

ABORIGINAL AND TORRES STRAIT ISLANDER AUSTRALIANS AND CANCER

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Abstract

It is increasingly evident that inequalities exist for Indigenous people with cancer. Incidence for all cancers combined is similar to or lower than that of non-Indigenous people, but incidence of cancers with a poorer prognosis, such as lung cancer, is higher among Indigenous people, largely due to higher rates of smoking. Indigenous Australians with cancer are diagnosed with more advanced disease and are less likely to receive or complete curative treatment than non-Indigenous Australians. Wide disparities exist in cancer survival between Indigenous and non-Indigenous Australians, particularly in the first year after diagnosis. The need to improve cancer-related health services for Indigenous Australians is apparent, however the available evidence is currently inadequate to effectively direct efforts. For example, despite high cancer mortality rates, there is little information about palliative care services, their models of care or their uptake by Indigenous cancer patients. Through an increased understanding of how cancer affects Indigenous Australians and the establishment of collaborations, in particular the recently funded Centre for Research Excellence DISCOVER-TT, and networks such as the Clinical Oncological Society of Australia, an opportunity for targeted efforts in improving cancer outcomes for Indigenous Australians is tangible.

Until recently, little information has been available about the impact of cancer on Aboriginal and Torres Strait Islander (hereafter respectfully referred to as Indigenous) Australians. There were few Indigenous cancer survivors and few Indigenous health professionals specialising in oncology and cancer-related fields. Cancer was not viewed as a high priority issue, obscured by many other health conditions which seemingly had a much greater impact on Indigenous people (relative to other Australians). Now, based on new higher-quality data sources, it is evident that there is an urgent need for our health care system to address the specific needs of Indigenous people and improve its performance across the spectrum of cancer control, from prevention and early diagnosis to effective treatment, palliation and support for cancer patients and their families.

Reliable semi-national cancer incidence statistics that cover 84% of the Indigenous population have recently become available.¹ The incidence rate for all cancers combined for Indigenous people is similar to, or slightly lower than, that of other Australians. However, compared with other Australians, Indigenous Australians have much lower incidence of some cancers (breast, prostate, testis, colorectal and brain cancer, melanoma of skin, lymphoma and leukaemia), but much higher incidence of others (lung and other smoking-related cancers, cervix, uterus and liver cancer), many of which are largely preventable.¹ In contrast to incidence, cancer mortality is higher for Indigenous than other Australians. The death rate for all cancers combined and for most individual cancers is higher for Indigenous than other Australians; for example, although the incidence of breast cancer is lower for Indigenous than other Australian women, their mortality rate is 30% higher.²

Cancer risk factors: smoking is key

The prevalence of several cancer risk factors is different for Indigenous than other Australians. Some of these are protective against cancer, such as higher melanin levels in skin, earlier age at first pregnancy and longer periods of breastfeeding. Others increase the risk of cancer occurrence, such as lower participation in cancer screening, higher prevalence of Hepatitis B infection and higher prevalence of smoking.

Smoking is the single most damaging risk factor for Indigenous people, for cancer and many other health problems. Most of the cancers that occur more commonly among Indigenous than other Australians are smoking-related, including lung, oesophagus, pancreas and stomach.¹ Indigenous smoking prevalence is more than double that of other Australians; 47.7% of Indigenous people aged 18 and over were daily smokers in the most recent reliable national survey.³ However, indigenous smoking prevalence has been falling (except among women living in remote areas), accompanied by reductions in the proportion who smoke more than 20 cigarettes per day and increased proportions who have successfully quit.^{4,5} The Council of Australian Governments has committed to halving the Indigenous prevalence of daily smoking by 2018, with commitments of nearly \$140 million over four years.⁶ This investment is being used to expand the Indigenous tobacco control workforce, enhance Quitlines, and implement the first national indigenous anti-tobacco marketing campaign, 'Break the Chain'. This will complement other mainstream Australian tobacco control measures.

Cancer screening

BreastScreen Australia, the National Cervical Screening Program and the National Bowel Cancer Screening Program make up the three cancer screening programs in Australia.

Despite over 15 years of national coverage, the National Cervical Screening Program still cannot provide comparable information on screening participation and outcomes for Indigenous women because pathology request forms and reports, and therefore Pap test registers, do not include information on indigenous status. Although some regional studies have consistently reported lower participation rates in cervical screening among Indigenous than other women, participation rates higher than the national average have been reported from the Tiwi Islands in the Northern Territory, indicating that high participation rates are in fact achievable.⁷

BreastScreen Australia has recently produced comprehensive information about breast screen participation and outcomes for Indigenous women for the first time. Compared to other Australian women, Indigenous women have lower screening participation rates (although this difference appears to be diminishing), are less likely to attend post-screening assessment, and those diagnosed with breast cancer have larger cancers.⁸

Indigenous Australians are significantly less likely to accept an invitation to screen in the national program than non-Indigenous Australians (17.0% c/w 38.6%). Indigenous people have higher faecal occult blood test positivity rates (8.6 c/w 7.5%) than non-Indigenous participants (although this is not statistically significant) and a lower proportion of Indigenous people correctly complete the test.⁹

Diagnosis and treatment

Several studies from South Australia, the Northern Territory and Queensland have reported that Indigenous cancer patients have more advanced disease when diagnosed. In South Australia in 1988-1994, 50% of Indigenous patients were diagnosed with localised disease, compared with 60% of non-Indigenous patients (adjusted for age, sex and cancer site).¹⁰ In the Northern Territory in 1991-2000, 30% of Indigenous patients with non-Hodgkins lymphoma, cervical, colorectal and breast cancers had localised disease at diagnosis, compared to 49% of non-Indigenous patients (four cancers combined, adjusted for cancer site and age), although localised disease was more common for Indigenous patients diagnosed with lung cancer (44% c/w 31%).¹¹ In Queensland in 1997-2006, 47% of Indigenous people diagnosed with cancer had localised disease compared to 53% of non-Indigenous people (matched for age, sex, place of residence, cancer site and year of diagnosis).¹² These studies highlight the need for identifying and reducing the barriers to early detection of cancer among Indigenous people.

Studies in the Northern Territory and Queensland have found that Indigenous cancer patients are less likely to be recommended for, choose and complete curative treatment than non-Indigenous patients. In the Northern Territory in 1991-2000, Indigenous patients with non-

Hodgkins lymphoma, cervical, bowel, breast and lung cancers were less likely to be recommended for curative treatment (Indigenous 59% compared with non-Indigenous 70%); among those offered curative treatment, Indigenous patients were less likely to choose it (90% c/w 96%); and among those who chose it, Indigenous patients were less likely to complete it (85% c/w 94%).¹³

In Queensland in 1997-2002, Indigenous patients, in general, were also 24% less likely than non-Indigenous patients to receive surgery, 20% less likely to receive chemotherapy and 9% less likely to receive radiotherapy.¹² Indigenous patients with head and neck cancers (1998-2004) were significantly less likely to receive any cancer treatment (75% c/w 95%),¹⁴ as were Indigenous women with gynaecological cancers (91% c/w 98%).¹⁵ In contrast, Indigenous women with breast cancer received comparable treatment to their non-Indigenous counterparts (96% c/w 96%) and treatment completion rates were similar ($p > 0.05$).¹⁶

Taken together, these studies indicate the importance of reducing barriers to Indigenous patients accessing high quality specialist care.

Survival

Survival rates for most cancers are lower for Indigenous than other cancer patients. Recently in Queensland, it was found that Indigenous patients had much higher mortality than non-Indigenous patients in the first two years after diagnosis (50% higher in the first year, adjusted Hazard Ratio, 1.50; 95% CI, 1.38-1.63), but similar mortality thereafter (HR 1.03; 95% CI, 0.78-1.35 in the third year after diagnosis).¹⁷ Indigenous patients are more likely to have advanced disease when diagnosed and have higher prevalence of chronic diseases than non-Indigenous patients but these factors only partly explain their lower survival.^{12,13} Other factors related to cancer treatment and the effect of their economic, social and environmental circumstances may also be involved.

Another study in Queensland found that crude cancer survival was 30% worse (HR 1.30, 95%CI 1.15-1.48) and non-cancer deaths were over twice as common among Indigenous than non-Indigenous cancer patients (HR 2.39, 95%CI 1.57-3.63). When stage at diagnosis, socioeconomic status, comorbidities and treatment uptake were taken into account, the risk of cancer death became non-significant.¹⁸ These results suggest that treatment, comorbidities and stage at diagnosis explain most of the poorer cancer outcomes among Indigenous patients. This has critical implications for the design and delivery of the full spectrum of health services.

Palliative care

Cancer patients comprise a large part of palliative care services' caseload. Given the high cancer mortality rates among Indigenous Australians, culturally appropriate palliative care services are warranted. However, to date there is little information available about services on offer, or their uptake by Indigenous Australians with cancer. More broadly, a key finding from a National Indigenous Palliative Care Study reported a lack of comprehensive

data on the rates of Indigenous access to palliative care.¹⁹ Recent attempts have been made to increase Indigenous communities' understanding of the concept of palliative care through the Program of Experience in the Palliative Approach, a national program funded in 2003 by the Australian Government. As a result, Indigenous health workers have reported being more empowered by knowledge, skills and confidence to provide, coordinate or facilitate appropriate and holistic end of life care, and increase communication between these workers and specialist palliative care services.²⁰ A study investigating the referral patterns to a palliative care service in the Northern Territory reported Indigenous patients were younger (54 v 70 years), more likely to be female (52 v 29%), living rurally (52% v 12%) and more likely to die at home (47% v 11%) in comparison to non-Indigenous Australians.²¹ This indicates the need for these services to have broadly-encompassing service plans and flexible delivery models.

Support services

Although prevention, screening, diagnosis and treatment are important determinants of health outcomes for Indigenous people with cancer, many do not access these services.^{22, 23} Basic infrastructure and logistical issues such as a lack of transport and having appropriate travel arrangements, and suitable accommodation for both the patient and their support person, may also impede Indigenous people's access to cancer care and treatment services.²⁴ A recent Queensland study identified that Indigenous adult cancer patients have substantial unmet supportive care needs and that they have most need for additional support with psychological and practical assistance.²⁵ In Queensland, Indigenous cancer patients have indicated that they most frequently accessed Indigenous health workers (68.8%) for support and use printed cancer information (66.9%) to source information about their cancer rather than access Cancer Council Helpline (12.1%).²⁶

Policy, programs, service models

The gaps in diagnosis, treatment and survival indicate that current programs and models of service delivery do not fully meet the needs of Indigenous Australians with cancer. A recent review highlighted the inadequate participation in and ownership of cancer health services by Aboriginal people outside the realm of community-controlled health services, as well as a shortage of Indigenous cancer care workers. Both deficiencies can have a major impact on Indigenous people's use of cancer services.²⁷ The National Cancer Control Initiative recommended "... *that the needs of special populations, especially Aboriginal peoples, be the focus of special efforts to bridge the current gaps in access to and utilisation of culturally sensitive cancer service.*"²⁸

Some service initiatives appear to be implemented successfully, but formal evaluations have been rare. For example, telemedicine services have been used to overcome some of the barriers to access and utilisation of medical services by Indigenous cancer patients, especially those living in rural and remote areas. Teleoncology allows

the patient to stay in their community for treatment and/or follow-up. The patient and their family, in the presence of a health worker, doctor or nurse, are able to link in at their local health centre via video conference with the specialist located elsewhere. This model of care has received high satisfaction levels when delivered to Indigenous patients located in remote areas of North Queensland.²⁹

Recent national initiatives

The first national meeting to focus on cancer as a health issue for Indigenous Australians was convened by Cancer Council Australia in Darwin in 2004, the proceedings of which were published in a dedicated issue of *Cancer Forum*.^{30, 31} From this workshop, Cancer Council Australia established a working party to focus on cancer control for Indigenous Australians. In 2010, Cancer Australia commissioned a report to provide direction for reducing the disparities Indigenous people experience across the cancer control continuum. This report was published in July 2010; Cancer Australia is still considering what actions to take.

In December 2010, the Lowitja Institute hosted a national workshop on priorities for indigenous cancer research in partnership with the Queensland Institute of Medical Research. This workshop was widely supported by leading cancer experts, Indigenous survivors, Indigenous community representatives and advocacy groups.³² As a direct result of this workshop, a collaboration of Australia's leading researchers working in the area of cancer in Indigenous Australians, together with collaborators from New Zealand, Canada and the United States, developed a proposal for a Centre for Research Excellence in Indigenous Cancer Control, which was funded by the National Health and Medical Research Council in 2012. This new national centre, DISCOVER-TT (Discovering Indigenous Strategies to improve Cancer Outcomes via Engagement, Research Translation and Training), was established in late 2012. The DISCOVER-TT research program will address some of the key recommendations of the Cancer Australia review, particularly those relating to pathways and outcomes of care and improving models of care and service delivery. An international conference on cancer in Indigenous peoples is planned for 2014. One of DISCOVER-TT's first initiatives has been to establish the National Indigenous Cancer Network (NICaN), a network devoted to making sure that what is known about cancer in Indigenous Australians is available to people with cancer, their families, practitioners, policy makers and researchers. NICaN has been developed through a partnership involving the Menzies School of Health Research, the Australian Indigenous HealthInfoNet, the Lowitja Institute and Cancer Council Australia. For more information or to join NICaN, visit www.cancerinonet.org.au.

The Clinical Oncological Society of Australia (COSA) is Australia's peak national body representing multidisciplinary health professionals whose work encompasses cancer control and care. COSA members are doctors, nurses, scientists and allied health professionals involved in the clinical care of cancer patients, and therefore have the potential to play an important role in addressing poorer survival outcomes for Indigenous Australians. At COSA's

Annual Scientific Meeting in 2012, inequalities in cancer care were highlighted across a number of poster and oral sessions. COSA embraced this further by including in the program a plenary session on inequalities in cancer care, which included a presentation on *'Inequality in cancer care for Indigenous Australians'* and a symposium on *'Translating the evidence to improve cancer care for Indigenous people'*.

With the momentum and synergies established through these national partnerships, it is anticipated that inequities that exist for Indigenous Australians with cancer won't be overlooked, and that prevention and treatment strategies will be enhanced, translating to improved survival and quality of life for Indigenous people.

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