9 CONCLUDING REMARKS [1]

The aims of this project were to document the descriptive epidemiology of cancer in Indigenous people in the NT, and to investigate why they have lower cancer survival than other Australians. The first of these aims has been achieved, and the second achieved in large part, although further questions remain to be investigated. Previously, there was no information on long-term cancer mortality trends for Indigenous Australians, incidence statistics were of questionable reliability because of uncertain data quality (particularly the classification of indigenous status) and there had been only one report of cancer survival; now, there is comprehensive and reliable information on cancer for the Indigenous population of the NT, if not yet for Indigenous people elsewhere in Australia. The development of time-series data on Indigenous deaths and population estimates has also provided a basis on which to investigate trends in the overall health status of the NT Indigenous population, and in mortality from other specific conditions.

At the conclusion of this project I do not make specific recommendations on priority issues to be addressed, or on individual actions required to address them, because: there is little evidence for Indigenous Australians on what specific actions would be effective; there has been little attention given to the issue of cancer by Indigenous health organisations or government policy development processes; and this project has not involved consultation with Indigenous people to support such recommendations. The first national conference on cancer and Indigenous Australians occurred only recently, in late 2004, after this thesis was completed. In the absence of consultation with Indigenous health organisations and a consultative policy development process, it is not appropriate to make recommendations on priority actions on the basis of the inadequate evidence currently available.

9.1 Cancer in the NT Indigenous population: descriptive epidemiology

In the 1990s Indigenous people in the NT had higher incidence of some cancers, but lower incidence of others, compared with total Australian rates. The differences in cancer incidence between NT Indigenous and other Australians were large for several cancers; incidence rate ratios (comparing NT Indigenous to total Australian rates) ranged from 0.1 for melanoma to 7.4 for liver cancer.

For most of the cancers examined, Indigenous survival (as measured by relative risk of cancer death after diagnosis of cancer) was lower than that for other Australians. For cancers with little chance of curative treatment for all patients, Indigenous or otherwise, such as cancers of the lung, liver and pancreas, survival was only a little lower for Indigenous patients. For these cancers, incidence rate ratios were similar to mortality rate ratios; higher Indigenous mortality rates were due almost entirely to higher incidence rates. Reduction in NT Indigenous mortality from these cancers requires reduction in their incidence. For other cancers such as those of the breast, cervix, vulva, thyroid, colon

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[1] This is the concluding chapter of the thesis: Condon JR. Cancer and Indigenous Australians in the Northern Territory. Doctoral Thesis, Charles Darwin University. 2004. Research results presented, and external material referred to and cited, in preceding chapters have not been specifically cited in this chapter; a list of published papers is included in the reference list (section 9.5)

and rectum, survival was much lower for Indigenous than for non-Indigenous patients. For cancers of the cervix and thyroid, higher Indigenous mortality rates were due to a combination of higher incidence and lower survival. For breast and colorectal cancers, Indigenous incidence rates were lower than total Australian rates, but mortality rates were higher than would be expected because survival was lower for Indigenous than other Australians. Breast and colorectal cancers are two of the few health issues for which Indigenous people have lower incidence than other Australians, but this advantage is eliminated by less effective health care and lower chance of cure.

9.1.1 Smoking-related cancers

The prevalence of smoking in Indigenous adults is approximately double that of other Australians. This is directly reflected in the much higher incidence and mortality rates of lung and most other smoking-related cancers for NT Indigenous people than for other Australians. The large increase in Indigenous mortality rates from smoking-related cancers between 1977 and 2000 indicates that incidence also increased over that period. Although there are no reliable data on smoking prevalence trends over that period, the very large increase in mortality rates suggests that tobacco consumption was much lower for Indigenous people in the 1950s and 1960s than in more recent decades. This would be consistent with an increase in tobacco supply to, and an increase in purchasing power of, Indigenous people as a welfare-based cash economy was introduced for most of the NT Indigenous population after the 1967 referendum (which reduced the constitutional discrimination against Indigenous Australians) and subsequent changes in the status of Indigenous people in Australia.[1]

For most people with a smoking-related cancer there is little or no chance of curative treatment at present; prevention is the overwhelmingly the most important strategy to reduce the impact of these cancers on Indigenous as on other Australians. Smoking prevention programs commenced later for Indigenous than other Australians, and there is little reliable evidence of recent trends in tobacco consumption, or of changes in knowledge of and attitudes to tobacco consumption, among NT Indigenous people.[2,3] It will be many years before a reduction in tobacco consumption is apparent in cancer incidence and mortality rates; more direct information about the impact of tobacco prevention programs on Indigenous people, and about trends in tobacco consumption, is urgently required.

9.1.2 Cancers of the breast, cervix and vulva.

Breast cancer incidence and mortality rates for NT Indigenous women were lower than total Australian rates in the early 1990s, but increased in the late 1990s; their survival was much lower than that of other Australian women. The reasons for their increasing breast cancer incidence have not been investigated in this study, but are likely to be, at least in part, related to increasing prevalence of obesity and changes in reproductive behaviour. Although it is attractive to think that lower breast cancer incidence could be maintained in Indigenous women, the rapidly changing environments, aspirations and life-styles of Indigenous people in the NT, and the related changes in reproductive behaviour, are not likely to be amenable to reversal in the name of breast cancer prevention. However, the level of obesity is amenable to intervention; reversing the trend of increasing obesity is an important, and increasingly recognised, public health issue in the Indigenous and wider Australian community.

Other strategies to reduce the impact of breast cancer on NT Indigenous women through early detection, more effect treatment and greater support, are also necessary, as for other Australian women. Since its commencement in the NT in the mid-1990s, the National Breast Screening Program has not targeted Indigenous women in remote communities, because of the low incidence of breast cancer in this population and the high cost and technical difficulties of providing reliable mammography screening in remote areas. This policy needs to be reviewed if breast cancer incidence and mortality rates have increased for Indigenous women in remote areas to the same extent as the total NT rates (which needs to be confirmed), and if these increases have been sustained since 2001.

Cervical cancer mortality was over eight times higher for NT Indigenous women than for other Australian women, partly because of higher incidence and partly because of lower survival. Rapid reduction in cervical cancer incidence is possible through improving the participation of Indigenous women in Pap test screening. There is strong, if indirect, evidence that Pap test coverage is low for Indigenous women in the NT. However, this is not the case in remote communities in Central Australia, where Pap test coverage rates are comparable to, or better than, those achieved for Australian women overall.[4,5] There are also indications, although not conclusive, that Pap test coverage has increased for Indigenous women since the commencement of the Women's Cancer Screening Program in 1994 and that cervical cancer incidence and mortality fell during the 1990s. If these trends are confirmed, and continue or preferably accelerate, NT Indigenous women may in several years be at little or no greater risk of getting cervical cancer than other Australian women.

Unfortunately, information on Pap test coverage for NT Indigenous women is only indirect. Since 1994 the NT has had a Pap Test Register (PTR) that records all Pap test results for women resident in the NT (except those who choose to opt out of the register) and sends reminders to women who are overdue for their next Pap test. The effectiveness of the Women's Cancer Screening Program for Indigenous women is not certain because of the lack of data on Pap test coverage for Indigenous women.[4] Indigenous status is not recorded on the register because indigenous status cannot be reliably obtained from pathology request forms, so Pap test coverage rates cannot be calculated separately for Indigenous and non-Indigenous women. Alternative methods to identify Indigenous women recorded in the PTR, such as data linkage with the NT public hospitals patient registration system, are available and should be used, as was done during the data quality audit of the NT Cancer Register for the project. Reporting of Pap test coverage for Indigenous women should be one of the highest priorities of the Women's Cancer Screening Program, to understand what have been the program's achievements and where they have occurred.

The higher incidence of vulval cancer as well as cervical cancer in NT Indigenous women raises the possibility that there may be differences in the prevalence of oncogenic genotypes of Human Papilomavirus (HPV) in NT Indigenous than other Australian women. Unlike cervical cancer, higher vulval cancer incidence in Indigenous women is not due to lower participation in screening because there is no screening program for vulval cancer. The higher incidence of both cervical and vulval cancer suggests that the prevalence of oncogenic types of HPV may be higher in Indigenous women, although the evidence that HPV is involved in the causation of vulval cancer is not as conclusive as for cervical cancer. Nevertheless, this finding suggests that the occurrence of HPV in Indigenous women should be investigated, as should the detection and treatment of vulval cancer, and the awareness of this cancer among Indigenous women and their health care providers increased.

9.1.3 Cancer of the liver

The very high prevalence of chronic Hepatitis B carriage and, to a lesser extent, the high prevalence of heavy alcohol consumption are the most obvious causes of higher liver cancer incidence. Hepatitis B vaccination of Indigenous children commenced in the NT in 1987. This should eventually reduce liver cancer incidence by reducing the prevalence of chronic Hepatitis B carriage in Indigenous adults, but it may be two or more decades yet before liver cancer incidence falls. Reduction in the very high prevalence of heavy alcohol consumption in Indigenous adults would also assist in reducing liver cancer incidence; there is little indication that there has been much progress in this area over the past two decades, although evidence of time trends in Indigenous alcohol consumption is incomplete.

9.1.4 Cancers with lower incidence

The darkly pigmented skin of most NT Indigenous people is obviously the reason for low incidence of melanoma, and the reproductive factors which may have contributed to lower breast cancer incidence have been discussed above. The reasons for the low incidence of other cancers, and the means to maintain this low incidence as Indigenous environments and lifestyles changes in the NT, are not apparent. In particular, the low incidence of colorectal cancer is a mystery; the previous hunter-gatherer nutritional pattern changed to a predominantly store-oriented, processed food pattern for almost all NT Indigenous people more than four decades ago. Many Indigenous people aged over 60 years in the 1990s spent their childhood and adolescent years living a nomadic hunter-gatherer lifestyle, before their tribal groups were ‘settled’ in government settlements or church mission stations.[6] It may be that the low incidence of colorectal cancers is related to the hunter-gatherer diet of these older people in their childhood and adolescence, but this is only speculation.

There are even fewer clues to the reason for the relatively low incidence of prostate, kidney and bladder cancers. Low levels of Prostate-Specific Antigen (PSA) screening in Indigenous men may be partly responsible for their low incidence of prostate cancer, but there is no evidence of the level of PSA screening in the NT Indigenous population. The low incidence of bladder cancer is a particular surprise since, as a smoking-related cancer, it would be expected to be more rather than less common in Indigenous people.

To some extent, cancer prevention lags several decades behind for Indigenous Australians than for the rest of the Australian population. In the general Australian community, the campaign against smoking took many decades to achieve widespread recognition of its dangers and support for persuasive, and later coercive, measures to reduce tobacco consumption. Specific campaigns designed for Indigenous people are only recent developments; in the absence of evidence of changes in attitudes to, and levels of, tobacco consumption, their impact is unknown.

Pap test coverage is over 60% for the total Australian population, and cervical cancer mortality has been declining for many years; for Indigenous women, Pap test coverage appears to be much lower, although perhaps beginning to increase in the past ten years, and there was no fall in cervical cancer mortality in the NT Indigenous population until the late 1990s. The only area of cancer prevention in which Indigenous people are ahead of the rest of the population is in childhood Hepatitis B vaccination, which commenced several years earlier for Indigenous than other Australian infants, but only because the incidence of Hepatitis B infection in childhood, and the prevalence of Hepatitis B carriage in adulthood, was so much greater in the Indigenous population.

9.2 Cancer diagnosis and treatment

Indigenous survival rates were lower than non-Indigenous rates for most cancers studied and, among Indigenous people, lower for Indigenous-language speakers than English-language speakers. For all Indigenous people, late diagnosis was part of the explanation for lower survival; for some, deficiencies in cancer treatment, and other unidentified factors, were also involved.

9.2.1 Diagnosis

Regardless of first language, Indigenous people were more likely than non-Indigenous people to be diagnosed with advanced disease for four of the five cancers studied in more detail. Other than an association with older age at diagnosis, no reason was found for later cancer diagnosis in Indigenous people among the factors which could be investigated in this study.

Further investigation of the reasons for late diagnosis, and the means to rectify this problem, should focus on primary care services and Indigenous people themselves. There are many possible reasons for later cancer diagnosis in Indigenous people. Indigenous people may delay seeking medical advice about potentially serious symptoms because they are not aware of their significance; they may have little confidence in their primary care or specialist health services or seek initial treatment from traditional healers; they may have no ready access to primary care services; they may have fatalistic or nihilistic beliefs about cancer in particular or chronic disease in general; or they may have many other problems in their own lives and those of their families which take precedence over seeking early medical attention for non-urgent problems. Primary care services may not recognize the significance of symptoms with which Indigenous people present, or respond appropriately to them. Primary care services may have inadequate resources such as: lack of appropriate staff (particularly medical practitioners); lack of staff of the appropriate gender; insufficient and overworked staff; high staff turnover; lack of training and experience in cross-cultural communication and the cultural and social norms of the Indigenous community in which they are working, and in which they are guests; inadequate clinical supervision of Aboriginal Health Workers; or lack of administrative support to organize further investigation and follow-up. Primary care practitioners may be 'de-sensitized' by the high proportion of acutely ill clients and sometimes slow to respond to less dramatic symptoms. Many primary care services in the NT are geographically isolated; travel for specialist investigations, including simple x-rays, is very expensive, may involve one or more days travel, and is time-consuming for both the patient who undertakes it and the health service that organizes it. Late diagnosis may also be because of poor co-ordination between primary care and specialist services, particularly for Indigenous-language speakers where communication difficulties may be important issues.

Further research into the reasons for late diagnosis of cancer in Indigenous people should include qualitative research with Indigenous people themselves and their health care providers; quantitative approaches demonstrate differences between Indigenous and non-Indigenous people, and pose questions as to why these differences occur; the answers to these questions need to be sought in the complexity of system capacity and organization, and of individual knowledge and belief, priorities and trust. Such matters require the greater depth and subtlety of intensive, qualitative inquiry.

9.2.2 Treatment

Ineffective cancer treatment played a part in lower cancer survival for only some Indigenous people: those whose first language was an Indigenous language. For English-language speakers, lower cancer survival was entirely explained by late diagnosis and their higher proportion of lung cancer (among the five cancers studied in more detail); after adjusting for these factors, their relative risk of cancer death was similar to that of non-Indigenous patients. While Indigenous people who have been raised throughout their lives in a predominantly English-speaking environment retain many distinctive features of Indigenous culture and society, it appears that once cancer is diagnosed, treatment outcomes for these Indigenous people are no different to those for non-Indigenous people.

Cancer treatment is not as effective for Indigenous-language speakers, however, partly because they were more likely to decline all medical intervention once diagnosed with cancer and they were less likely to be offered, choose and complete curative treatment. The deficiencies found in cancer treatment did not fully explain the lower cancer survival of Indigenous-language speakers, and identification of these differences does not answer the question of why they occur. The distinction found between Indigenous groups based on whether they speak an Indigenous language is unlikely to be solely an issue of poor communication, although this is clearly an important issue. Other educational, economic, environmental, geographic, cultural and social factors may also be involved. Until these questions are answered, the means to improve treatment outcome for Indigenous-language speakers remain unknown.

The distinction between English- and Indigenous-language speakers identified here should not be taken to indicate that there are no cultural or communication barriers between health services and English-language speakers. English-language speakers are diagnosed later, and consequently have lower cancer survival, than non-Indigenous patients. Similar issues of knowledge and beliefs about cancer and chance of cure, confidence in and access to primary care services, and other cultural and social factors need to be investigated to determine why these Indigenous people are also at a disadvantage when they develop cancer.

9.3 Monitoring health service performance for Indigenous people

9.3.1 Cancer prevention programs

With the exception of cervical cancer, incidence and mortality rates do not provide useful information for monitoring the performance of preventive programs; the time between exposure to modifiable causative factors and diagnosis of cancer is too long, and there are too many factors involved in cancer causation and the timing of diagnosis. Intermediate measures of performance are required, such as smoking prevalence rates, Hepatitis B vaccination coverage, obesity prevalence and measures of nutrition and physical activity.

For cervical cancer, monitoring of disease incidence is a useful measure of a cancer prevention program because improvements in Pap test coverage can produce a relatively rapid fall (over several years rather than decades) in cervical cancer incidence and mortality. However, even for cervical cancer, the intermediate outcome measure of Pap test coverage is a more direct measure of overall program performance, and more sensitive to short-term changes and the performance of individual services. Achieving direct measurement of Pap test coverage rates for Indigenous women should be a high priority for the national Pap test program, and for individual primary care services.

9.3.2 Cancer diagnosis and treatment services

Stage at diagnosis was the principal determinant (other than type of cancer) of lower cancer survival for English-language speakers in the NT, and is probably of similar importance for Indigenous people elsewhere in Australia. Stage at diagnosis is an important measure of health service performance, although in itself it does not identify specific deficiencies in particular primary care or diagnostic services. This project did not identify factors responsible for late cancer diagnosis in Indigenous people; further investigation is required to identify the particular issues involved, and to define indicators that can be used to evaluate strategies to improve diagnostic services.

Deficiencies in treatment were partly responsible for lower cancer survival only for Indigenous-language speakers, the majority of whom live in the NT. Comparison of the proportion of Indigenous people who are recommended curative treatment, and who complete all recommended treatment, may not be important for Indigenous people elsewhere in Australia, if their experience is similar to that of English-language speakers in the NT. However, it cannot be assumed that the experience of Indigenous people elsewhere is the same as that of the NT Indigenous population; cancer diagnosis, treatment and survival should be investigated elsewhere in Australia before these factors are dismissed as useful measures of health service performance.

9.3.3 Cancer data and general health service performance

It is likely that a wide range of changes are required in health services, and the way that Indigenous people use them, to improve cancer diagnosis and treatment outcomes for Indigenous people in the NT. Some changes would be specific to cancer prevention programs such as Pap test and mammography screening. However, most changes would affect primary care and specialist services more generally, be they earlier presentation with suspicious symptoms, or earlier referral for investigation, or improved collaboration between primary care and specialist services, or better training of hospital staff in cross-cultural communication. Such improvements would not be restricted to people with cancer alone; they would very likely also improve the diagnosis and treatment of people with other chronic conditions.

Because of the serious and discrete nature of cancer and the intensive nature of cancer treatment, compared to many other chronic diseases, there is a more comprehensive information infrastructure available to monitor diagnosis, treatment and outcome for cancer than for most other health problems. Indicators of health service performance for Indigenous people with cancer may be a useful indirect indictor of overall health service performance for Indigenous people with chronic diseases, until reliable data becomes available for other health care outcomes.

There is currently almost no information available on health system performance for Indigenous people in urban areas and in the eastern states, or on time-trends in health status and health system performance. Existing data on cancer diagnosis and treatment from cancer registers and related sources offers one of the best possibilities for monitoring health system performance for Indigenous Australians, not only in the NT but elsewhere in Australia. The success of this project in the NT demonstrates that this can be done where conditions are most favorable; the possibilities for similar success elsewhere should be explored.

9.4 Summary

Cancer has a greater impact on Indigenous than non-Indigenous Australians, for a variety of reasons, including greater incidence of some cancers, later diagnosis and, for some, less effective treatment. These deficiencies need to be addressed through a variety of strategies; some, particularly preventive strategies, have already commenced and need to be evaluated, extended and probably improved. But equally as importantly, the reasons for the deficiencies in diagnosis and treatment found here need to be further investigated to identify the means to redress them. For Indigenous-language speakers, much more needs to be done to identify the distinctive factors about these Indigenous people that cause them to have the greatest disadvantage in cancer survival.

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