

Cancer incidence and survival for Indigenous Australians in the Northern Territory

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Cancer mortality rates are higher for Indigenous than non-Indigenous Australians for many specific cancers,¹ but the extent to which higher Indigenous cancer mortality is due to higher cancer incidence or lower survival has not been established. Large differences between Indigenous and other Australians in cancer incidence for many specific cancers have been reported from four Australian States or Territories (Queensland, South Australia, the Northern Territory, and Western Australia), with higher Indigenous rates for cancer of the lung, liver and cervix, but lower rates for cancer of the breast, colon and rectum, prostate, melanoma of skin and lymphoma.²⁻⁵ These differences were relatively consistent for the specific cancers reported from more than one State, but the possibility of consistent error cannot be completely excluded because of misclassification of, or absent data on, Indigenous status in cancer registers.^{6,7} The Queensland Cancer Registry cannot report Indigenous cancer incidence rates but has reported incidence rates for 13 remote communities where Indigenous people comprise 90% or more of the population.⁵

The Western Australian Cancer Registry has reported Indigenous incidence rates, but in 1996 and 1997 17-18% of registrations had missing data on Indigenous status.^{8,9} The South Australian Cancer Registry has also reported Indigenous incidence rates, but only after a special project to identify Indigenous cases.³ None of these reports included assessment of the degree of misclassification of Indigenous status.

There is even less evidence available about the survival of Indigenous people with cancer. The only reported study of Indigenous cancer survival compared 139 Indigenous patients with cancer diagnosed in South Australia in 1988-94 with a sample of non-Indigenous cancer patients matched for year of diagnosis, age at diagnosis, sex and primary site; Indigenous patients had lower cancer-specific five-year survival than non-Indigenous (37% *c/w* 49%).³ Survival for specific cancers was not reported.

A thorough assessment of data quality has recently been done for the Northern Territory Cancer Registry (NTCR), including re-screening of notification sources.¹⁰ For patients diagnosed in the period 1991-2001,

Abstract

Objective: To compare cancer incidence and survival for the Northern Territory (NT) Indigenous population with that of other Australians, and to assess NT Indigenous incidence time trends.

Methods: Cancer registry data were used to calculate cancer incidence rate ratios (NT Indigenous to total Australian), the average annual change in NT Indigenous cancer incidence and the relative risk of cancer death after diagnosis of cancer (NT Indigenous to combined Western Australian and Tasmanian cases) for 1991-2001.

Results: For NT Indigenous people, incidence rates were high for cancers of the liver, gallbladder, cervix, vulva and thyroid and, in younger people only, for cancers of the oropharynx, oesophagus, pancreas and lung, but low for cancers of the colon and rectum, breast, ovary, prostate, bladder, kidney, melanoma and lymphoma. Incidence rate ratios ranged from 0.1 for melanoma to 7.4 for liver cancer. Incidence increased for breast and pancreatic cancers. Survival was low for almost all specific cancers examined, and for all cancers combined (relative risk of death 1.9, 95% CI 1.7-2.1).

Conclusions: Compared with other Australians, NT Indigenous people have higher, and increasing, incidence for some cancers (particularly smoking-related cancers) and lower survival for most.

Implications: Cancer has a greater impact on NT Indigenous people than other Australians. Well-established cancer risk factors should be more effectively tackled in Indigenous people and known effective screening programs more effectively implemented. Research is urgently required into the reasons why survival from cancer in NT Indigenous people is so much lower than in other Australians.

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case ascertainment was estimated to be over 95% complete, compared with ascertainment by other Australian cancer registries. A small degree of misclassification of Indigenous status was found; it was estimated that approximately 5% of cases registered as non-Indigenous were actually Indigenous people. While Indigenous status data in the NTCR is not completely accurate, the extent of misclassification has been estimated and can be taken into account when interpreting Indigenous incidence rates.

This report summarises cancer incidence and survival statistics for the Indigenous population of the Northern Territory (NT), providing the most detailed and reliable information on cancer occurrence available for an Indigenous Australian population and the first report for any Indigenous Australians of trends in cancer incidence and of survival for specific cancer sites.

Methods

Data sources

Cancer incidence and survival data for the NT Indigenous population were obtained from the NTCR for cases recorded as being Indigenous and diagnosed in 1991-2001. A time-series of NT Indigenous population estimates was produced by a back-casting method and used to calculate incidence rates: these are the most reliable NT Indigenous population estimates currently available.¹¹ Deaths were identified in incident cancer cases by matching to the NT Deaths Register and the National Death Index, which is compiled from death registrations in all States and Territories of Australia.

Total Australian cancer incidence data for the same period were obtained from the National Cancer Statistics Clearing House.¹² The Australian mid-year Estimated Resident Population was used for calculation of total Australian rates.¹³

NT Indigenous cancer survival was compared with that of all Western Australian and Tasmanian residents diagnosed with cancer in 1991-2001 (97,000 cases in total). Suitable data were not available from other State cancer registries. NT non-Indigenous cases were not used as the comparison group because of the small number and the possibility that survival from cancer in non-Indigenous people in the NT may not be representative of that in Australia as a whole.

Statistical analysis

NT Indigenous cancer incidence was compared with total Australian incidence by estimation of incidence rate ratios (NT Indigenous to total Australian) using negative binomial regression modelling for 20 specific cancers, and for cases with unknown primary site. The model included terms to adjust for age (in five-year age-groups), the square of age, sex (where appropriate), population group (NT Indigenous and total Australian) and four indicator terms for NT Indigenous aged 0-64 years, NT Indigenous 65+, total Australian 0-64 and total Australian 65+. These indicator terms were included after preliminary analysis with a model including interaction terms for specific age-groups (0-24, 25-44, 45-64, 65+) indicated that the incidence rate ratio in younger age

groups was different from that in age group 65+ for several specific cancers. The term for square of age was included because cancer incidence did not increase exponentially with age in older age groups.

To examine trends in NT Indigenous cancer incidence, the average annual change in incidence rate was estimated by negative binomial regression modelling for the 13 most common cancers in NT Indigenous people. The model included terms to adjust for age (in five-year age groups), the square of age, year of diagnosis and sex where appropriate. Trends were not examined separately for younger and older people because preliminary analysis did not indicate that there were differences in trends between the two age groups.

A proportional hazards regression model was used to compare cause-specific survival for NT Indigenous cases with that for combined Western Australian and Tasmanian cases for each of the 13 most common specific cancers in NT Indigenous people. The model included terms for age at diagnosis and sex (where appropriate). Cases notified at the time of death from cancer, for which no information about the diagnosis of cancer could be found, were excluded. The survival period was censored at 31/12/2002. Survival for all cancers combined was also estimated using a model which included terms for age at diagnosis, sex and primary site of cancer (at the three-digit ICD-9 coding level). The proportional hazards model estimates the 'hazard ratio', which is the relative risk of death due to the diagnosed cancer for NT Indigenous cases compared with that of the comparison group. A hazard ratio greater than 1.0 indicates a lower survival rate for NT Indigenous cases than for those in the comparison group.

The project was approved by the Human Research Ethics Committee (HREC) of the Menzies School of Health Research and the NT Department of Health and Community Services (and by its Aboriginal subcommittee), by the HREC of the Charles Darwin University, and by six HRECs in other States.

Results

Incidence comparisons

NT Indigenous cancer incidence rates were higher than total Australian rates for cancers of the liver, gallbladder, cervix, vulva and thyroid, and, in younger people only, for cancers of the oropharynx, oesophagus, pancreas and lung, but were lower than total Australian rates for cancers of the colon and rectum, breast, ovary, prostate, bladder and kidney and for melanoma of skin and lymphoma (see Table 1). The differences in incidence were large; NT Indigenous incidence rates ranged from 90% less than total Australian rates for melanoma of skin to over seven times more for cancer of the liver. For cancers of the oropharynx, oesophagus, pancreas and lung, Indigenous incidence rates were higher than total Australian rates for younger but not for older people, and the difference between age groups was statistically significant; all four are smoking-related cancers.

Incidence trends

The NT Indigenous incidence rate for cancers of the pancreas and breast increased by more than 200% between 1991 and 2001, and 95% confidence intervals for the annual average increase did not include zero for these two cancers (see Table 2). Incidence rates for several other cancers also increased by a large amount, but their confidence intervals were wide and included zero. There were no cancers for which there were large falls in cancer incidence.

Survival comparisons

Compared with people diagnosed with cancer in Western Australia and Tasmania, NT Indigenous patients had poorer survival for most cancers (see Table 3). The relative risk of death was higher, and confidence intervals did not include 1.0, for cancers of the oropharynx, colon and rectum, pancreas, lung, breast, uterus, cervix, vulva, lymphoma and leukaemia, with the relative risk ranging from 60% higher for lung cancer to over six times higher for oropharyngeal cancer.

Discussion

These findings for cancer incidence and survival probably explain most or all of the differences in cancer mortality between

NT Indigenous people and the whole Australian population for most specific cancers.¹⁵ For cancers of the liver, lung, and oesophagus, higher NT Indigenous mortality rates are due almost entirely to higher cancer incidence rates. Survival rates are very low for all people with these cancers, and are only a little worse in NT Indigenous people than in all Australians. For other cancers that have better survival rates in all Australians, such as cancer of the cervix and thyroid, high Indigenous mortality rates are a product of higher incidence and lower survival. Compared with the total Australian population, incidence rates in NT Indigenous people are lower for cancers of the breast, colon and rectum and lymphoma, but their mortality rates are higher than would be expected because their survival rates are lower than those of other Australians.

The NT Indigenous incidence rates reported here under-estimate actual cancer incidence by approximately 15-20%, because of a small degree of under-ascertainment of cases and misclassification of Indigenous status in the NTCR. However, this does not explain the differences between NT Indigenous and total Australian incidence rates for specific cancers reported here. While for cancers with rate ratios less than one, actual NT Indigenous incidence was not as low as estimated, the differences between NT Indigenous and total Australian rates were large and would

Table 1: Cancer incidence rate ratios comparing NT Indigenous people with the whole Australian population by age group in 1991-2001.

Site	Age 0-64 years	Age 65+ years	All ages ^a	Age interaction p-value ^b	NT Indigenous cases (n)
Oropharynx ^c	2.5 (1.9-3.2) ^d	0.8 (0.4-1.6)	– –	0.01	65
Oesophagus ^c	4.0 (2.4-6.7)	1.3 (0.6-2.8)	– –	0.03	21
Stomach ^c	0.9 (0.5-1.8)	0.4 (0.2-1.1)	0.7 (0.4-1.2)	0.17	13
Colon/rectum	0.6 (0.4-0.9)	0.2 (0.1-0.4)	– –	0.01	44
Liver	7.9 (5.4-11.4)	6.5 (3.9-11.0)	7.4 (5.4-10.0)	0.56	45
Gallbladder	4.5 (2.5-8.1)	1.7 (0.7-4.1)	3.0 (1.8-4.8)	0.07	16
Pancreas ^c	3.2 (2.1-4.9)	0.8 (0.4-1.7)	– –	0.00	28
Lung ^c	3.1 (2.5-3.8)	1.2 (0.9-1.6)	– –	0.00	152
Melanoma	0.1 (0.1-0.1)	0.1 (0.0-0.3)	0.1 (0.0-0.1)	0.64	8
Breast	0.4 (0.3-0.6)	0.5 (0.3-0.8)	0.4 (0.3-0.6)	0.50	63
Uterus	1.6 (1.0-2.6)	0.4 (0.1-1.6)	1.2 (0.8-1.9)	0.06	20
Cervix	2.3 (1.6-3.3)	3.9 (2.0-7.6)	2.6 (1.8-3.5)	0.19	46
Ovary	0.4 (0.2-1.0)	0.5 (0.1-2.1)	0.5 (0.2-0.9)	0.81	7
Vulva ^c	12.2 (7.5-19.7)	3.4 (1.1-10.5)	– –	0.04	20
Prostate	0.2 (0.1-0.5)	0.2 (0.1-0.4)	0.2 (0.1-0.3)	0.84	17
Bladder ^c	0.2 (0.0-0.8)	0.5 (0.3-1.1)	0.4 (0.2-0.7)	0.21	9
Kidney ^c	0.1 (0.0-0.6)	0.1 (0.0-0.8)	0.1 (0.0-0.4)	0.83	3
Thyroid	1.5 (1.0-2.3)	1.3 (0.3-5.3)	1.5 (1.0-2.2)	0.89	24
Lymphoma	0.4 (0.3-0.7)	0.2 (0.1-0.7)	0.4 (0.2-0.6)	0.32	18
Leukaemia	1.0 (0.7-1.5)	0.6 (0.2-1.3)	0.9 (0.6-1.3)	0.22	31
Unknown primary	3.7 (2.8-4.9)	1.8 (1.3-2.6)		0.00	78

Notes:

(a) The rate ratio for all ages combined is reported only for cancers for which the interaction term was not statistically significant.

(b) p-value for regression model interaction term testing whether rate ratio is the same in the two age-groups (p-value <0.05 indicates difference in rate ratios is statistically significant).

(c) Smoking-related cancers.¹⁴

(d) 95% confidence intervals in brackets.

have been reduced by only a small amount if NT Indigenous incidence rates were 20% higher than calculated. Low ascertainment of Indigenous cases could also have produced lower Indigenous incidence rates, but this does not seem plausible when Indigenous incidence rates for several cancers were 2-7 times higher than Australian incidence rates, and for liver and lung cancers NT Indigenous incidence rate ratios were almost the same as mortality rate ratios.¹⁵ Misclassification of Indigenous status would only influence NT Indigenous survival rates if Indigenous people recorded as non-Indigenous had different (most likely better) survival than those correctly recorded as Indigenous. If this were the case, the estimated relative risk of death would slightly over-estimate actual risk.

The high incidence of lung and liver cancer in NT Indigenous people is consistent with their very high prevalence of smoking and hepatitis B carriage.¹ The high incidence of cervical cancer may be related to lower Pap test coverage or to higher prevalence of infection with carcinogenic types of the Human Papillomavirus (HPV) for NT Indigenous than other Australian women. There is indirect evidence that Pap test coverage is lower for NT Indigenous than Australian women generally.¹ There is little evidence available about the prevalence of HPV genotypes in Indigenous women.¹⁶ However, the very high incidence of vulvar cancer in NT Indigenous women, particularly in younger women, also suggests that genital infection with carcinogenic HPV genotypes may be more prevalent in them, although the evidence that HPV is a causative factor is not as strong for vulvar cancer as for cervical cancer.¹⁷

There are indications that the incidence of smoking-related cancers is increasing in the NT Indigenous population. The incidence of cancers of the oropharynx, oesophagus, stomach and pancreas all increased between 1991 and 2001, although the

confidence intervals for the average annual change in incidence rate included zero for all except pancreatic cancer, and the incidence of lung cancer fell. In addition, smoking-related cancers appear to be having a greater impact on younger than older Indigenous people, relative to other Australians; the rate ratios for NT Indigenous to total Australian incidence were much higher in the age group 0-64 than 65+ for all smoking-related cancers examined except bladder cancer. The higher incidence rate ratios for smoking-related cancers in younger people may be due to earlier commencement or higher levels of tobacco consumption in them. A 'healthy survivor' effect may also be involved, if Indigenous smokers died from other smoking-related diseases in early and middle adulthood, so that smokers were less likely than non-smokers to live beyond age 65. Unlike other smoking-related cancers, the incidence of bladder cancer was much lower for NT Indigenous than other Australians; why this was the case is not apparent.

There was a moderate increase in NT Indigenous breast cancer mortality in the late 1990s,¹⁵ which is consistent with the increase found in breast cancer incidence, but the size of the increase in incidence, over 200% in only 11 years, is surprising. The increase in the incidence rate could have been the result of under-ascertainment of cases in the early 1990s, but the increase in breast cancer deaths over the same period indicates that there has been a real increase in incidence. This could be partly because of increasing levels of obesity, the prevalence of which has increased over the past four decades.¹⁸⁻²⁰ There has been a considerable fall in fertility rates for NT Indigenous women since the late 1960s,¹¹ which would be expected to be followed by an increase in breast cancer incidence, but such an effect is not evident in the incidence rate ratios in Table 1 where the ratio is less in women aged 0-64 years than in those aged 65+. Despite the large increase in breast

Table 2: NT Indigenous cancer incidence rates, percentage change 1991-2001.

Primary site	Average annual change % (CI) ^a	Change over 11 years (%) ^b
Oropharynx	6.4 (-1.7-15.1)	75
Oesophagus	10.3 (-4.3-27.0)	141
Colon and rectum	6.0 (-4.2-17.3)	69
Liver	4.0 (-5.3-14.2)	42
Pancreas	14.2 (0.5-29.6)	230
Lung	-2.2 (-7.0-2.8)	-18
Breast (female)	13.9 (4.7-23.9)	223
Uterus ^c	1.7 (-11.6-16.8)	16
Cervix	-3.4 (-11.8-5.9)	-26
Vulva	7.3 (-7.2-24.0)	89
Thyroid	9.7 (-5.3-27.2)	131
Lymphoma	4.6 (-9.8-21.3)	50
Leukaemia	0.2 (-10.6-12.3)	1

Notes:

(a) Average annual percentage change.

(b) Percentage increase over 11 years calculated as annual estimated raised to power of 10.

(c) Excluding cervix.

Table 3: Cancer survival, hazard ratio NT Indigenous to WA and Tasmania combined, cases diagnosed 1991-2001.

Primary site	Hazard ratio ^a	95% CI
Oropharyngeal	6.3	4.6-8.7
Oesophagus	1.6	0.9-2.6
Colon and rectum	2.2	1.5-3.3
Liver	1.0	0.7-1.5
Pancreas	3.0	2.0-4.5
Lung	1.6	1.4-2.0
Breast	4.7	3.1-7.0
Uterus	5.4	2.5-11.7
Cervix	3.6	2.4-5.4
Vulva	3.6	2.2-4.0
Thyroid	2.6	0.8-8.4
Lymphoma	5.5	3.3-9.0
Leukaemia	3.5	2.3-5.2
All cancers combined	1.9	1.7-2.1

Note:

(a) Adjusted for age at diagnosis and (where applicable) sex.

cancer incidence, the NT Indigenous rate remained lower than the total Australian rate throughout this period (annual rates not shown).

Although NT Indigenous cervical cancer mortality rates fell by over 50% in the period 1997-2000 compared with the previous 20 years,¹⁵ the estimated reduction in incidence between 1991 and 2001 was small (26%) and confidence intervals for the average annual percentage change included zero (see Table 2). However, a fall in mortality before a fall in incidence is consistent with the early impact of increased Pap test coverage. Screening of previously unscreened women detects some cancers early and thereby maintains or even transiently increases the incidence rate, but early detection and treatment improves the chance of cure, thereby decreasing the mortality rate. Whether the fall in mortality in the late 1990s was the first sign of reduced long-term mortality due to increasing Pap test coverage, or a temporary fluctuation due to random variation in the number of cases in a small population, may not be clear for several years.

There are many possible reasons why survival is so much lower in NT Indigenous people than in other Australians with cancer. There is evidence that Indigenous people are diagnosed later and with more advanced disease than non-Indigenous people.^{3,21} Other possibilities include delayed or incomplete treatment, choice against intensive curative treatment, and the presence of other chronic diseases. Indirect factors such as poor environmental conditions and unsafe housing, which increase the risk of infectious diseases, may also increase the risks associated with chemotherapy and radiotherapy. High levels of tobacco and alcohol consumption might also play a role. There is no evidence available about the impact of any of these factors on cancer survival in Indigenous people.

NT Indigenous survival is not low because specialist health services in the NT lack the technical capacity to treat cancer effectively. The relative risk of death from cancer for non-Indigenous people in the NT (compared with Western Australian and Tasmanian cases) for the same period for all cancers combined was 1.17 (95% CI 1.11-1.24). This indicates that the chance of survival was slightly lower for non-Indigenous cases in the NT than in other Australians, but the relative risk of death was much less than that for NT Indigenous people (see Table 3). Although specialist cancer diagnosis and treatment services are present in the Territory, access to and effectiveness of these services may be less for Indigenous people, particularly those from remote areas.

The differences in cancer incidence described here have direct implications for cancer control in the NT, and indirectly for other parts of Australia. The higher incidence of cancers of the liver and cervix and smoking-related cancers are each amenable to preventive measures. Hepatitis B vaccination commenced for Indigenous children in the late 1980s;²² reduction in liver cancer incidence will take several decades. Tobacco control programs are relatively underdeveloped and need to be much more effective before the occurrence of smoking-related cancers and other health problems is reduced.²³ Pap test programs have not yet reported recent Pap test coverage or time-trends specifically for Indigenous

women, and it is too early to determine whether the moderate reduction in cervical cancer incidence between 1991 and 2001 is a random fluctuation or a real reduction in disease occurrence. However, there are indirect indications that Pap test coverage is increasing, and mortality may have fallen in recent years.^{15,24}

For breast cancer, the increase in both incidence and mortality is an important finding for the breast cancer screening program in the NT. When established in the mid-1990s, the program did not specifically target Aboriginal women living in remote communities, partly due to the lower incidence of breast cancer in NT Indigenous women.^{25,26} A holistic program addressing several aspects of women's health, the Well Women's Screening Program, was established instead.²⁷ In light of the increasing breast cancer incidence and mortality among NT Indigenous women, the degree of emphasis on mammography screening for remote Indigenous women should be reconsidered. However, this is not a simple decision based on disease incidence rates alone; other factors are also important, including the high degree of acceptability of the holistic approach offered by the Well Women's Screening Program and the physical, technical and financial obstacles to providing mammogram services in very isolated communities in central and northern Australia.

Cancer has a greater impact on Indigenous than other Australians, partly because of higher incidence of some cancers and partly because of poorer prospects for survival in those who have cancer. Cancer risk factors must be more effectively tackled in Indigenous people and screening programs more effectively implemented. Tobacco control and cervical screening, which are established and effective cancer prevention strategies in the general Australian population, must become just as effective in the Indigenous population. Equally important is reducing excessive cancer mortality by improving survival for those with cancer. Research is urgently required into the reasons why cancer survival is so much lower for Indigenous than other Australians. This may be partly related to the fundamental disadvantages of Indigenous people in Australian society, and beyond the reach of health services to intervene directly, but it may also be related to access to and delivery of health services, which may be amenable to relatively rapid remediation. The specific factors responsible for low Indigenous cancer survival need to be urgently identified so that remediation may begin.

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