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An assessment of intellectual disability among Aboriginal Australians

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Abstract

Background The health and well-being of Indigenous people is a significant global problem, and Aboriginal Australians suffer from a considerably higher burden of disease and lower life expectancy than the non-Indigenous population. Intellectual disability (ID) can further compromise health, but there is little information that documents the prevalence of ID among indigenous populations. This study provides information on ID among the Aboriginal population of Western Australia.

Methods The Disability Services Commission (DSC) of Western Australia has maintained a statewide database of people with ID since 1953. Data on people of Aboriginal descent were extracted from the DSC database and linked to two other state-based databases, the Hospital Morbidity Data System and the Deaths Registry, with additional linkage to the National Death Index. The linked data were used to assess the prevalence, survival patterns and causes of death in Aboriginal people with ID.

Results Although comprising 3.5% of the population, Aboriginal Australians represented 7.4% of all people registered for ID services. The level of ID was assessed as borderline or mild in 40.7% of cases, moderate in 19.9%, severe or profound in 12.1%, but had not been specified in 27.2% cases. Median survival was 55.1 years for men and 64.0 years for women, with a mean age at death ($n = 102$) of 19.6 years. The leading causes of death were respiratory diseases, diseases of the circulatory system, and accidents.

Conclusions The study presents unique population summary data for ID in the Aboriginal community of Western Australia. To provide appropriate prevention and intervention strategies, there is an urgent need for more detailed information on the prevalence and patterns of ID.

Introduction

Although the overall health status of Indigenous peoples is an ongoing concern in many developed and low income countries, very few studies have addressed the subject of intellectual disability (ID) (Evans *et al*. 1985). Aboriginal and Torres Strait Islanders comprise 2–3% of the total Australian pop-

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ulation (Australian Bureau of Statistics 2001c). It is recognized that they are seriously disadvantaged in terms of both physical and mental health by comparison with the non-Indigenous population (Australian Bureau of Statistics, Australian Institute of Health and Welfare 2003). Prevalence rates for acute and chronic health problems are considerably higher among Indigenous Australians (O'Dea 1992; Veroni *et al.* 1994; Torzillo *et al.* 1995; Cass *et al.* 2001; Thompson *et al.* 2003), and their life expectancy of 57 years for men and 63 years for women is some 20 years less than that of the general population (Australian Bureau of Statistics 2001b). There have been significant positive shifts in attitude towards Aboriginal health matters, with the development of more appropriate networks linking Indigenous communities to the relevant health services. However, these initiatives have primarily focused on improvements in basic health care and social support, the prevention of communicable diseases and lifestyle-related disorders.

Intellectual disability (ID) affects approximately 1–2% of all Australians (Wen 1997). People with ID have poorer general health and restricted health care opportunities. As a result they usually have reduced life expectancy (Evenhuis *et al.* 2000; Eastgate & Lennox 2003), although their survival rates increased significantly during the latter half of the 20th century (Bittles *et al.* 2002; Bittles & Glasson 2004). To date, ID in the Indigenous Australian community has received only limited attention, with little available information on its prevalence and causes. The aim of the present study was to investigate and characterize Indigenous people presenting for ID services in Western Australia, using as the primary information source a statewide database that now spans 50 years.

Materials and methods

Western Australia covers a land area of 2.5 million square kilometres and has a population of 1.91 million people (Australian Bureau of Statistics 2003). Approximately three quarters of the population reside in or near the capital city, Perth, with many of the remaining inhabitants living in rural or remote areas. Indigenous Australians comprise 3.5% of the state population (Australian Bureau of Statistics 2001c). All health, disability and education services in Western Australia are centralized and coordinated by the state government in Perth.

Since 1952 the Disability Services Commission of Western Australia (DSC) has been the central support body for people with ID. Referrals to DSC originate from a variety of statewide sources, including medical professionals, hospital services, child health centres, the education system and family members. An internal committee of DSC considers eligibility for services, and clients are offered different levels of support depending on the severity of their disability. Information on all referrals since 1953 is held in the DSC client database, which contains demographic information, data on the level of ID according to the AAMR guidelines (AAMR 1992), co-morbid conditions, and up to three clinical diagnoses based on Heber (1959) classifications.

The Heber classification is still used by DSC and therefore is of relevance to the present study. Severity of disability is determined by clinical assessment of IQ and is categorized as borderline (IQ 85–70), mild (IQ 69–55), moderate (IQ 54–40), severe (IQ 39–25) or profound (IQ < 25). A field indicating Aboriginality is also present and is completed if clients indicate Aboriginal or Torres Strait Islander heritage.

To obtain additional and updated information regarding health status, all people with a diagnosis of ID listed in the DSC database until 31 December 2000 were electronically linked to two other statewide databases maintained by the Department of Health in Western Australia: the Hospital Morbidity Data System and the Deaths Registry (http://www.populationhealth.uwa.edu.au/welcome/research/dlu/linkage/source). Information on Indigenous status was extracted from the two systems and used to supplement the DSC data.

Information on deaths among the Indigenous cohort was obtained from the DSC database, complemented by record linkage to the Deaths Registry. Cause of death was coded by International Classification of Diseases – Ninth Revision (ICD-9) classifications (World Health Organization 1978) on both databases, with additional descriptive information obtained from the Deaths Registry. In cases where a specific cause of death had not been recorded ($n = 38$), permission was granted by the Registrar General of Western Australia to review the text on the original Death Certificate. Because there is significant migration within and between Aboriginal com-

munities, particularly in remote areas which may be close to state borders, records also were linked to the National Death Index maintained by the Australian Institute for Health and Welfare (http://www.aihw.gov.au/cancer/ndi/index.html). This Index has been used to collate national mortality data from each of the state-based death registries since 1980, and thus allows the identification of Western Australian residents who die outside the state.

Statistical analysis

Median age at death was calculated and life expectancy was estimated by Kaplan-Meier survival probabilities. Log rank tests were used to compare survival between men and women. All analyses were performed using Stata version 7 for PC (Statacorp, College Station), with a P-value < 0.05 indicative of statistical significance. Causes of death were categorized based on the underlying pathology and as entered on the Death Certificates. As the cause of death in both the DSC and Deaths Registry followed the ICD-9 classification, these categories were used for the analyses rather than the more recent ICD-10 classifications. The relative frequencies of different causes of death were then ranked and compared.

Ethical approval

Ethical approval for the study was granted by the Confidentiality of Health Information Committee located at the Department of Health of Western Australia, the Disability Services Commission, and the Human Research Ethics Committee at Edith Cowan University. Approval for linkage to the National Death Index was obtained from the Australian Institute for Health and Welfare.

Results

Demographics

The records of DSC indicated that 330 of 9925 registered clients with ID were of Indigenous heritage. But after linkage with the Department of Health records this number increased to 734, comprising 423 (57.6%) men and 311 (42.4%) women. The years of birth of the Indigenous cohort ranged from 1923 to 2000. The mean age at DSC registration for Aboriginal clients was 7.8 years (SD 7.6, range 0.1–52 years), with a median age of 6.0 years. There was an increase in the number of Aboriginal clients registered with DSC over time, and the median age at time of registration decreased from 7.0 years prior to 1980, to 4.0 years during 1981–1990 and 5.0 years between 1991 and 2000. There also was an increase in the number of older people registered for services during the study period (Table 1). The mean age of Aboriginal clients at the censor date was 24.8 years (SD 13.5), with a median age of 24.0 years.

At the censor date, 414 (56.4%) Aboriginal clients were actively receiving services at DSC, 218 (29.7%) were inactive for services but remained registered, and 102 (13.9%) were deceased. Of the 632 persons alive at the censor date, 67.4% lived at home, 4.7% lived in a foster home, and 8.5% of cases did not have a specified residence. The remaining 19.4% lived in group homes or other forms of residential care. Most cases (40.9%) were registered in the Perth metropolitan area, 18.6% in northern rural areas of the state, 12.6% in the south-west rural region, 9.3% in the mid-west region, and 3.8% in eastern rural areas. No regional area was listed for 14.8% of cases.

In Western Australia since 1980, the attending midwife has recorded obstetric information on a Midwives Notification Form at the time of birth, with subsequent transfer to the Maternal and Child

Table 1 Mean age at Disability Services Commission (DSC) registration (n = 738)

Year of registration	Number registered	Mean age at registration	Median age	Range
Before 1971	127	10.0	7.0	0–43 years
1971–1980	219	7.9	7.0	0–40 years
1981–1990	168	6.0	4.0	0–56 years
1991–2000	224	7.8	5.0	0–52 years

Health Research Database (Stanley *et al.* 1994). Prior to 2000, this database was regularly linked with the DSC database, to which parental age, plurality and birth weight were added. Maternal age at birth was available for 233 of the 284 cases born since 1980. The mean age of Aboriginal mothers was 24.8 years (SD 6.1 years, range 14–43 years), and the median maternal age at birth was 24.0 years. Information on plurality was recorded for 232 cases, with 4.3% recorded from a twin pair. Birth weight was available for 245 clients, with a mean value of 2763 g (SD = 771 g) and median birth weight of 2910 g.

Clinical information

The level of ID was reclassified into three categories: borderline and mild (IQ 85–55), moderate (IQ 54–40), and severe and profound (IQ < 40). Information on the level of ID was available for 534 cases (72.8%), of whom the majority ($n = 299$) had borderline or mild ID, 146 had moderate ID, and 89 had severe or profound ID (Table 2). The remaining 200 (27.2%) cases did not have a specific assigned level of ID, but a diagnosis of ID had been made and/or they were in receipt of DSC services at the time of sampling.

Table 2 Levels of intellectual disability (ID) and clinical classification of Indigenous Australians with ID

	Number of cases	% of cases
Level of ID		
Borderline or mild	299	40.7
Moderate	146	19.9
Severe or profound	89	12.1
Unspecified	200	27.2
Clinical classification (Heber 1959)*		
Functional reaction	252	40.3
Structural abnormalities of CNS	140	22.4
Genetic influence	127	20.3
Prenatal, perinatal or postnatal injury	77	12.3
Prenatal or postnatal cerebral infection	75	12.0
Intoxication	72	11.5
Disorders of growth, metabolism or nutrition	16	2.6
New growths (cancers)	4	0.6
Unspecified	108	14.7

*112 people had more than one diagnosis.

At least one Heber classification was recorded for 626 cases (Table 2). A large proportion of these cases (40.3%) had a functional manifestation to their ID, i.e. the cause of their ID was unknown at the time of registration but it was considered to incorporate a psychological influence. The functional reaction category included ID associated with various factors, such as cultural-familial causes of ID (i.e. evidence of ID in at least one of the parents and in one or more siblings), which was identified in 11.2% of cases. Psychogenic factors associated with environmental deprivation (i.e. ID due to deprivation at an early age of the opportunity for learning experiences essential for adequate functioning, including sensory deprivation and environmental restrictions) were identified in 4.6% of cases, and psychogenic factors associated with emotional disturbance were classified in a further 0.6% of individuals. Intellectual disability associated with a psychotic or major personality disorder was found in 2.6% of cases, while ID associated with language delay accounted for 1.1% of cases. In 20.1% of individuals an 'uncertain' cause was associated with the functional reaction category.

Structural manifestations were present in 22.4% of cases, and included epileptic disorders ($n = 59$), cerebral palsy ($n = 29$), prematurity ($n = 18$), and sensory defects ($n = 4$). Genetic influence was reported in 20.3% of all cases. These included Down syndrome ($n = 32$), encephalopathies ($n = 17$), moya moya disease ($n = 5$), Prader–Willi syndrome ($n = 5$) and Noonan syndrome ($n = 3$).

Mortality

Of the 734 Aboriginal clients investigated, 102 had died. A large proportion of deaths ($n = 75$) were already recorded in the DSC database, with 25 additional deaths identified from linkage with the state Deaths Registry, and a further two deaths identified via linkage with the National Death Index. Mean age at death was 19.6 years (SD = 16.6, range 0.2–67.7 years), with a median age at death of 16.6 years. Kaplan-Meier analyses estimated 25% survival as 48.1 years of age, 50% survival as 61.1 years, and 75% survival as 67.7 years of age (Table 3). Median survival was higher in women than in men (64.0 years compared with 55.1 years), but the difference was not statistically significant ($\chi^2 = 1.6$, $P = 0.2$). Survival was also influenced by a genetic, structural or func-

tional cause of ID (Fig. 1). For example, the Kaplan-Meier survival estimates showed that those with an identified genetic cause for ID had a 25% survival estimate of 20.3 years, compared with 48.1 years for those with structural and 51.8 years for functional manifestations of ID.

The leading causes of mortality in the Indigenous client cohort are listed in Table 4. Respiratory disorders accounted for the largest number of deaths (35.3%), followed by diseases of the circulatory system (16.7%) and accidents (13.7%). Pneumonia was the most frequent cause of death within the category of respiratory disorders, but a lack of specific detail made identification of the precise nature of other reported respiratory tract infections difficult. The

Table 3 Survival probabilities for Indigenous Australians with intellectual disability

Sex	Time at risk*	Incidence rate	*n*	Survival time (years) 25%	50%	75%
Male	9952.29	0.006	423	45.7	55.1	61.1
Female	8222.52	0.005	311	55.3	64.0	67.7
Overall	18174.80	0.006	734	48.1	61.1	67.7

*Computed as person-years.

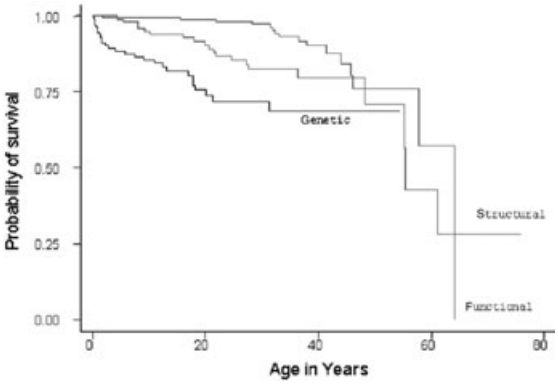

Figure 1 Survival estimates by genetic and other causes of intellectual disability.

Table 4 Leading causes of death among Indigenous Australians with intellectual disability

Group	Primary cause	Number of cases	% of total
Accidents*		14	13.7
Circulatory			16.7
	Acute myocardial infarction	4	
	Cerebrovascular accident	3	
	Hypertensive heart disease	2	
	Other	8	
Congenital anomalies		5	4.9
Infectious diseases		8	7.8
Malignancies		3	2.9
Nervous system			3.9
	Epilepsy/Status epilepticus	4	
Respiratory			35.3
	Pneumonia	24	
	Other respiratory tract infection	5	
	Chronic obstructive lung disease	1	
	Other	6	
Digestive diseases			2.9
	Chronic liver failure and cirrhosis	2	
	Other	1	
Other		4	3.9
Unknown		8	7.8
Total		102	100

*Includes 1 suicide.

main causes of death within the circulatory system category were ischaemic heart disease, cerebrovascular accidents and hypertensive heart disease. Accidents included deaths because of injuries sustained after being hit by a motor vehicle or train, and drowning. There was a single recorded case of suicide.

Discussion

The data indicate that Indigenous Australians, who comprise 3.5% of the Western Australian population, form 7.4% of the total number of people registered at DSC, i.e. a figure approximately double that expected based on population ratios. The disadvantaged social circumstances of many Indigenous communities mean that Aboriginal people have a significantly lower overall socio-economic profile than non-Indigenous Australians (Australian Bureau of Statistics, Australian Institute of Health and Welfare 2003). Poor socio-economic status has been particularly associated with an increased risk of mild to moderate ID in low income countries (Najman *et al.* 1992; Croen *et al.* 2001; Durkin 2002), and the patterns of ID observed in the present study are in keeping with these reports. The degraded physical environments in which many Indigenous Australians live confer a further increased risk of general infections (some of which can lead to ID, e.g. meningitis), respiratory diseases and parasitic diseases. This may be especially relevant in remote areas where sanitation is poor and the water supplies may be contaminated (Brennan & Patel 1990; Torzillo *et al.* 1995; Gracey *et al.* 1997).

Non-genetic prenatal or perinatal risk factors known to be associated with ID were common in the present study cohort, representing some 36% of cases. These factors included maternal drug or alcohol use during pregnancy, physical trauma, multiple births, birth complications, infections and low birth weight. The potential impact of conditions such as fetal alcohol syndrome (FAS) remains unknown in the study cohort. A recent data linkage study in Western Australia estimated the prevalence of FAS in Aboriginal children at 2.97 per thousand live births (Bower *et al.* 2000). Other Australian data suggest that Indigenous mothers tend to be less educated and younger (Australian Bureau of Statistics, Australian Institute of Health and Welfare 2003; Gee & O'Neill 2003), to reside in rural or remote regions (Gee & O'Neill 2003), and to be less likely to seek early prenatal care (Bower *et al.* 1989; Crowe 1995), all of which can be disadvantageous to childhood development. Women living in rural and remote areas also may find it difficult to access prenatal care and neonatal screening, and thus be infrequent users of these services.

More Indigenous men (57.6%) than women (42.4%) were registered for DSC services, a feature that is common to ID studies in virtually all populations (Leonard & Wen 2002). Men are at greater risk of adverse outcomes from low birth weight and other prenatal/maternal influences (Leonard & Wen 2002). They also outnumber women in their risk of ID because of unknown causes (Croen *et al.* 2001), and possibly to X-linked genetic causes of ID.

The majority of Indigenous ID cases were registered with DSC during their early school years, with few children registered at preschool ages. For this reason, only 32 children born after 1996 had been registered by 2000. Referral at school age is predictable, as developmental disabilities in children may not be detected until their performance is compared with that of other children in a formal or semiformal setting (Croen *et al.* 2001). A large proportion of the Aboriginal cases lived in non-metropolitan areas where appropriate services may be difficult to access. It was disappointing that 30% of cases were recorded as inactive for receipt of services, suggesting either that contact may have been lost with clients living in remote areas or that social or cultural barriers were preventing service utilization. In overall terms it seems probable that a significant proportion of cases had not been adequately assessed or were not directed towards appropriate services.

Median survival in the Indigenous study group was 61.1 years, which could be an overestimate associated with the method of data collection. For example, few clients under 5 years of age were included in the analysis and a number of affected children may have died prior to registration with DSC. Adult clients who ceased contact with DSC prior to their death may not have been identified, especially where there had been a change of name or address, thus preventing a match through linkage with the state Deaths Registry and the National Death Index. Even so, life expectancy for Aboriginal clients with ID is lower than in their non-Indigenous counterparts (Bittles

et al. 2002), a trend also consistently reported in the general Australian population (Australian Bureau of Statistics 2001b). Higher mortality rates are also reported for the indigenous populations of New Zealand, the USA and Canada (Grim 2003; McPherson *et al.* 2003; Allard *et al.* 2004). But the improvements in health status and gains in life expectancy among indigenous populations in those countries (Ring & Firman 1998; Brady 2003; Ring & Brown 2003) have yet to be matched in the Australian Aboriginal community.

In common with other studies on ID (Carter & Jancar 1983; Strauss & Shavelle 1997; Hollins *et al.* 1998), the data show that respiratory diseases, in particular pneumonia, and circulatory diseases were the most common causes of death. Accidents and trauma accounted for high number of deaths (13.7% of all deaths). External causes of death were the third most common cause of death reported in a population-based study of causes of death among people with ID in eastern Australia (Durvasula *et al.* 2002). Although the authors did not classify their data by ethnicity, given the geographical area covered it seems unlikely that the sample included many Indigenous people with ID. Accidents and injuries as cause of death are not specific to Aboriginal people with ID but largely reflect the overall situation in Indigenous Australian communities, where accidents rank as the second most common cause of death after diseases of the circulatory system (Australian Bureau of Statistics 2001a).

During the investigation, much of the information held on clients was found to be incomplete, vaguely coded or missing. The collection of information on ethnicity or Indigenous status can be a very sensitive issue. Therefore appropriate questions may either have been omitted or not recorded electronically which, in turn, could account for the large number of clients on the DSC database not specifically identified as being of Indigenous birth. This situation is not unique, with inadequate collection of Indigenous information recently noted in the registries of other Australian health service organizations, and it highlights the importance of using best practice protocols in data collection (Adams *et al.* 2004). As Indigenous people are more likely to change addresses both within- and between-states, they may find it difficult to follow the appropriate pathways to ensure receipt of services in their area of current residence. However, without more specific information on geographical locations, levels of disability, and client profiles, the development and targeting of services and policies for meeting the needs of Indigenous Australians will continue to be a major problem.

Well-maintained population databases that allow detailed and flexible monitoring of health and well-being can play a major role in assessing the burden and impact of ID in already disadvantaged indigenous communities. The present study has provided an important preliminary description of the numbers and prevalence of Indigenous Australians registering for ID services. Ongoing work entails revisiting the raw data, and performing additional linkage to other local and national resources to enhance the quality and quantity of information available for analysis. This information will permit a clearer insight into significant disease aetiologies, will heighten our understanding and appreciation of access issues, and should help to accelerate the formulation and implementation of suitable prevention and intervention strategies. Given the highly unsatisfactory level of ID among Indigenous Australians, this is being undertaken as a priority matter. It may also prove a useful model for addressing the health concerns and the delivery of health services among other indigenous populations worldwide.

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