International comparisons

Much is written about the incidence and prevalence of acute rheumatic fever and rheumatic heart disease in developing countries. The World Health Organization (WHO) estimated that in 1994 acute rheumatic fever and rheumatic heart disease affected 12 million people, mostly children, with 400,000 deaths annually (WHO 1995). For developing countries it has also been estimated that acute rheumatic fever and rheumatic heart disease are responsible for almost half of the cardiovascular disease in all age groups and are leading causes of death in the first five decades of life (Limbu & Maskey 2002). By contrast, the dramatic decline in the incidence of acute rheumatic fever from 100–200 cases per 100,000 in the early 1900s (Limbu & Maskey 2002) to current estimates of 0.2–0.5 per 100,000 is indicative of the trend in most developed countries (Carapetis et al. 1996). In 1980, however, WHO noted an incidence rate of 100 per 100,000 of acute rheumatic fever or rheumatic heart disease among the younger age groups of socially disadvantaged populations in developed countries.

Despite the much lower incidence and prevalence of acute rheumatic fever and rheumatic heart disease in developed countries, they remain important causes of morbidity and mortality in some parts of Australia and in similar countries (Table 6). In New Zealand, acute rheumatic fever and rheumatic heart disease continue to be major health problems, particularly among Maori and Pacific Islander peoples. For the period 1995–00, the annual incidence of acute rheumatic fever was 2.8 per 100,000, an increase of 12% over that reported in 1990–95. The annual rate among those aged 5–14 years was 13.8 per 100,000 (Thornley et al. 2001). In a review by Franks (2002), acute rheumatic fever incidence rates of between 100 to 200 per 100,000 among Samoan children in Hawaii and Maori and Pacific Islander children in Auckland aged less than 20 years were reported throughout the 1980s.

Table 6: International comparisons of acute rheumatic fever incidence

Country	Period	Age range	Incidence[a]	Source
New Zealand (all population groups)	1995–00	5–14	14	Thornley et al. (2001)
Samoan children in Hawaii	1987	0–19	206	Reported in Franks (2002)
Maori children in Auckland	1988	5–15	125	Reported in Franks (2002)
Pacific Islander children in Auckland	1988	5–15	114	Reported in Franks (2002)
Australian data – Aboriginal and Torres Strait Islander children				
Top End of the Northern Territory	1998–02	5–14	245	Top End Rheumatic Heart Disease Register
Central Australia	1998–02	5–14	351	Central Australian Rheumatic Heart Disease Register
Kimberley region in Western Australia	1988–92	5–14	375	Richmond & Harris (1998)
Far North Queensland	1995	5–14	161	Streeton & Hanna (1995)

(a) Annual incidence rates per 100,000 population.

In the United States, acute rheumatic fever is rare. It may also be under-reported because of a lack of awareness of the disease among younger doctors (Wolfe 2000). Despite the low number of new cases, acute rheumatic fever and rheumatic heart disease remain prevalent in the community. In 2001, they were responsible for the deaths of 3,489 Americans (70% of these were female and 30% male). In 2001, the death rates per 100,000 population for white males were 0.9, for black males 0.7, for white females

1.5 and for black females 1.3 (AHA 2003). These rates are similar to the death rates among the total Australian population (less than two per 100,000 in 2002) but are considerably lower than the death rates among Aboriginal and Torres Strait Islander peoples, who are up to 20 times as likely to die from acute rheumatic fever and rheumatic heart disease as other Australians.

Australian data presented here and elsewhere show much higher incidence rates for new and recurrent episodes of acute rheumatic fever and prevalence rates of rheumatic heart disease among Indigenous Australians than those reported for other countries. The Top End register indicated an annual incidence rate of acute rheumatic fever of 245 per 100,000 among 5–14 year olds between 1998 and 2002, and the Central Australia register a rate of 351 per 100,000 over the same period. Similarly high results have been published for the Kimberley region in Western Australia where the incidence was 375 per 100,000 among Aboriginal and Torres Strait Islander children aged 5–14 years between 1988 and 1992 (Richmond & Harris 1998) with no evidence of any downward trend throughout the 1990s (Ramsay 2000). In Far North Queensland, Streeton & Hanna (1995) reported an annual incidence of acute rheumatic fever of 161 per 100,000 Aboriginal and Torres Strait Islander children aged 5–14 years.

Discussion

The data from regional rheumatic heart disease registers presented in this bulletin confirm the very high incidence and prevalence of acute rheumatic fever and rheumatic heart disease among the Indigenous Australian population compared with other Australians and other regions of the world. However, ascertaining trends is more problematic.

Early indications are that the trend in incidence of acute rheumatic fever among 5–14 year olds has been fairly stable in recent years in the Top End of the Northern Territory, but that it is increasing in Central Australia. However, the relatively small number of cases compared with other diseases, difficulties in diagnosis, substantial changes in Indigenous Australian population numbers over time, and yearly fluctuations in incidence make it difficult to confirm a trend in the short term. In addition, the relatively recent establishment of the Central Australia register will identify residual cases of both diseases thus artificially inflating incidence in the early years.

National hospital data presented here reflect the disparity in the occurrence of acute rheumatic fever and rheumatic heart disease between the Indigenous Australian population and other Australians, with Indigenous Australian people accounting for 15% of all hospitalisations for these conditions in 2001–02. In addition, hospitalisation rates among Indigenous Australian males are six times as high, and among Indigenous Australian females are eight times as high, as the rates among other Australians. However, since these diseases among the total population are rare, one might expect the Indigenous Australian hospitalisation rates compared with those for other Australians to be even higher. The lower than expected differences between the rates may be due to poorer identification of Indigenous Australians in hospital records, lower than desirable rates of hospitalisation among Indigenous Australian people and/or hospitalisation for rheumatic heart disease among older non-Indigenous Australians who had acute rheumatic fever as children.

The number of heart valve surgery procedures also reflects the impact of acute rheumatic fever and rheumatic heart disease on the Indigenous Australian population, with nearly half of Indigenous Australian people undergoing surgery for these diseases aged less than 25 years compared with just 4% of other Australians of a similar age.

Unfortunately the data do not indicate the procedures performed on individual patients or the severity of rheumatic heart disease at the time of hospitalisation. The data do show, however, that when Indigenous Australian people are hospitalised for rheumatic heart disease they are less likely to undergo heart valve procedures (about one procedure for every three people hospitalised) compared with other Australians being hospitalised for this condition (about one in two). Coupled with the significantly younger average age at death in the Northern Territory due to acute rheumatic fever or rheumatic heart disease (36 years among Indigenous Australian people compared with 67 years among other Australians in 1996 and 1997) (Carapetis & Currie 1999), this suggests that there may be scope for improved treatment for Indigenous Australian people with these diseases, but further investigation is required.

As identification of Indigenous status in both hospital records and on death certificates has only recently begun to improve, national trends in morbidity and mortality from rheumatic heart disease among the Indigenous Australian community cannot be ascertained. Based on the register data, there has been an apparent rise in the reported prevalence of rheumatic heart disease in the Top End of the Northern Territory, but this is likely to be attributable to improved reporting and better awareness of the condition. The fall in the death rate for rheumatic heart disease among the total Australian population in the past 20 years also masks the ongoing problem in the Indigenous Australian population.

To conclude, in addressing the purpose of this bulletin—to describe patterns of acute rheumatic fever and rheumatic heart disease in Australia today—the importance of register data in estimating the incidence and prevalence of these diseases is clear. However, gaps remain in these data. There are regions in Australia that are known to have a high incidence of these diseases but are not covered by the registers. Without similar quality register-based data from these areas it is difficult to extrapolate regional incidence and prevalence rates to national rates, although national hospital and mortality data highlight the extent of the problem, particularly among Indigenous Australians.

Rheumatic heart disease

Abbreviations

AHA	American Heart Association
AIHW	Australian Institute of Health and Welfare
CARHDSC	The Central Australian Rheumatic Heart Disease Steering Committee
DHA	Australian Government Department of Health and Ageing
ICD-9	International Classification of Diseases, 9th revision
ICD-10	International Classification of Diseases, 10th revision
ICD-10-AM	International Classification of Diseases, 10th revision Australian Modification
SMR	Standardised Mortality Ratio
U.S. NLOM & NIH	United States National Library of Medicine & National Institutes of Health
WHO	World Health Organization

Methods

Incidence and prevalence

In this bulletin, incidence includes the number of new and recurrent cases of acute rheumatic fever over a given period of time, and prevalence refers to the number of cases of rheumatic heart disease present in the population at a given time. Incidence and prevalence data have been obtained from the Top End and Central Australian Rheumatic Heart Disease Registers.

Rates

Age-specific rates

Age-specific rates were calculated by dividing the number of events (in this case incidence and prevalence) occurring in each specified age group by the mid-year estimated resident population for the corresponding age group.

Age-standardised rates

Age-standardised rates for hospitalisations and deaths were used to remove the influence of age when comparing populations with different age structures. This was done by applying age-specific rates to a standard population. The 2001 Australian population has been used as the standard population in these analyses.

Direct age standardisation

Direct age standardisation is the most common method of age standardisation, and is used in this bulletin for hospitalisation and death data. This method is generally used when the populations under study are large and the age-specific rates are reliable.

Indirect age standardization and the standardised mortality ratio

Due to the small number of deaths from acute rheumatic fever and rheumatic heart disease creating uncertainty about the stability of age-specific rates, indirect age standardisation has also been used. This effectively removes the influence of the age structure, but does not provide a measure of prevalence in terms of a rate. Rather, the summary measure is a comparison of the number of observed cases compared with the number expected if the age-specific prevalence rates of the standard population are applied to the study population.

An SMR of one indicates the same number of observed cases that were expected (suggesting rates between populations are similar). A result greater than one indicates more cases than expected. A result less than one indicates fewer cases than expected. For example, if there are ten times as many deaths as expected then the rate of deaths can be assumed to be ten times that of the comparison population.

In this bulletin, the indirect method has been used for comparing death rates between Indigenous Australians and other Australians.

Rheumatic heart disease

Data sources and data quality issues

Data sources

The Top End and Central Australian Rheumatic Heart Disease Registers

Both registers are integral to the Top End and Central Australian Rheumatic Heart Disease Programs and have been developed in keeping with WHO recommendations (WHO 1995) for regions with high incidence of rheumatic heart disease. Both registers include data related to diagnosis, hospitalisations, compliance with preventive penicillin, clinical progress, surgery, and mortality.

The Top End program became fully operational in June 1998 and the Central Australian register in June 2002. Confidentialised data from the registers were provided to AIHW for inclusion in this bulletin. Estimates of incidence from these Central Australian register, exclude cases from South Australia and Western Australia because of difficulties ascertaining denominator populations.

AIHW National Hospital Morbidity Database

This database is held at the AIHW and contains demographic, diagnostic, procedural and length of stay information on episodes of care for patients admitted to hospital. The data are supplied to the AIHW by the state and territory health authorities. The database can be used to determine the number of hospitalisations for a particular condition or procedure. It is not possible to count patients individually.

AIHW National Mortality Database

This database is held at the AIHW and contains information on the cause of death as supplied by the medical practitioner certifying the death or by a coroner. Registration of deaths is the responsibility of the state and territory Registrars of Births, Deaths and Marriages. Registrars provide the information recorded on the death certificates to the Australian Bureau of Statistics for coding of cause of death and compilation into aggregate statistics.

Identification of Indigenous status

The hospitalisation and death rates for the Indigenous Australian population obtained from the National Hospital Morbidity Database and the National Mortality Database are likely to be underestimates because identification of Indigenous status in hospital data collections and on death certificates is in need of improvement.