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# Stage at diagnosis and cancer survival for Indigenous Australians in the Northern Territory

John R Condon, Tony Barnes, Bruce K Armstrong, Sid Selva-Nayagam and J Mark Elwood

Cancer mortality rates are higher for Indigenous Australians than for other Australians for many specific cancer sites. This is partly because of the higher incidence of some cancers (particularly lung and other smoking-related cancers, cervical and liver cancers), and partly because of lower survival for most cancers.<sup>1-3</sup>

Lower cancer survival rates for Indigenous people compared with non-Indigenous people have been reported from South Australia (for all cancers combined),<sup>4</sup> and from the Northern Territory (for most specific cancers examined).<sup>3</sup> Survival rates have not been reported for Indigenous people elsewhere in Australia.

In South Australia, Indigenous people were more likely to have advanced disease at diagnosis than non-Indigenous people (for all cancers combined), but this explained only part of the difference in survival.<sup>4</sup> Stage at diagnosis has not been reported for Indigenous people elsewhere in Australia, or for individual cancer sites.

Our study investigated whether, in the Northern Territory (NT), Indigenous people with cancer had more advanced disease at diagnosis than non-Indigenous people with cancer, and whether later diagnosis explains their lower cancer survival.

## METHODS

All residents of the NT diagnosed with cancers of the colon and rectum (including anus), lung, female breast, cervix or non-Hodgkin lymphoma in 1991–2000 were eligible for inclusion in this study. These five cancers were chosen as they are designated “priority” cancers in Australia, and as there were sufficient numbers of both Indigenous

## ABSTRACT

**Objective:** To investigate whether Indigenous Australians with cancer have more advanced disease at diagnosis than other Australians, and whether late diagnosis explains lower Indigenous cancer survival rates.

**Design:** Retrospective cohort study.

**Setting and participants:** Indigenous and non-Indigenous people diagnosed with cancers of the colon and rectum, lung, breast or cervix and non-Hodgkin lymphoma in the Northern Territory of Australia in 1991–2000.

**Main outcome measures:** SEER summary stage of cancer at diagnosis (local, regional or distant spread), cause-specific cancer survival rates and relative risk of cancer death.

**Results:** Diagnosis with advanced disease (regional or distant spread) was more common for Indigenous people (70%; 95% CI, 62%–78%) than for non-Indigenous people (51%; 95% CI, 53%–59%) with cancers of the colon and rectum, breast, cervix and non-Hodgkin lymphoma, but for lung cancer the opposite was found (Indigenous, 56% [95% CI, 46%–65%] v non-Indigenous, 69% [95% CI, 64%–75%]). Stage-adjusted survival rates were lower for Indigenous people for each cancer site. With few exceptions, the relative risk of cancer death was higher for Indigenous people for each category of stage at diagnosis for each cancer site.

**Conclusions:** Health services apparently could, and should, be performing better for Indigenous people with cancer in the Northern Territory, and probably elsewhere in Australia. This study has demonstrated that data from cancer registers, enhanced with data on stage at diagnosis, can be used to monitor health service performance for Indigenous Australians in the Northern Territory; similar data is available in other States, and could be used to monitor health service performance for Indigenous people throughout Australia.

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and non-Indigenous cases to enable comparison. Cases were identified from the NT Cancer Registry.<sup>5,6</sup> Hospital and private specialists' medical records were examined to collect data on stage at diagnosis and to verify data obtained from the Registry, including Indigenous status and cause of death.

## Cancer staging

Cancer stage at diagnosis was classified using the SEER summary staging system.<sup>7</sup>

This staging system was used as it is the only system that applies to all five cancers included in the study. It classifies cancers as localised, regional or distant spread. Cancer stage was also classified using the TNM staging system (except for non-Hodgkin lymphoma, to which TNM staging does not apply) and site-specific staging systems (Dukes for colorectal cancer, FIGO for cervical cancer and Ann Arbor for non-Hodgkin lymphoma); results for these systems were published elsewhere.<sup>8</sup>

## Statistical analysis

The proportion of Indigenous and non-Indigenous people with advanced disease (regional or distant spread), adjusted for age at diagnosis, was compared for each of the five cancers.

For each cancer, Cox regression analysis was used to estimate the stage-specific and stage-adjusted hazard ratios (relative risks of cancer death) and their 95% confidence

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### 1 Number of cases and proportion with advanced disease\* at diagnosis among people diagnosed with cancer in the Northern Territory, 1991–2000

Cancer site	Total cases <sup>†</sup>		Proportion with advanced disease (95% CI) <sup>‡</sup>		P <sup>§</sup>
	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous	
Colon and rectum	34	268	89% (80%–99%)	68% (62%–83%)	0.05
Lung	109	258	56% (46%–65%)	69% (64%–75%)	0.02
Breast	44	315	55% (40%–70%)	38% (33%–44%)	0.04
Cervix	40	55	37% (21%–52%)	24% (13%–35%)	0.19
Non-Hodgkin lymphoma	16	62	91% (76%–100%)	65% (53%–76%)	0.05

\* Regional or distant spread of disease.

<sup>†</sup> Number of cases with known stage for each cancer site.

<sup>‡</sup> Number of cases with regional or distant spread of disease at diagnosis as a proportion of the total number of cases with known stage, for each cancer site, adjusted for age at diagnosis to the age distribution of non-Indigenous cases.

<sup>§</sup> Test for difference between proportions of Indigenous and non-Indigenous patients with advanced disease, adjusted for age at diagnosis.

### 2 Relative risk (RR) of cancer death for Indigenous versus non-Indigenous patients by cancer site and stage at diagnosis

Cancer site	Age-adjusted RR (95% CI)			Age- and stage-adjusted RR (95% CI)
	Localised	Regional	Distant	
Colon and rectum	na	6.9 (3.6–13.1)	2.0 (0.8–4.6)	6.5 (3.7–11.3)
Lung	1.4 (0.9–2.1)	1.8 (1.1–3.0)	0.8 (0.5–1.2)	1.4 (1.1–1.8)
Breast	2.1 (0.5–9.3)	2.7 (1.2–6.4)	2.7 (0.8–9.5)	2.4 (1.1–5.2)
Cervix	2.1 (0.7–6.0)	6.5 (1.7–25.5)	na	3.0 (1.4–6.2)
Non-Hodgkin lymphoma	na	2.5 (0.5–12.2)	8.5 (2.9–24.4)	5.2 (2.2–11.9)

na = not available: there were insufficient numbers of cancer deaths to estimate relative risks in these categories.

intervals for Indigenous compared with non-Indigenous people. Follow-up for death was to 31 December 2002. Stage-adjusted, cause-specific cancer survival rates were also estimated from regression models. All regression analyses included adjustment for age at diagnosis by individual year of age.

Because of empirical evidence for the existence of important interacting effects, regression models used to estimate stage-specific hazard ratios included an interaction term for Indigenous status by age at diagnosis. Models used to estimate stage-adjusted hazard ratios also included interaction terms for Indigenous status by stage and age by stage. Cox regression analysis of cause-specific relative risk of cancer death was used to analyse cancer survival rather than relative survival because of the complexity of these interactions. For the same reason, the contribution of diagnosis with more advanced disease to lower Indigenous

cancer survival could not be validly assessed by comparing survival rates before and after adjustment for stage at diagnosis. A more detailed report of both analytical methods and results is available elsewhere.<sup>8</sup>

The study was approved by the Menzies School of Health Research Human Research Ethics Committee (HREC), the Charles Darwin University HREC and the Central Australian HREC.

## RESULTS

We found that 1373 people were eligible for inclusion; medical records containing details of cancer diagnosis and treatment could not be found for 165 of these, including 32 who were recorded by the NT Cancer Registry as Indigenous. This left 1208 participants in the study (88% of those eligible).

Sufficient information was found in medical records to enable classification of SEER

summary stage at diagnosis for 1201 people (99.4% of those for whom medical records were available). Five of the seven patients for whom stage at diagnosis could not be determined were non-Indigenous (two with colorectal cancer, one with lung cancer, and two with breast cancer), and two were Indigenous (both with lung cancer).

## Cancer stage at diagnosis

Indigenous people with cancer of the colon and rectum, breast, cervix, and non-Hodgkin lymphoma, were more likely to be diagnosed with advanced disease than non-Indigenous people, although the difference was not always statistically significant (Box 1). For all four cancers combined (adjusted for cancer site and age at diagnosis), 70% of Indigenous people were diagnosed with advanced disease (95% CI, 62%–78%) compared with 51% of non-Indigenous people (95% CI, 53%–59%).

For lung cancer, Indigenous people were less likely than non-Indigenous people to be diagnosed with advanced disease (Box 1).

## Cancer survival rates

With one exception (lung cancer with distant spread), the relative risk of cancer death, adjusted for age at diagnosis, was greater for Indigenous than for non-Indigenous people in each category of stage at diagnosis for each cancer site, although not all 95% confidence intervals excluded 1.0 (Box 2). The stage-adjusted relative risk of cancer death was significantly greater in Indigenous than non-Indigenous people for each cancer site.

These differences were reflected in a lower age- and stage-adjusted 5-year cause-specific cancer survival rate in Indigenous people compared with non-Indigenous people for each cancer site (Box 3).

## DISCUSSION

Between 1991 and 2000 in the NT, Indigenous people with cancer of the colon and rectum, breast, cervix and non-Hodgkin lymphoma were more likely to be diagnosed with advanced disease than non-Indigenous people. Only for cancer of the lung were Indigenous people less likely to be diagnosed with advanced disease than non-Indigenous people.

Cancer survival was lower for Indigenous patients than non-Indigenous patients for all five cancer sites examined and, with few exceptions, for each stage at diagnosis for

### 3 Adjusted cause-specific 5-year cancer survival rates,\* by cancer site and Indigenous status

Site	Non-Indigenous	Indigenous
Colon and rectum	55.0%	30.7%
Lung	11.5%	5.2%
Breast	83.7%	67.5%
Cervix	70.0%	27.1%
Non-Hodgkin lymphoma	65.2%	16.3%

\* Derived from Cox regression models, adjusted for age at diagnosis and stage at diagnosis; confidence intervals could not be calculated.

each cancer site. Thus while the more advanced cancer stage at diagnosis in Indigenous patients for four of the five cancer sites may explain part of their poorer survival from cancer, it is unlikely to explain it all.

Although up to 12 years had elapsed between diagnosis and data collection, all but 165 records were available (12% of eligible cases). Including these additional cases could have changed the results of the study to only a small extent. A data-quality audit of the Registry for cases diagnosed in the period 1991–1999 estimated that completeness of case ascertainment was about 94%.<sup>6</sup> A recent project by the Registry to identify previously unregistered cases increased the number of registered cases diagnosed in 1991–1999 by 3%.<sup>6</sup> These additional cases were not included in this study, but would have made little difference to the results reported here.

The degree of misclassification of Indigenous status was small. A data-quality audit of the NT Cancer Registry estimated that about 15% of Indigenous people in the Registry were misclassified as non-Indigenous;<sup>6</sup> this was reduced to about 12% for people included in this study after examination of their medical records during data collection. We have no data from which to estimate the effect of Indigenous under-identification on the difference between Indigenous and non-Indigenous cancer survival rates. Bias in either direction could be argued.

Cause-specific survival analysis relies on the accuracy of recording of cause of death, to differentiate cancer deaths from non-cancer deaths. Cause of death was verified during examination of medical records, rather than relying on death registration data recorded by the Cancer Registry. Cause-

specific analysis was also found to give similar results to relative survival analysis (not reported here).

Our finding that a higher proportion of Indigenous people had localised lung cancer compared with non-Indigenous people is inconsistent with the findings for the other four cancer sites. Indigenous people in the NT have very high prevalence of chronic respiratory disease and a high incidence of tuberculosis; consequently, they may have more frequent chest x-rays and other investigations as part of clinical management or long-term follow-up and contact tracing by the tuberculosis control program.<sup>9,10</sup> This might explain why they are more likely to be diagnosed with early-stage disease. Alternatively, the proportion of Indigenous people with regional disease at diagnosis may have been underestimated if Indigenous patients with lung cancer were less likely to have intensive investigations, such as mediastinoscopy, thoracoscopy and exploratory thoracotomy.

A reason that Indigenous people with cancer had a later stage at diagnosis and lower survival rates could be that all five cancers are more “aggressive” in Indigenous people, either because there is something different about the biology of these cancers in Indigenous people or because Indigenous people are more susceptible to rapid cancer spread. However, the distribution of histological grade was similar in Indigenous and non-Indigenous people for all five cancer sites.<sup>8</sup> There was also little difference in morphological type, except in colorectal cancer, which was more likely to be squamous cell carcinoma in Indigenous people.<sup>8</sup> It is much more likely that more advanced disease at diagnosis in Indigenous people is due to late diagnosis, possibly because of low awareness of potentially dangerous early symptoms and tardiness in seeking medical advice, poor access to or low quality of primary care, diagnostic or specialist services, or reluctance to seek attention when symptoms cause concern because of nihilistic beliefs about cancer and the chance of cure.<sup>11–13</sup> For breast and cervical cancer, low participation of Indigenous women in screening programs may also be involved.<sup>14</sup>

The 5-year cancer survival rates in non-Indigenous people were similar to those for Australia as a whole for cancer diagnosed in 1992–1997: colon cancer, 61.6%; rectal cancer, 59.7%; lung cancer, 14.2%; breast cancer, 83.3%; cervical cancer, 76.3%; non-Hodgkin lymphoma, 69.3% (Australian rates adjusted to the age and sex distribution

of NT Indigenous cases, from the Australian Institute of Health and Welfare<sup>15</sup>). While this comparison is not exact, because of the different methods used to estimate survival rates (relative survival for Australian rates, and regression-modelled cause-specific survival for NT non-Indigenous rates), it does suggest that NT cancer services can perform at near to national levels for non-Indigenous patients.

Although SEER summary staging is not as detailed as staging by other systems, comparison of stage-adjusted hazard ratios using summary staging and more detailed staging indicated that summary staging provided effective adjustment for stage at diagnosis (results not shown). Lower stage-adjusted cancer survival in Indigenous people may be due to choices against more aggressive, curative treatment (particularly if treatment requires interstate travel); delayed or incomplete treatment; or factors which make Indigenous people more susceptible to the life-threatening complications of cancer treatment. The latter could include presence of other chronic diseases; heavy alcohol and tobacco consumption; and poor housing and environmental conditions, which increase the risk of infectious diseases during and after chemotherapy and radiotherapy.<sup>16,17</sup>

Our results suggest that health services apparently could, and should, be performing better than they currently are for Indigenous people with cancer in the NT, and probably elsewhere in Australia. In the NT, Indigenous people are more likely to be diagnosed late and, once diagnosed, have a lower chance of cure than non-Indigenous people. The reasons for later diagnosis and lower survival for Indigenous patients should be identified and remedied.

This study has demonstrated that analysis and reporting of cancer stage at diagnosis and cancer survival can be used to assess the performance of the NT health services in providing cancer diagnosis and treatment services to Indigenous people. Data sources are available for the same purpose from cancer registries in other States, but have either not been analysed or are too limited by inadequacy of identification of Indigenous people to be useful. These limitations should be remedied as soon as possible so that the performance of cancer services for Indigenous Australians can be measured and improved nationally and, on the evidence of our data, urgently.

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## COMPETING INTERESTS

None identified.

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