeness and accuracy of breast cancer staging data in the New Zealand Cancer Registry (NZCR) against a regional breast cancer register.

Methodology: Data from 2562 women diagnosed with invasive primary breast cancer between 1999 and 2011 included in the Waikato Breast Cancer Register (WBCR) were used to audit data held on the same individuals by the NZCR. WBCR data were treated as the benchmark.

Results: Of 2562 cancers, 315(12.3%) were unstaged in the NZCR. For cancers with a known stage in the NZCR, staging accuracy was 94.4%. Lower staging accuracies of 74% and 84% were noted for metastatic and locally invasive (involving skin or chest wall) cancers, respectively, compared with localized (97%) and lymph node positive (94%) cancers. Older age (>80 years), not undergoing therapeutic surgery and higher comorbidity score were significantly ($p < 0.01$) associated with unstaged cancer. The high proportion of unstaged cancer in the NZCR was noted to have led to an underestimation of the true incidence of metastatic breast cancer by 21%. Underestimation of metastatic cancer was greater for Māori (29.5%) than for NZ European (20.6%) women. Overall 5-year survival rate for unstaged cancer (NZCR) was 55.9%, which was worse than the 5-year survival rate for regional (77.3%), but better than metastatic (12.9%) disease.

Conclusions: Unstaged cancer and accuracy of cancer staging in the NZCR are major sources of bias for the NZCR based research. Improving completeness and accuracy of staging data and increasing the rate of TNM cancer stage recording are identified as priorities for strengthening the usefulness of the NZCR.

1. Introduction

Population based cancer registries are a valuable resource for monitoring incidence and mortality from cancer and play a vital role in cancer control programmes [1]. Established in 1948, the New Zealand Cancer Registry (NZCR) collects details of all newly diagnosed primary cancers (excluding non-melanoma skin cancers) in New Zealand. Many national cancer control strategies including the New Zealand Cancer Control Strategy have recognized the importance of a high quality national cancer registry as a core component of cancer control [2].

According to the World Health Organization, a modern cancer registry is expected to provide data on a number of key areas [1]. These include enabling the assessment of the current magnitude of the cancer burden and future projections, providing a basis for research on cancer causes and prevention, providing information on prevalence of risk factors, and monitoring the effects of prevention, screening, treatment and palliative care. Quality of a cancer registry forms a cornerstone from which to achieve these tasks. The International Agency for Research on Cancer describes of five main components of quality for cancer registries [3]. These include completeness in cover,

* Corresponding author at: Breast Cancer Research Office, Waikato Hospital, PO Box 934, Hamilton 3240. New Zealand. Tel.: +64 7 8398726x97842; fax: +64 7 8343657; mobile: +64 212389039.
E-mail addresses: Sanjeewa.Seneviratne@waikatodhb.health.nz, sanjeewa_sa@yahoo.com (S. Seneviratne).

http://dx.doi.org/10.1016/j.canep.2014.06.008
1877-7821/

completeness in detail, accuracy in detail, accuracy of reporting and accuracy of interpretation.

Cancer stage is considered to be the most important factor in determining the prognosis of most cancers. Several studies have raised the issue that substantial proportions of cancers are unstaged or staged inaccurately in the NZCR [4–6]. For example an audit on colon cancer by Cunningham and colleagues reported a staging accuracy of 80% in the NZCR compared with stage determined from a clinical notes review [6]. Another audit comparing lung cancer staging in the NZCR against a regional database reported a staging accuracy of only 43.8% [5]. The same audit reported that 12% of cases out of 565 included were not known to the NZCR. Missing or inaccurate cancer stage data may lead to biased research results. A good understanding of completeness, accuracy and characteristics associated with unstaged cancer in the NZCR is required to understand the magnitude of bias and will enable rational conclusions to be drawn from cancer research.

The Surveillance Epidemiology and End Results (SEER) programme cancer staging definitions are preferred by many cancer registries for cancer stage recording [7], including the NZCR due to its simplicity. However, clinicians and pathologists widely use the Tumour Node Metastases (TNM) staging system which is more detailed and more relevant for clinical decision making [8]. Since its introduction to the NZCR in 2001, TNM stage recording has slowly been increasing and was approximately 50% complete for breast cancer in 2010 (personal communication) which is well below the SEER stage completion rate in the NZCR over this period [9]. Comparatively, cancer registries from countries such as Denmark and the Netherlands have achieved TNM completion rates of more than 90% for many cancers including breast cancer [10,11].

We conducted this study to evaluate the completeness and accuracy of breast cancer data from the NZCR against a regional breast cancer register; the Waikato Breast Cancer Register. We further aimed to describe patient characteristics associated with unstaged cancer and to compare outcome for unstaged against staged cancers.

2. Materials and methods

2.1. Data sources

2.1.1. New Zealand Cancer Registry (NZCR)

The NZCR is the national population based cancer registry that records all primary cancers (excluding non-melanoma skin cancers) in New Zealand. Under the Cancer Registry Act 1993 [12], all newly diagnosed cancers are legally required to be reported to the NZCR by the person in charge of the reporting laboratory. Thus, a copy of the pathology report for each newly diagnosed cancer is sent electronically to the NZCR, and is the major source for new cancer registrations. Other sources of new cancer registrations include discharge reports from publicly funded and private hospitals, death certificates and autopsy reports. The Ministry of Health is responsible for funding and maintaining the NZCR.

The NZCR primarily uses the SEER programme cancer staging definitions published by the National Cancer Institute of the USA [7]. For each reported case of cancer to the NZCR, stage is manually determined by experienced cancer coders, primarily using pathology report from the primary tumour excision together with additional information from hospitalization records, death certificates and autopsy reports. Stage is assigned for each cancer based on staging data available at the end of the first course of therapy, or within four months of the date of diagnosis, whichever is earlier [13]. The NZCR includes a quality assurance process which is through cross-referencing with data from other population registers such as the National Minimum Data Set, Mortality Register and other national collections.

2.1.2. Waikato Breast Cancer Register (WBCR)

The WBCR is a prospectively maintained database that includes all invasive breast cancers in women who are residents of the Waikato District Health Board area at the time of diagnosis. Eligible women with newly diagnosed breast cancer are identified through clinic records, operation records, multi-disciplinary meeting records, oncology, palliative care and other private and public hospital records. All clinical and pathologic reports of identified women are accessed and relevant presenting, diagnostic and treatment information are extracted in a structured format and then entered into the WBCR database manually by trained data entry personnel. Each woman is followed up prospectively through public and private clinic follow ups and, outcomes including cancer recurrence and death are recorded. Validity and completeness of the WBCR records are compared annually with breast cancer records for the Waikato area from the NZCR. Quality assurance of the WBCR is maintained through a regular audit process. The WBCR is the most complete regional breast cancer register in New Zealand at present and validity of its data has been established previously [14].

2.2. Data

All newly diagnosed primary invasive breast cancer records over a 13-year period from 01/01/1999 to 31/12/2011 were identified from the WBCR and compared with the same records for the Waikato region from the NZCR. Each record was matched by date of diagnosis and National Health Index number; a unique personal identification number used in all New Zealand health records for patient identification. From a total of 2623 invasive breast cancers identified for the period under review from the WBCR and the NZCR, women with a post mortem diagnosis of breast cancer ($n = 4$) and women recorded under a different area ($n = 9$) were excluded. Four cases from the WBCR not known to the NZCR and 43 cases from the NZCR not included in the WBCR (ineligible due to residence outside Waikato or due to records not available to the WBCR) were excluded from comparisons.

2.3. Variables

Extent of disease (i.e. degree of spread of the tumour within the body/tumour stage) from the NZCR for selected breast cancers were compared with same data from the WBCR. WBCR data were treated as the benchmark and completeness and accuracy of the NZCR staging records were analyzed against the WBCR.

All stage comparisons were performed according to SEER extent of disease classification which classifies tumours into 4 categories; localized, locally invasive (into skin or chest wall), involving regional lymph nodes (LN) and metastatic (i.e. tumour spread beyond breast and regional lymph node) disease [7].

Patient ethnicity was identified from the WBCR, which records self-identified ethnicity collected as a part of the WBCR consent process as per the Ministry of Health ethnicity data protocols. If self-identified ethnicity was not available from the WBCR consent form then ethnicity from the patient health service records was used. Socioeconomic status of each woman was determined based on the New Zealand Deprivation Index 2006 (NZDep2006) [15]. NZDep2006 assigns small areas of residence (mesh block areas with a median population of approximately 100) a socioeconomic deprivation decile on a scale of 1–10 based on nine socio-economic variables measured during 2006 population census; 1-most deprived, 10-least deprived.

As a pathology report from primary tumour excision would only be available for women undergoing primary surgical interventions, primary therapeutic surgical intervention was included as a predictor for staged cancer in the NZCR. Women undergoing only diagnostic or palliative surgical interventions or undergoing no surgical treatment were classified as no therapeutic surgical intervention.

Individual patient comorbidities were identified from the WBCR. The WBCR records all existing comorbid illnesses at the time of diagnosis of breast cancer, based on patient clinical records and the National Minimum Dataset, which includes comorbid illnesses for all hospital treated patients. A comorbidity score for each patient was calculated using the Charlson Comorbidity Index (CCI). CCI uses 19 medical conditions, each allocated a weight of 1 to 6 depending on the adjusted relative risk of 1-year mortality, and added together to give an overall score [16]. Comorbidity index score was grouped into 3 categories: 0, 1–2 and 3+.

2.4. Statistical analysis

Statistical analysis was performed in SPSS (Version 22). WBCR data for all women with an unknown stage in the NZCR were explored in a univariate analysis using Chi squared (χ^2) tests for trend. For staged cancers in the NZCR, sensitivity and specificity for each stage were calculated against the WBCR stage. Factors associated with unstaged cancer were explored in a multivariable logistic regression model. Survival each cancer stage in the NZCR and the WBCR were compared using Kaplan–Meier survival curves. A Cox proportional hazard model was used to estimate the risk of mortality for unstaged compared with staged cancers adjusting for age, comorbidity, ethnicity and cancer stage.

Ethical approval for this study was obtained from the New Zealand Northern 'A' Ethics Committee (Ref. No. 12/NTA/42).

3. Results

From a total of 2623 newly diagnosed primary invasive breast cancers identified from the WBCR and NZCR, 2563 cancers were found to be eligible for this study. Of these, 1 cancer for which the stage was not recorded in the WBCR was excluded leaving 2562 cancers for stage comparison.

Table 1 shows the distribution of discrepancies between the WBCR and the NZCR in relation to extent of disease. Overall, 315 (12.3%) of cancers in the NZCR were recorded as unknown stage. Of the cancers with a known stage in the NZCR, 2121 (94.4%) were found to be accurately staged compared with the WBCR. Higher proportions of unstaged and inaccurately staged cancers were seen for metastatic and locally invasive cancers compared to localized and lymph node positive cancers (Fig. 1). Sensitivity of each extent of disease category in the NZCR was 97.7%, 84%, 93.7% and 73.9% for localized, locally invasive, LN involved and metastatic cancer, respectively. Specificities for respective extents of disease were 95.3%, 99.5%, 96.5 and 99.4%.

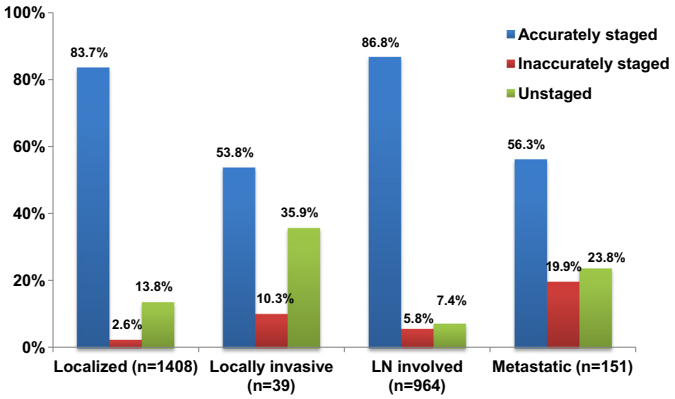

Fig. 1. Distribution of accurately staged, inaccurately staged and unstaged breast cancer in the New Zealand Cancer Registry compared with the Waikato Breast Cancer Register 1999–2011.

Stage distribution for staged cancers in the NZCR was highly and significantly ($p < 0.001$) correlated with the overall stage distribution in the WBCR over the study period and is shown in Fig. 2. Highest correlation was observed for locally invasive cancers (correlation coefficient = 0.81), while the correlations of 0.75 and 0.69 were observed for regional and metastatic cancer, respectively.

Table 2 shows a comparison of factors associated with stage known and unknown cancers in the NZCR. Advanced stage, higher comorbidity score, not undergoing therapeutic surgery and overall mortality were significantly higher for unstaged cancers ($p < 0.001$). No significant difference in the rate of unstaged cancer between Māori and NZ European (the two main ethnic groups included) were observed. However, because a higher proportion of Māori women were noted to have metastatic breast cancer compared to NZ European women (11.6% vs. 4.7%), a separate analysis was performed for unstaged metastatic cancer by ethnicity. Of the Māori women with unstaged cancer, 27.7% (13 out of 48) had metastatic cancer compared to 7.8% (20 out of 257) for NZ European women, a difference which was statistically significant ($p < 0.001$). Overall underestimation of the incidence of metastatic breast cancer in the NZCR was 21% (5.9% in the WBCR vs. 3.8% in the NZCR); 29.5% for Māori and 20.6% for NZ European women, respectively.

A multivariate logistic regression was performed with unstaged cancer as the outcome variable and age category, ethnicity, deprivation, comorbidity index and therapeutic surgery as covariates. This identified advancing age (OR = 1.63, 1.37–1.93), higher comorbidity score (OR = 1.51, 1.20–1.71) and not undergoing therapeutic surgery (OR = 7.43, 5.37–10.3) as

Table 1
Extent of cancer (stage) at diagnosis in the New Zealand Cancer Registry compared with extent of cancer at diagnosis in the Waikato Breast Cancer Register 1999–2011.

	WBCR extent of cancer									
	Localized		Locally invasive		LN involved		Metastatic		Total	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
NZCR extent of cancer										
Localized	1186	84.2	4	10.3	44	4.6	1	0.7	1235	48.2
Locally invasive	4	0.3	21	53.8	4	0.4	2	1.3	31	1.2
LN involved	20	1.4	0	0.0	837	86.8	27	17.9	884	34.5
Metastatic	4	0.3	0	0.0	8	0.8	85	56.3	97	3.8
Unknown	194	13.8	14	35.9	71	7.4	36	23.8	315	12.3
Total	1408	100	39	100	964	100	151	100	2562	100

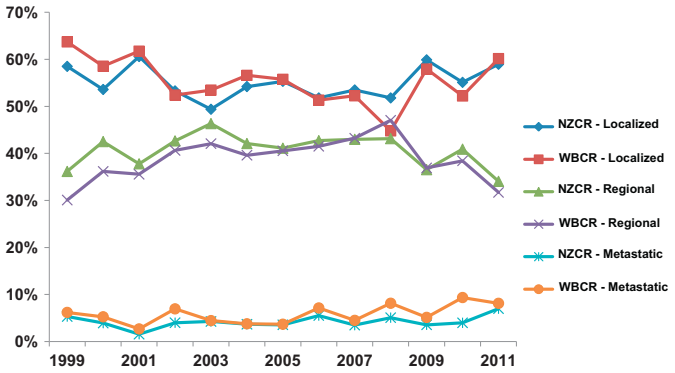

Fig. 2. Trends in proportional distribution of cancer stage in the Waikato Breast Cancer Register compared with staged cancers in the New Zealand Cancer Registry 1999–2011.

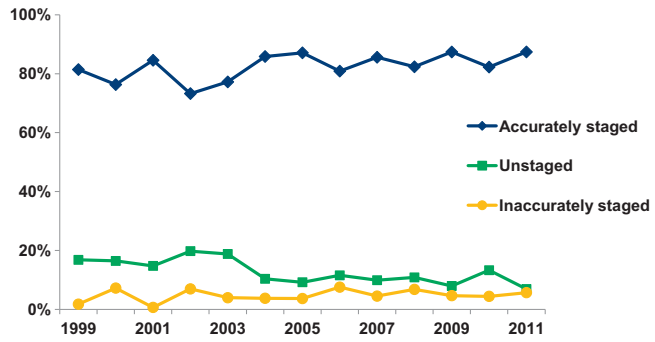

Fig. 3. Trends in unstaged, accurately staged and inaccurately staged breast cancer in the New Zealand Cancer Registry compared with the Waikato Breast Cancer Register 1999–2011.

factors significantly associated with unknown cancer stage in the NZCR (data not shown).

A gradual and a significant reduction ($p < 0.001$) in unstaged cancers and a complementary increase in accurately staged cancers in the NZCR were observed (Fig. 3). Reduction in unstaged cancer was more pronounced from 1999 to 2004 and since had only a minimal change. Even in 2011, approximately 12% of breast cancers included in the NZCR were either unstaged or staged inaccurately (i.e. unstaged 6.9% and inaccurately staged 5.7%) compared with the WBCR.

A survival analysis was performed to compare overall crude survival rate by extent of cancer in the NZCR and the WBCR (Fig. 4). Unstaged cancer in the NZCR showed a 5-year survival of 55.9% which was between the survival rates for regional (locally invasive and/or regional lymph node positive) at 77.3% and metastatic disease at 12.9%, respectively. For women with regional disease, both the NZCR and the WBCR exhibited almost similar survival rates (5-year survival 77.3% vs. 76.4%). For localized disease WBCR women had a worse survival (5-year survival 86.6% vs. 90.1%) while for metastatic cancer, the WBCR survival was better (5-year survival 17.3% vs. 12.9%) compared with the NZCR.

Cox proportional hazard model (Table 3) identified that unstaged cancers were associated with a significantly higher risk of overall mortality (HR = 1.59, $p < 0.001$) compared with staged cancers in the NZCR after adjusting for age, comorbidity index and cancer stage.

4. Discussion

A high rate of overall case completeness and a high accuracy of staging for staged breast cancer in the NZCR were observed in this study. Further, between the two registries, a high correlation in stage distribution over the study period and roughly comparable overall survival rates by stage was observed, despite the substantial proportion of unstaged invasive breast cancers

Table 2
Distribution of characteristics associated with stage known and unknown breast cancers in the New Zealand Cancer Registry for the Waikato region 1999–2011.

Characteristic	Total ($N = 2563$)		Stage known		Stage unknown		p
	n	%	n	%	n	%	
Age group							
<40	134	5.2	124	92.5	10	7.5	<0.001
40–59	1150	44.9	1055	91.7	95	8.3	
60–79	977	38.1	877	89.8	100	10.2	
80+	302	11.8	191	63.2	111	36.8	
Ethnicity							
NZ European	2077	81.0	1820	87.6	257	12.4	
Māori	380	14.8	332	87.4	48	12.6	0.887
Pacific	50	2.0	40	80.0	10	20.0	0.164
Other	56	2.2	55	98.2	1	1.8	0.028
Deprivation							
1–2	255	9.9	229	89.8	26	10.2	0.586
3–4	257	10.0	225	87.5	32	12.5	
5–6	573	22.4	504	88.0	69	12.0	
7–8	813	31.7	700	86.1	113	13.9	
9–10	665	25.9	589	88.6	76	11.4	
Charlson score							
0	2066	80.6	1875	90.8	191	9.2	<0.001
1–2	418	16.3	318	76.1	100	23.9	
3+	79	3.1	54	68.4	25	31.6	
Therapeutic surgery							
Yes	2348	91.6	2143	91.3	205	8.7	<0.001
No	215	8.4	104	48.4	111	51.6	
Outcome							
Non-death	1875	73.2	1729	91.0	170	9.0	<0.001
Death	686	26.8	516	77.9	146	22.1	
Deaths ($n = 686$)							
Breast cancer	409	59.6	334	81.7	75	18.3	<0.001
Other cause	272	39.7	177	65.1	95	34.9	
Unknown	5	0.7	5	100.0	0	0.0	

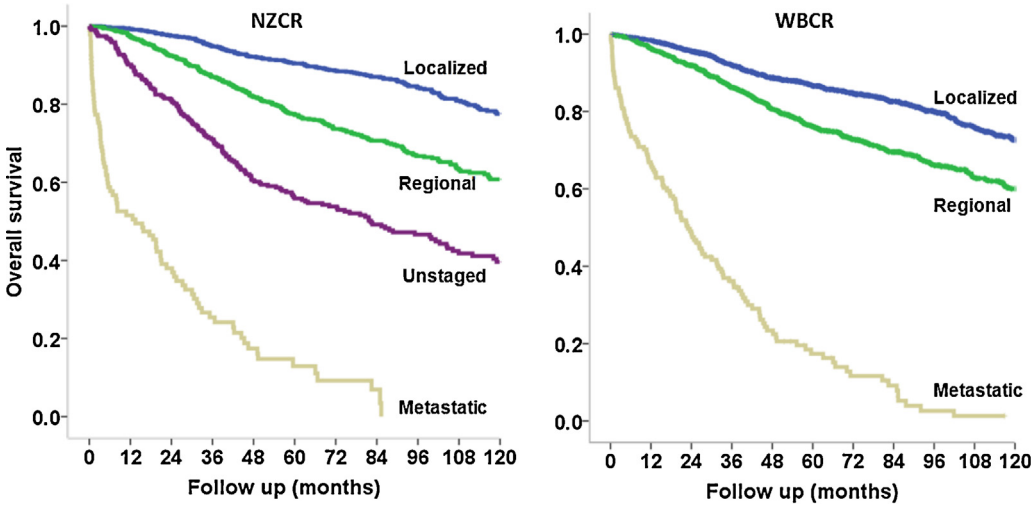

Fig. 4. Kaplan–Meier survival curves by cancer stage for invasive breast cancers included in the New Zealand Cancer Registry and the Waikato Breast Cancer Register for the Waikato region 1999–2011.

included in the NZCR. Although the proportion of unstaged cancer has improved, in 2011 the proportion of unknown and inaccurate staging was still 12%. Women with advanced stage cancers, higher comorbidity score and women who were not receiving therapeutic surgical interventions were significantly over-represented among unstaged cancers. Maori women were significantly over-represented in unstaged metastatic breast cancer. Comparable rates of case completeness, staging accuracy and unstaged tumours have previously been reported for breast cancer from population based cancer registries in the United States, the United Kingdom, the Netherlands, Denmark and Germany [11,17–21]. To our knowledge this is the first independent audit of the breast cancer records of the NZCR performed since mandatory reporting was introduced in New Zealand in 1994.

Reasons for unstaged cancer can be grouped into two categories; lack of staging and lack of reporting. Lack of staging occurs, for example when life expectancy is limited due to severe comorbidities or old age, due to patient refusal and in situations where necessary staging investigations were not available locally or where a patient could not afford investigations [22–24]. Second, where the cancer stage was known to the treating physician or recorded in clinical documents but was not reported to the cancer registry [24]. Since the breast and axilla are relatively easily accessible areas both clinically and with simple imaging, clinical stage at least is expected to be available for most, if not all women with breast cancer. This is confirmed by the fact that the WBCR has been able to record cancer stage for all but one woman, based on one or more of clinical, imaging and histopathology records.

Staging of cancers by the NZCR depends on diagnostic and therapeutic information obtained from pathology reports and other hospital records provided by reporting laboratories and hospitals. However, it appears that there has been a relative lack of non-pathologic (i.e. clinical and imaging) information being provided to the NZCR, which is evident by a high rate of unstaged cancer seen among women not undergoing therapeutic surgery. This is further supported by a high proportion of metastatic breast cancer (43.7%), which in most situations is diagnosed through imaging, being under-staged or unstaged in the NZCR. This error has led to a significant underestimation of the true incidence of metastatic breast cancer by almost 30% for Maori and by 20% for NZ European women. This underestimation explains the reason for unstaged cancers exhibiting a rate of survival worse than regional disease. Similar patterns of survival for several types of unstaged cancers in the NZCR including breast, colon and lung has been reported by Gurney and colleagues [9].

As we have observed, unstaged cancer was more likely to be associated with metastatic disease compared to localized or lymph node involved disease. As such, statistical analyses which exclude

Table 3
Multivariable Cox proportional hazard model for overall mortality risk for unstaged vs. staged cancer in the New Zealand Cancer Registry.

Characteristic		HR	95% CI	*p*
Staging status (NZCR)	Staged	Ref		<0.001
	Unstaged	1.59	1.32–1.92	
Charlson score[a]	0	Ref		<0.001
	1–2	2.16	1.81–2.57	
	3+	3.60	2.69–4.80	
Stage (WBCR)[b]	Localized	Ref		<0.001
	Locally invasive	2.39	1.58–3.61	
	Regional LN involved	1.87	1.58–2.23	
	Metastatic	12.2	9.77–15.3	
Age category (years)	<40	Ref		<0.001
	40–59	0.65	0.45–0.95	
	60–79	0.92	0.63–1.33	
	80+	2.19	1.48–3.24	

HR, hazard ratio; CI, confidence interval.
[a] Charlson Comorbidity Score.
[b] Waikato Breast Cancer Register.

these unstaged cancers, or analyses that consider these data as missing at random and apply statistical techniques such as simple multiple imputation or inverse probability weighting will likely lead to biased estimates of the true stage distribution [25]. Although more complex methods including multiple imputation combined with either chained equations or stage modelling have been shown to provide more accurate estimates of stage distribution [20], these are not used widely due to their complex nature.

This study assumes that the WBCR breast cancer data were captured perfectly without errors from all available records. The WBCR involves collecting breast cancer data from clinical records and pathology reports and entering data into a database by trained data entry personnel. Close supervision by two breast surgeons (IC and SS) and a stringent quality control and audit process is in place to maximize the completeness, quality and accuracy of the WBCR records. All these measures we believe have helped to minimize errors in the WBCR database and underlie the main strength of this study.

In 2010, an independent review of the NZCR recommended an increase in breadth of data collected, particularly through collection of clinical and imaging staging information at the time of diagnosis (clinical TNM/cTNM) to enhance accuracy of staging and to minimize number of unstaged cancers [26]. As we have reported, more than 50% of unstaged breast cancers were from women not undergoing therapeutic surgical interventions and using cTNM was expected to capture clinical staging data for a majority of otherwise unstaged cancers. Based on these recommendations, a focussed pilot project is currently being trialled by the NZCR to identify the feasibility of collecting and relaying cTNM data through Multi-Disciplinary Meetings (MDM) to the NZCR [26]. In New Zealand, the vast majority of cancers will be managed through MDM's once the National Tumour Standards of Service Provision are implemented. If this system is successful, it is expected to capture accurate cTNM staging data for a majority of cancers. As more structured and reliable information is expected to be provided through synoptic reporting, the NZCR is considering a system for automated electronic transfer of pathology information for more efficient transfer of pathology data to the NZCR.

Population based national cancer registries including the NZCR has the objective of providing key cancer variables such as incidence, mortality, inequities, stage and basic cancer characteristics with a complete nationwide coverage. The NZCR has performed a commendable job over time to provide these key cancer variables with a very high coverage, which is in par with the top national cancer registries in the world. Despite some deficiency in stage coverage as observed in this study, the NZCR has captured proportional as well as trends in stage distribution over the study period with a fairly high accuracy. From an epidemiological point of view, this evidence confirms the NZCR stage as a valid marker for most population statistical purposes, despite some limitations in areas including metastatic breast cancer.

The NZCR does not possess details of other important cancer related data such as diagnostic process, treatment details and timeliness of treatment and outcomes including local and metastatic recurrence as these aspects are beyond the scope of a national cancer registry [26]. Tumour specific regional or national registries like the regional breast cancer registries are equipped to capture comprehensive and accurate tumour specific information. Detailed information helps to identify quality of care issues around and to recognize where quality improvement could be undertaken to achieve better patient outcomes. Further, there is potential for these regional registries to be linked electronically to the NZCR in the future to enhance accuracy and completion of NZCR data. Currently, the four regional breast cancer registries, prospectively collect comprehensive breast cancer data from diagnosis through treatment, follow up and outcomes. Unfortunately, lack of recognition of the importance of these breast cancer registries and hence lack of funding is threatening the continuation of the registries and has prevented further expansion to incorporate other regions of the country.

In conclusion, while acknowledging the commendable performance of the NZCR, we emphasize that to increase the usefulness of the NZCR, improvements need to be made in completeness and accuracy of staging data and rate of TNM recording. To this end, it is crucial that all avenues for relaying cancer information to the NZCR are explored and that appropriate methods are implemented. Improvements to the completeness and quality of data on the NZCR will allow a more reliable estimation of important cancer issues, especially for metastatic breast cancer incidence. We found an almost 30% underestimation of metastatic breast cancer incidence for Maori compared with an almost 20% underestimation for NZ European women. These findings provide reference for analysis of the NZCR data, in particular for consideration of analysis of unstaged cancers by ethnicity. Alongside these improvements in the NZCR, national and regional cancer registries need to be supported to continue and improve to provide detailed cancer data to inform cancer control for the New Zealand population.

Conflicts of interest

None.

Authorship contribution

SS, RL and IC developed the concept and designed the study. SS, RS and TP developed the methodology, collected data and performed the analysis. SS wrote up the initial version of the manuscript and IC, NS, RL and RS provided comments. All authors contributed to the final version of the manuscript.

Acknowledgements

We acknowledge funding received from the Waikato Breast Cancer Trust, New Zealand Cancer Society, New Zealand Breast Cancer Foundation, WEL Energy Trust and the Lion Foundation towards the WBCR and for additional data collection for this study. We also wish to thank Robert Hipkiss, from the Ministry of Health New Zealand for providing data from the Cancer Registry for comparisons.

References

[1] National Cancer Control Programmes. Policies and managerial guidelines. 2nd ed. Geneva: World Health Organization, 2002.
[2] New Zealand Cancer Control Strategy. Wellington: Ministry of Health and the New Zealand Cancer Control Trust, 2003.
[3] Skeet RG. Quality and quality control. In: Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG, eds. Cancer registration: principles and methods. Lyon, France: International Agency for Research on Cancer, 1991: 101–7.
[4] Dockerty JD, Becroft DM, Lewis ME, Williams SM. The accuracy and completeness of childhood cancer registration in New Zealand. Cancer Causes Control 1997;8(6):857–64.
[5] Stevens W, Stevens G, Kolbe J, Cox B. Comparison of New Zealand Cancer Registry data with an independent lung cancer audit. N Z Med J 2008;121(1276):29–41.
[6] Cunningham R, Sarfati D, Hill S, Kenwright D. An audit of colon cancer data on the New Zealand Cancer Registry. N Z Med J 2008;121(1279):46–56.
[7] Adamo MB, Johnson CH, Ruhl JL, Dickie LA. SEER program coding and staging manual. Bethesda, MD: National Cancer Institute, 2010 , NIH Publication number 10-5581.
[8] AJCC cancer staging manual. 7th ed. New York: Springer-Verlag, 2010.
[9] Gurney J, Sarfati D, Stanley J, Dennett E, Johnson C, Koea J, et al. Unstaged cancer in a population-based registry: prevalence, predictors and patient prognosis. Cancer Epidemiol 2013;37(4):498–504.
[10] Ording AG, Nielsson MS, Froslev T, Friis S, Garne JP, Sogaard M. Completeness of breast cancer staging in the Danish Cancer Registry, 2004–2009. Clin Epidemiol 2012;4(Suppl. 2):11–6.

[11] Sogaard M, Olsen M. Quality of cancer registry data: completeness of TNM staging and potential implications. Clin Epidemiol 2012;4(Suppl. 2):1–3.
[12] Cancer Registry Act Stat. Public act 1993 No 102; 1993.
[13] New Zealand Cancer Registry. Available from: http://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections/new-zealand-cancer-registry-nzcr.
[14] Seneviratne S, Campbell I, Scott N, Coles C, Lawrenson R. Treatment delay for Maori women with breast cancer in New Zealand. Ethn Health 2014. http://dx.doi.org/10.1080/13557858.2014.895976.
[15] NZDep2006: index of deprivation. Wellington: Department of Public Health, University of Otago, Ministry of Health, 2007.
[16] Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. J Chronic Dis 1987;40(5):373–83.
[17] Thoburn KK, German RR, Lewis M, Nichols PJ, Ahmed F, Jackson-Thompson J. Case completeness and data accuracy in the Centers for Disease Control and Prevention's National Program of Cancer Registries. Cancer 2007;109(8):1607–16.
[18] Gulliford MC, Bell J, Bourne HM, Petruckevitch A. The reliability of Cancer Registry records. Br J Cancer 1993;67(4):819–21.
[19] Schouten LJ, Langendijk JA, Jager JJ, van den Brandt PA. Validity of the stage of lung cancer in records of the Maastricht cancer registry, The Netherlands. Lung Cancer 1997;17(1):115–22.
[20] Eisemann N, Waldmann A, Katalinic A. Imputation of missing values of tumour stage in population-based cancer registration. BMC Med Res Methodol 2011;11:129.
[21] Dregan A, Moller H, Murray-Thomas T, Gulliford MC. Validity of cancer diagnosis in a primary care database compared with linked cancer registrations in England. Population-based cohort study. Cancer Epidemiol 2012;36(5):425–9.
[22] Koroukian SM, Xu F, Beaird H, Diaz M, Murray P, Rose JH. Complexity of care needs and unstaged cancer in elders: a population-based study. Cancer Detect Prev 2007;31(3):199–206.
[23] Worthington JL, Koroukian SM, Cooper GS. Examining the characteristics of unstaged colon and rectal cancer cases. Cancer Detect Prev 2008;32(3):251–8.
[24] Lengerich EJ, Tucker TC, Powell RK, Colsher P, Lehman E, Ward AJ, et al. Cancer incidence in Kentucky, Pennsylvania, and West Virginia: disparities in Appalachia. J Rural Health 2005;21(1):39–47.
[25] Sterne JA, White IR, Carlin JB, Spratt M, Royston P, Kenward MG, et al. Multiple imputation for missing data in epidemiological and clinical research: potential and pitfalls. BMJ 2009;338:b2393.
[26] Review of the New Zealand Cancer Registry. Wellington: Cancer Control New Zealand, 2010 , Available from: http://cancercontrolnz.govt.nz/sites/default/files/Review%20of%20the%20NZ%20Cancer%20Registry.pdf.