A Review of the Literature

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I  Brian Draper  I  Simon Chalkley and GA (Tony) Broe
Acknowledgement of Country

In the spirit of respect, we acknowledge the traditional owners of Country, this gesture acknowledging Aboriginal and Torres Strait Islander custodianship for millennia. As our mark of respect, we acknowledge the Elders and the peoples who are talked about in this publication. We acknowledge the Land on which this work was done. Australia is the only place in the world where Aboriginal and Torres Strait Islander Australians belong, and there is no place in Australia where this is not true.

Acknowledgments

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Suggested citation

This Report is a review of the literature to-date on dementia in the Aboriginal and Torres Strait Islander population. A literature search, including electronic database searches, journal and organizational website searches as well as Google search engine and citation searches were conducted over a three year period between late 2006 and 2009.

The Review was funded by the Primary Dementia Collaborative Research Centre, as a joint initiative of the ARC/NHMRC Ageing Well Network, the Primary Dementia Collaborative Research Centre, the Prince of Wales Medical Research Institute (now known as Neuroscience Research Australia) and the Muru Marri Indigenous Health Unit, UNSW.

The literature review was conducted in light of data showing evidence of demographic changes in the Indigenous population toward population ageing, with additional exposures to multiple risk factors across the life span for cognitive decline and dementia. Preliminary data on dementia prevalence from remote living Indigenous communities in the Kimberley region of Western Australia signalled an emerging public health concern.

The main findings of the literature review are, that dementia prevalence amongst Indigenous Australians is almost five times the rate as that in the general population and that it presents at an earlier age; that the perception of dementia differs across communities and situations, but may not be viewed as a medical condition; that the social and health profile of Indigenous Australians show many of the risks associated with a greater chance of developing dementia in non-Indigenous populations; that there are multiple and confounding risk factors for cognitive decline and dementia across the lifespan in this population and that many Indigenous Australians with dementia and their families experience problems accessing needed services, due to lack of transport and services adapted to local language, culture or circumstance.

The Review demonstrates the importance of a framework for addressing dementia in the Indigenous population that takes account of the impact of history, context and culture in understanding the potential risk factors that this population faces, in both the development of dementia syndromes, and of approaches required to ameliorate and address these at a community health, public health and service provision level.

Significant knowledge gaps are noted in relation to the need for population level data, including, Indigenous data capture across service domains and dementia prevalence and incidence data. This would provide a more comprehensive picture of dementia in the Indigenous Australian population and enable better estimates of the need for, and access to, dementia support services. There are currently few data on the dementia experience for Indigenous families in diverse locations and circumstances.

In light of these knowledge gaps, the Review makes a number of recommendations.
Executive summary

This Report is a review of the literature to-date on dementia in Aboriginal and Torres Strait Islander Australians.

We reviewed the research in comparable Indigenous communities internationally as well as dementia research in non-Indigenous populations, both nationally and internationally, to illuminate cognitive development, growth and decline across the life-cycle and its application to the ‘brain health’ of Indigenous Australians.

The Review was conducted over a three year period between late 2006 and 2009.

The following are the main findings of the Review:

1. Prevalence of dementia
   - The prevalence of dementia amongst Indigenous Australians is almost five times the rate in the general Australian population
   - The most detailed picture of dementia to-date comes from rural and remote living communities in Western Australia, where 12.4 percent of Indigenous people are affected, compared with 2.6 percent in the general population
   - Currently, more Indigenous males than females are affected, which is the reverse trend in the rest of the Australian population
   - Dementia affects Indigenous Australians at an earlier age than in the general population, with much greater proportions of Indigenous Australians in the 45 - 69 year age group affected compared to the general Australian population
   - Acquired brain injury is most prevalent in the Northern Territory and Indigenous Australians are 21 times more likely to suffer a head injury with serious implications for cognitive and behavioural changes

2. Description of dementia
   - ‘Dementia’ in Indigenous communities has been described in the literature in a number of different ways: as “childlike” (benign behaviours); “madness” (aggressive or inappropriate behaviours) or, as “a sick spirit”, in suffering from the consequences of colonization and loss of connection to Land and traditional relationships
   - Dementia may not be recognised as a medical condition in some Indigenous communities

3. Demographic change
   - The Indigenous Australian population is beginning to age in a manner consistent with Indigenous populations in comparative countries and non-Indigenous populations in Australia
   - These trends toward population ageing include: increases in longevity (notably in the age group 45 - 64), different patterning in causes of death, reduction of chronic disease mortality in selected jurisdictions, and declining fertility rates and increased age at first birth
   - Despite these demographic changes, the Indigenous population is currently a younger population (mean age 21 years by comparison to 37 in the general Australian population); has a life expectancy some 17 years less than the general Australian population, and has the poorest morbidity and mortality patterns in the population
   - The Indigenous population is highly urbanised, with the majority population residing in the suburbs of Sydney, and is also dispersed widely through regional and remote areas of the country. Indigenous people reside in the remotest areas of the country in the greatest proportions to the rest of the population
4. Risk factors for dementia

The social and health profile of Indigenous Australians show many of the risks associated with a greater chance of developing dementia in later life in non-Indigenous populations

There are multiple and confounding risk factors for cognitive decline and dementia across the life-cycle which include: early-life risk factors such as exposure to inflammatory disease, low educational attainment, adverse childhood experiences; and life-style and environmental factors such as, smoking, substance abuse and brain injury from traumatic injury; and mid-life vascular and metabolic risk factors such as, high cholesterol, obesity, hypertension, inactivity, and the presence of diseases such as cardiovascular disease and diabetes

More knowledge about protective factors such as social connectivity, connection to culture and other lifestyle factors is required.

5. Access to services

Information about Indigenous peoples’ use of dementia services and other aged care programs is currently limited by deficiencies in data capture common across service domains. These include under-enumeration caused by the reticence of workers to ask the question about a person’s Indigenous status; under-disclosure of Indigenous status by Indigenous clients when asked; inadequate data collection protocols and inconsistency in how data are captured across and within linked systems; as well as data on dementia prevalence, and lack of data on dementia incidence, to inform rates of dementia in the Indigenous population

Given these problems and the fact that the diagnosis of dementia in the Indigenous Australian population is still in its relative infancy, we are unable to ascertain the real extent to which Indigenous people are accessing dementia services

The review of dementia in Australia published by the Australian Institute of Health and Welfare in 2006, provides some data on the percentages of Indigenous clients compared to non-Indigenous clients with dementia using the following programs and services: Aged Care Assessment Program (ACAP), National Respite for Carers Program (NCRP), Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) and a Commonwealth Carer Respite Centre (CCRC). The percentage of Indigenous clients with dementia by comparison to non Indigenous clients with dementia using these programs and services, ranges from a low of 0% in the case of the EACH Program, to a high of 3% of clients in receipt of a Community Aged Care Package, with the other programs reporting about 1.8% of their clients with dementia as reporting Indigenous status. Given the lack of denominator data, that is, data on dementia prevalence and incidence in the Indigenous population, as well as the more generic data collection problems of under or inaccurate reporting of Indigenous status, these data cannot be meaningfully interpreted

There appears to be mostly an under-representation of Indigenous people with dementia using government services, given what is known about dementia prevalence in remote living Aboriginal communities and given that Indigenous Australians comprise about 2.6% of the total Australian population. In some programs, there may be an over-representation of Indigenous clients with a dementia, but we do not currently have the population level data to provide an accurate picture of service use by Indigenous people

As an interim measure, some modelling based on the known Aboriginal population, on known dementia prevalence in the Aboriginal population, and taking into account estimates of over and under service utilization, may provide a reasonable approximation of service use by Indigenous people with dementia.
What the literature reports is that many Indigenous Australians in rural and remote areas can’t access needed services due to transport difficulties and the unavailability of staff and services capable of delivering care adapted to local languages, culture and circumstances.

In urban areas, many Indigenous people experience problems accessing services due to social isolation and lack of transport, personal and health problems, and because services are not experienced as being culture-friendly.

Other reasons for non-accessing of services relate to the fact that dementia is not always recognised as a medical condition, may be undiagnosed, and that some families fear the medical system.

6. Care arrangements

The literature on palliative care tells us that Aboriginal Elders wish to be cared for in their communities where they are close to family and kin and where they can die on their Land.

There is great concern amongst many older Indigenous people about the erosion of their local culture and a wish to reverse this trend. We know little about the impact of this on families and their care arrangements.

Indigenous peoples’ experience of treatment in other contexts, for example, disability services or dialysis, where Elders (and others) from the community have been removed to residential care or other residential areas for treatment, has often been experienced as a cultural threat or described as a cultural trauma for the community.

7. Approaches to dementia in Indigenous populations

Solutions to the problem of dementia in the Aboriginal and Torres Strait Islander population need to take account of cultural perspectives and approaches to wellness, ageing and care giving preferences.

While old age, cognitive confusion and problems with memory are not new phenomenon for Indigenous people, the naming of symptoms and behaviours through medical diagnosis, as a disease of the brain called dementia, is a relatively new phenomenon, and fear and stigma are fairly common.

Approaches in terms of brain health need to address factors across the life cycle which ‘grow’ or impair brains before cognitive decline begins.

A whole of life policy and services perspective is essential to address the interaction of social and biological determinants, both proximal (early life) and distal (mid to later life), impacting on late-life risk for dementia.

The conceptual framework for addressing dementia in Indigenous populations, needs to take account of the impact of history, context (language, residential location, socio-economic status) and culture in understanding the potential risk factors that this population faces, in both the development of dementia syndromes, and, of the approaches required to ameliorate and address these at a community health, public health and service provision level.
The Literature Review identifies the following research gaps and makes the following recommendations for further research;

<table>
<thead>
<tr>
<th>Research gaps</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>What understanding(s) do Indigenous people from different backgrounds have about dementia from a socio-cultural perspective?</td>
<td>Research is required about Indigenous understandings of ageing, spirituality and dementia in a number of contexts - traditional and non-traditional lifestyles, urban and rural</td>
</tr>
<tr>
<td>What is their dementia literacy?</td>
<td>Research is required to examine the role, impact and effects of being a carer for an Indigenous person with dementia in different socio-cultural contexts</td>
</tr>
<tr>
<td>What is the meaning, experience and impact of caring for a person with dementia for immediate and extended family groups? How do factors such as family and older person’s status; age, gender, and residential history, influence this experience?</td>
<td>Research is required on case identification and assessment of cognitive impairment in Indigenous people across diverse locations to establish best practice models. Communities’ own perceptions of what dementia means is an important part of this knowledge</td>
</tr>
<tr>
<td>What is best practice for the identification and assessment of Indigenous persons with suspected cognitive impairment – in remote and rural, regional and urban locations?</td>
<td></td>
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<tr>
<td>What is best practice for the provision of formal healthcare in both community and residential settings for indigenous persons with dementia from different backgrounds?</td>
<td>Research is required to establish best practice models of care and service for Indigenous people in diverse locations. This includes knowledge about individuals’ social histories and localised information about communities to inform individually tailored service provision and appropriate service planning at community level.</td>
</tr>
<tr>
<td>What is a reasonable estimate of formal service use by Indigenous Australians with dementia?</td>
<td>We recommend modelling Aboriginal service utilisation numbers against Aboriginal population data and against non-Aboriginal patterns of service utilisation to construct a better picture of how effective Aboriginal access to programs such as HACC, CACP and EACH services are, relative to need</td>
</tr>
</tbody>
</table>

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1. Introduction

Dementia is emerging as a global phenomenon, although it is predominantly defined in the literature as a, ‘Western diagnostic category’. There is general acceptance that ‘Culture’, namely, values, practices and beliefs, play an important role in understanding dementia, from uncovering risk factors for the disease, in particular, the interplay of environmental and genetic factors (Burchard, Ziv et al. 2003), to influencing what has been described as, “help-seeking behaviours”, across different populations (Dilworth-Anderson and Gibson 2002).

In Aboriginal communities, both in Australia and other comparative societies, what we know about the nature and extent of dementia, and of its sub-types, is still in its infancy, as is knowledge about the experiences, perceptions and meaning of dementia for Aboriginal people, the causes of, and risk factors for cognitive decline, and the need for and provision of dementia services (Pollitt 1997; Jervis and Manson 2002; LoGiudice, Smith et al. 2006).

These knowledge gaps pose a rapidly emerging public health concern. In the next four to five decades, Aboriginal and Torres Strait Islanders will age in a manner consistent with the current non-Indigenous population (Broe 2003). This trend is already well underway amongst older Indigenous populations in other comparative countries, such as Canada and New Zealand (Trovato 2001; Jervis and Manson 2002).

In addition, a high level of multiple risk factors for cognitive decline in Aboriginal people across the lifespan, as well as high incidence of premature systemic disease in this population, presage the development of higher rates of dementia as well as its manifestation at a younger age than in the non-Indigenous community. This raises questions of the adequacy of current frameworks for understanding and ameliorating the relationships between Indigenous health, ageing, neurodegenerative disease and dementia in this population.

Dementia describes a syndrome associated with a range of diseases which are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills.”

(Dementia in Australia: national data analysis and development; AIHW, 2007)

“Dementia is a sick spirit, a lost spirit looking for help ... It may not need to get fixed as long as the individual is safe and the family and the community is safe ... Other causes of a sick spirit ... is the past history of the stolen generation, dispossession, physical, social and emotional trauma, child abuse, drug and alcohol abuse, poor diet, a lack of traditional healers and herbal medicine being understood and used ...”

Mr Eric Deeral, Chairperson, Elders Justice Group, Hopevale Community, Queensland. In, Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities, 2007)
1.1 Frameworks for addressing dementia

A number of explanatory frameworks for understanding dementia have emerged in the literature (Kitwood and Brendin 1992; Mackenzie, Bartlett et al. 2006). Mackenzie and colleagues (2006) outline four broad frameworks, which impact on both the perceptions of people toward dementia and the nature of their care arrangements. These differing viewpoints include, the biomedical, the biopsychosocial, the perception of dementia as part of an inevitable ageing cycle, and, the interpretation of dementia as a spiritual or religious phenomenon.

In Westernised cultures, the dominant understanding of dementia remains that of a disease, and this underpins the way in which health and social care services are provided (Whitehouse, Gaines et al. 2005; Mackenzie, Bartlett et al. 2006). As noted by these researchers, there are both benefits and limitations to this approach. The benefits include the potential for early diagnosis, early interventions and access to services. The limitations lie in the way in which the ‘culture’ explains dementia, usually through powerful ‘gatekeepers’ or ‘experts’ to treatment (Mackenzie, Bartlett et al. 2006), and, through the potential for negative consequences of disease labelling, which it is argued, can create an, “artificial separation between the self, the family and the larger community” (Whitehouse, Gaines et al. 2005).

Another framework for understanding dementia is that which encompasses biological, psychological and social frameworks. The ‘bio-psychosocial framework’ tends toward a ‘whole person’ approach, including experiences and emotions, social world and family networks, as well as the aetiology and pathology of the disease. The benefits of this approach, as the authors note, include a focus on the individual, the potential for an active role taken by the family and person with dementia in treatment plans and exposure to treatment therapies, “beyond the pharmacological” (Ibid). However, as McKenzie and colleagues point out, this approach can still reflect a bias toward what is valued in Western cultures, such as independence, autonomy and freedom and overlook, “... religious, spiritual and cultural dimensions of the dementia experience and their capacity for healing” (Mackenzie, Bartlett et al. 2006).

The understanding of dementia as an inevitable part of ageing tends towards the view that the responsibility for care falls to the family. The individual with dementia is placed in a position of dependency on other family members, with variable consequences for the care of the dementia sufferer as well as the family’s capacity to cope (Olson 1999). It can also result in stigma, embarrassment and denial when the dementia sufferer’s condition worsens (Sutherland 2007).

A fourth explanatory framework for dementia, is one in which religious or spiritual meanings are attributed to behaviours characteristic of the disease (Henderson and Henderson 2002). Thus the notion that these behaviours reflect, ‘an Elder’s transition to the next world’, suggests the need for collaborative work with traditional healers or religious or spiritual approaches to treatment and the provision of care (Jervis and Manson 2002).

There is widespread recognition that cultural values, norms, perspectives and practices play a large role in defining and giving meaning to the experience of living with dementia and its related disorders - for both those with dementia and their caregivers. Pollitt and others thus make the case for an anthropological approach to uncovering dementia’s meaning and its specific socio-cultural manifestations (Pollitt 1996; Whitehouse, Gaines et al. 2005). For Henderson and Traphagan, the extension of dementia models beyond the biomedical is a necessary precursor for both dementia prevention and management (Henderson and Traphagan 2005).

An emerging area of scholarship in health research is the inquiry into the subjective experience of illness. This form of inquiry considers the “internal world” of the sufferer, “as a valid object of study” (Bender and Cheston 1997). The nascent literature on spirituality and dementia locates itself in, what is described as, ‘dementia from the inside’ (Doherty 2006; Hudson 2007). This largely narrative inquiry presents a pathway to understanding subjective
experiences of illness through the meaning ascribed to experiences and stories and seems particularly apposite to enquiries into different ‘ways of knowing’. These have been explored between Western and Aboriginal health belief systems in more traditional living Aboriginal communities (Weeramanthri 1997; Maher 1999; Vickary and Westerman 2004), but have yet to be explored in the context of a more urbanised Indigenous experience.

Subjective approaches have also been described as, “a relational methodology”, one in which life stories and narrative analysis are viewed through the prism of “interaction, continuity and situation” (Barton 2004). This opens the way for a deeper understanding of how social relationships, history and context contribute to understandings of the aetiology of disease as well as to the experience of living with disease, for both sufferers and their families and carers.

What emerges from a mapping of the literature on the physical and mental health of Indigenous Australians, with the known risk factors for dementia in non-Indigenous populations, and what we already know about the rates of dementia in remote living populations, broadens the conceptual framework around culture, cognitive decline and dementia to include, history and politics across a trans-generational perspective (BraveHeart and YellowHorse 2003; Zubrick, Lawrence et al. 2004; Pollard 2005; Wasserman 2005; Paradies 2006).

1.2 Culture and dementia

Dementia aetiologies differ both between ethnic groups and within ethnic groups across different population settings (Radebaugh and Ward-Robinson 2002; Hendrie, Murrell et al. 2006; Hou, Yaffe et al. 2006). This raises important questions about the extent to which environmental, social, cultural and biological factors influence the diagnosis and prevalence of the range of dementias amongst diverse ethnic groups. Further, the influence of literacy, education, socio-economic variables, residential location, and, the risk or ‘protective’ impact of cultural and social practices, form an integral part of the research landscape around dementia. Care, treatment and the research agenda around dementia, it is argued, is itself mediated by ‘culture’ (Powell 2002).

1.3 This report

This report reviews the current literature on dementia in the Aboriginal and Torres Strait Islander population of Australia, including, what is known about how dementia is experienced and understood and drawing on Indigenous perspectives around illness, ageing and end-of-life. It draws on dementia research in comparable Indigenous communities internationally as well as dementia research in the general population, to illuminate cognitive development, growth and decline across the life-cycle and its application to the cognitive health of Indigenous Australians.

The following broad themes underpin the literature reviewed:

- The demographic & health transition in Australia’s Indigenous population
- A life-cycle approach to cognitive growth, development and decline
- The concept of remediation for damaged brains
- The concept of capacity building and resilience on health
- ‘Brain health’ as the “New Public Health” of the 21st Century

More specifically, the literature review seeks to address the following in relation to Indigenous Australians:

- The risk and protective factors for cognitive growth and decline
- The experience and meaning of dementia
- Brain impairment and dementia rates
- Current systems of care and support for those with existing brain impairment and dementia within their communities
- The numbers of mid age (45 to 64), young old (65 to 74) and older-old Indigenous (75 up) people in urban, rural and remote areas
- The stage reached by Australia’s Indigenous population in the demographic and epidemiological transition
- A life cycle approach to risk factor for cognitive growth and development on the one hand and cognitive decline and possible dementia on the other:
Childhood experiences, education and resilience in relation to later-life cognitive decline and dementia including approaches to remediation

Mid life vascular risk factors in relation to later-life cognitive decline and dementia

The role of remediation (developmental, education and training programs) in the development of cognition and brain growth

**Chapter one** forms the introduction to the report and outlines frameworks for addressing dementia.

**Chapter two** provides the context for the review, namely, population ageing in a health transition framework, and, cognitive growth and decline within a life-cycle approach. A global snapshot of dementia is provided as is the demographic and health profile of Australia’s Indigenous population.

**Chapter three** outlines the methodology of the review process.

**Chapter four** addresses the determinants of dementia and discusses risk and protective factors for dementia in non-Indigenous populations and in Indigenous populations in both comparable Western countries and in Australia.

**Chapter five** reviews what is known about dementia and the dementia experience in Australia’s Indigenous population and includes relevant material from Indigenous populations in comparable countries.

**Chapter six** provides a summary of the main messages of the review and outlines gaps in knowledge and recommendations for further research.

**Chapter seven** provides the list of references for the literature reviewed.

### 1.4 Definition of terms and their usage in this report

**Culture:** The term ‘Culture’ is used to denote, ‘shared symbols, beliefs, customs and practices’ that shape both individual and group behaviour (Dilworth-Anderson and Gibson 2002). In this characterisation, ‘Culture’ is a fluid concept that is capable of adaptation and change over historical time and circumstance; but also one which is, ‘constrained by the expectations of other members of the group’;

**Dementia:** The term dementia in this Report is used in a broad sense to denote, a syndrome of progressive and persistent decline in (multiple) cognitive domains with associated changes in behaviour, personality, and/or social functioning, produced by brain impairment (Shulz 2006).

**Older Indigenous Australians:** This Review uses the term older Indigenous Australians to denote members of the Indigenous community who are, mid-aged (45-64); young old (65-74); and, older old (75 up). This understanding is distinguished from the term Aboriginal Elder which refers primarily to the cultural roles and responsibilities held by those who are recognised as older statespersons in the community.

**Indigenous:** The term Indigenous is used in this Report following Richard Borshay Lee’s characterisation into Indigenous One, Indigenous Two and Indigenous Three (Lee 2006): Indigenous One: defines Indigenous in relation to ‘settler’ societies such as, Canada, Australia (after 1788) and the United States (the Americas after 1492); Indigenous Two: defines Indigenous as those communities ‘encapsulated’ by ‘agrarian polities’ such as, scheduled tribes in India; Indigenous three: refers to groups reclaiming lost identities, such as the Neo-Khoisan in Southern Africa (Lee 2006).

The common thread across the three definitions being the, “… characteristics not shared with other fractions of the global underclass” (Lee 2006:459). These characteristics include the following features: ‘Otherness’: presented in music, art, folklore, cultural traditions;
Way of life’: for those who live in ‘small scale, communally based communities that speaks of spirituality, non-capitalist values and harmony with nature’; and, ‘Sense of Place’: that ‘compelling feature’, according to Lee, that sets Indigenous communities apart (Lee 2006: 460). In the Australian context, this is understood as, ‘belonging to country’.

For the purposes of this Report, Indigenous is understood to mean Indigenous One. The term Indigenous Australian, refers to people of both Aboriginal and Torres Strait Islander origin. The term Indigenous North American or Indigenous Canadian in this report refer to populations usually described in the literature as ‘Native Americans’ or ‘Alaskan Natives’.

1.5 A note on data collection

It should be noted that Aboriginal and Torres Strait Islander populations remain under-represented in community services and other official data collections, through both non-accessing of services and non-identification of Indigenous status in services and programs. Social demographers also note the ‘substantial undercounting of the Indigenous Population’, such as that occurring at the 2006 Census, with implications for needs assessment and resourcing of Indigenous programs and policies (Taylor and Biddle 2008).

Further, logistical challenges in the collection, analysis and interpretation of data on Indigenous people in Australia, as indeed in other comparable countries, fails to adequately capture diversity across Aboriginal and Torres Strait Islander culture, family structure, residential location including, differing conceptualisations of health and wellbeing (Australian Institute of Health and Welfare 2006).
2. Context of the Review

2.1 Population ageing and health transitions

The global population is aging, with relatively high proportions of people aged 65 and over in developed countries and rapid increases of elderly populations in developing countries (Kinsella 2000). Concomitantly, the percentage of the elderly who are in their 80s is growing. The following figures show the proportion of the population aged over 65 years in selected countries.

Table 1: The ageing of the elderly population

<table>
<thead>
<tr>
<th>Countries</th>
<th>Population (m)</th>
<th>% Aged 65+</th>
<th>% Aged 65-74</th>
<th>% Aged 75-84</th>
<th>% Aged 85+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sweden</td>
<td>9</td>
<td>17.6</td>
<td>53.9</td>
<td>35.6</td>
<td>10.5</td>
</tr>
<tr>
<td>USA</td>
<td>257</td>
<td>12.7</td>
<td>56.8</td>
<td>32.9</td>
<td>10.3</td>
</tr>
<tr>
<td>UK</td>
<td>58</td>
<td>15.7</td>
<td>55.8</td>
<td>33.9</td>
<td>10.2</td>
</tr>
<tr>
<td>Japan</td>
<td>124</td>
<td>6.0</td>
<td>60.0</td>
<td>32.2</td>
<td>7.5</td>
</tr>
<tr>
<td>Kazakhstan</td>
<td>17</td>
<td>6.0</td>
<td>60.3</td>
<td>32.2</td>
<td>7.5</td>
</tr>
<tr>
<td>China</td>
<td>1130</td>
<td>5.6</td>
<td>0.5</td>
<td>25.8</td>
<td>3.7</td>
</tr>
<tr>
<td>Australia</td>
<td>19</td>
<td>12.2</td>
<td>55.9</td>
<td>33.8</td>
<td>10.4</td>
</tr>
</tbody>
</table>

The demographic features of global ageing have been identified as, changes to fertility patterns, increasing urbanisation, increasing life expectancy, the “feminization” of later life, increases in the numbers of the “oldest-old” in the population and changing patterns in national disease profiles as a result of the epidemiological transition (Kinsella 2000). Suh and Shah’s analysis of changes over time in the prevalence and aetiology of dementia (both Alzheimer’s disease and vascular dementia) in selected regions of the world shows a societal patterning from, ‘low incidence-high mortality’ to ‘high incidence-high mortality’ to, ‘low incidence-low mortality’ (Garrett 1994; Suh and Shah 2001).

Following the disease transition framework of Omran (Omran 1971) and Olshansky (Olshansky and Ault 1986), Broe charts the historical trajectory of disease patterns, their impact on longevity and morbidity in populations of the developed and developing world, to argue that the neurodegenerative disorders will gradually come to replace the systemic degenerative disorders as, “the major causes of both death and morbidity in the 21st century” (Broe 2003). Amongst Indigenous fourth world populations, an epidemiological transition is underway. Researchers of North American Indigenous populations, describe a health transition for at least forty years, characterised by both, “the rapid emergence of the Indigenous elderly as one of the “fastest growing” population groups” ..., as well as by, “a shift from acute and infectious diseases to chronic and degenerative diseases associated with old age” (Jervis, Jackson et al. 2002).

Similar health and demographic transitions are beginning to emerge in the Australian Indigenous population, with a trend toward greater longevity, different patterning in causes of death amongst this population and a reduction of chronic disease mortality in selected jurisdictions (Thomas, Condon et al. 2006; Zhao and Dempsey, 2006).
Further, a strong measure of recent Indigenous population change is reflected in the declining fertility amongst Indigenous women by 11 percent in the period between the 1991-96 census and the 1996-2001 census, to below replacement levels (Kinfu and Taylor 2005). A consistent increase in age at first birth, decline in mean age at last birth and significant increase in birth interval amongst Indigenous women over the last four decades is part of this overall pattern (Kinfu and Taylor 2005). Geographic variations in the Indigenous fertility rate, measured across ATSIC regions, show lowered Indigenous fertility in more urbanised residences and in areas of higher socio-economic status (Kinfu and Taylor 2005).

These emerging demographic changes in the Indigenous Australian population are occurring notwithstanding the fact that infant mortality rates and life expectancy at birth are estimated to be about four and seven decades respectively behind those for the total Australian population (Kinfu and Taylor 2005). Higher rates of mortality and morbidity, their earlier manifestation over the lifespan, and, the presence of infectious diseases such as otitis media, skin infections and rheumatic heart disease, found overwhelmingly amongst sections of the Indigenous Australian population, are well documented in the health literature (Australian Bureau of Statistics and Australian Institute of Health and Welfare 2005). Indigenous Australians, as a population, occupy a different stage in the health transition to non-Indigenous Australians, manifesting greater health and social needs, with major implications for equity in health policy, health funding and the nature of health provision for this population.

However, the Aboriginal population is now ageing: increased numbers of older Aboriginal people (at least in the 45 to 64 age group) and changes in fertility patterns in urban, rural and remote Aboriginal people, are markers of this changing demographic indicating improvement in Aboriginal population health overall and not just in the Northern Territory (Thomas et al 2007). A number of caveats remain regarding further positive health transitions for Aboriginal people. Firstly, as shown by declining life expectancy in Russia, ex-Soviet countries and sub-Saharan Africa, demographic change may be reversed unless positive social and health policies are maintained. Secondly, the health and consequent life span of non-Indigenous Australians is also continuing to improve and the life expectancy gap for Aboriginal people may not be reduced, unless additional resources are provided on the basis of real equity in health policies and funding as well as in education, jobs, housing and self-determination. Thirdly, and particularly relevant to this Review, increased Aboriginal survival into older ages may be accompanied by earlier onset and increased rates of age-related dementias and a higher prevalence of neurodegenerative brain diseases than is currently present in non-Indigenous Australians (Smith, Flicker et al. 2008).

### 2.2 A life cycle approach to ageing, cognition and dementia

Major known, as well as emerging research in large cohorts of non-Indigenous populations internationally, point to key risk factors and transition points along the life-cycle impacting on neuro-cognitive growth and decline, and increased risk of neurodegenerative diseases such as Alzheimer’s disease and other dementias later in life. Furthermore, it is increasingly recognised that early life events, social and biological, may interact to influence the ageing process across the lifespan. This literature review will examine a life cycle approach to risk factors and protective factors for ageing, cognitive growth, cognitive decline and dementia in later life.

In early life, biological factors such as exposure to inflammation, including periodontal disease and tooth loss, are emerging as risk factors in the development of Alzheimer’s disease later in life (Gatz, Mortimer et al. 2006b). Social determinants, such as low educational attainment have been shown to increase risk of Alzheimer’s disease later in life (Gatz, Mortimer et al. 2006b), with lower brain capacity when young a predictor of earlier cognitive decline (Whalley, Starr et al. 2000). Adverse childhood experiences are increasingly implicated with chronic ill-health in mid- and later life (Draper, Pfaff et al. 2008; Middlebrooks and Audage 2008); with maladaptive lifestyle choices impacting on physical, social, emotional and brain health (Pollard 2005); and, supported by a substantial body of evidence, with disruptions to brain growth and functioning (De Bellis 2005; Anda, Felitti et al. 2006).
In mid-life, the presence of risk factors for heart disease – high cholesterol, hypertension, diabetes and smoking – are associated with a significantly increased risk of dementia in later life, which increases exponentially if more than one risk factor is present (Suh and Shah 2001; Whitmer, Gunderson et al. 2005). These mid-life vascular and metabolic risk factors are the major known risk factors for late-life dementia in non-Indigenous studies. In Indigenous people, mid-life vascular and metabolic risk factors (obesity, blood pressure, lipids, alcohol, cigarettes, inactivity) and diseases (cardiovascular, diabetes, kidneys) are known causes of early death and disability. While this reflects the current health transition of the Indigenous population as a whole in Australia, the demographic shifts now emerging, together with the chronic disease burden amongst Indigenous Australians, has major implications for the cognitive health of the Indigenous population and for their transition to the stage of neuro–degenerative diseases.

The relationship between early life socio-biological factors and mid-to later life physical, mental and cognitive health, and, the relationship between mid-life health and social factors and later life physical, mental and cognitive health, point to ageing as a whole of life process with constant interaction of social and biological determinants, both proximal (early life) and distal (mid to later life). The health and social questions that flow from this concern what factors across the lifecycle impair our brains, and consequently, what kinds of interventions in terms of brain health need to occur across the life span and before cognitive decline commences.

### 2.3 Prevalence of dementia: a global snapshot

The global presence of dementia is estimated at twenty five million people (Wimo, Winblad et al. 2003; Ferri, Prince et al. 2005). These figures are projected to double every twenty years to an estimated 81.1 million by 2040 (Ferri, Prince et al. 2005). Almost half of people with dementia (46%) live in Asia, 30 percent in Europe, and 12 percent in North America (Wimo, Winblad et al. 2003). The Organisation, Alzheimer’s Disease International (ADI), presents integrated statistics for a range of prevalence studies of dementia in more developed countries which show the exponential rise in dementia’s prevalence with increasing age.

<table>
<thead>
<tr>
<th>Age group</th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence</td>
<td>1.4%</td>
<td>2.8%</td>
<td>5.6%</td>
<td>11.1%</td>
<td>23.6%</td>
</tr>
</tbody>
</table>

In numerical terms, the majority of people with dementia live in the developing world, with numbers forecast to increase significantly, if unevenly, across different geographic regions (Wimo, Winblad et al. 2003). A projected increase of 78 percent in the number of people aged 65 or over between 1990 and 2010 in the less developed countries has been calculated (Ferri, Prince et al. 2005).

Suh and Shah’s review of the epidemiological transition in dementia, found that Alzheimer’s disease (AD) had become nearly twice as prevalent as vascular dementia (VaD) in Korea, Japan and China, since transition in the early 1990s; whilst in Nigeria, dementia prevalence was low. In studies of Indian populations, results were mixed with AD and VaD each being more prevalent in different population studies. Consistently, European and American studies have found AD to be more prevalent than VaD (Suh and Shah 2001), although the limited research on dementia in North American and Alaskan Indigenous populations, suggests that dementia, notably AD, may be less common in these populations at this transition stage (Jervis and Manson 2002). In Australia, projections by Jorm and colleagues of dementia’s prevalence and incidence, estimates increases from

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43,000 to 143,000 in the number of new cases per year over the period 2000 to 2050, and a corresponding prevalence increase from 172,000 to 588,000 over the same period (Jorm, Dear et al. 2005).

Alzheimer’s disease is the most common form of dementia in Australia, followed by vascular dementia (Australian Institute of Health and Welfare 2006). There may however, be substantial variation in the aetiology of dementia type within localized populations and within specific age groups - associated with particular types of risk. Inequalities in the transition of diseases associated with dementia, such as cerebrovascular disease (Burnley and Rintoul 2002), suggest further that the factors impacting on the prevalence and incidence figures for Alzheimer’s disease and vascular dementia, as well as some of the rarer forms of dementia (Almeida and Lautenschlager 2005), reflect differences in the health transitions of different population groups within and across national populations as well as in methodological discrepancies of accurate diagnosis.

2.4 A snapshot of dementia in Australia

Alzheimer’s Australia provides the following snapshot of dementia:

- Dementia is currently the second largest cause of disability after depression
- By 2016, it will become both the largest source of disability burden after depression, and, the largest source of burden of disease for women, and fifth largest for men
- There are currently 227,300 Australians with dementia and 9,600 diagnoses of younger onset dementia in people under the age of 65
- Between 2000 and 2050, the number of people with dementia in Australia is projected to increase by 327%, while total population increases will be less than 40%
- Alzheimer’s disease is the most common form of dementia, followed by vascular dementia, and more women than men are affected
- Approximately half of those with moderate to severe dementia live in the community, either in their own homes or in the homes of carers, while the other half live in residential facilities
- By contrast, studies of dementia prevalence using validated culturally adapted instruments for remote living Indigenous communities aged 45 and over, show that the dementia rate in this population is nearly five times higher, 12.4% compared to 2.6% in the general Australian population and that more males than females are affected. Further, the dementia prevalence ratio increases significantly amongst Indigenous Australians in the ‘younger-old’ age groupings by comparison to non-Indigenous Australians: by a factor of 26.00 in the age bracket 45-59; by a factor of 19.88 in the age bracket 60-69; and by factors of 4.10 and 2.98 in the age groups, 70-79 and 80 plus, respectively (Marsh, Inglis et al. 2006; Smith, Flicker et al. 2008)
- The fastest growth in dementia numbers will be in the Northern Territory (where the greatest proportions of Indigenous Australians live) with a sixfold increase projected between 2000 and 2050 (Access Economics 2005)

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6This information is available in, “Dementia: A Major Health Problem for Indigenous People”. Briefing prepared for Parliamentary Friends of Dementia, Paper number 12; August 2007, Alzheimer’s Australia
7These projections are based on very small numbers and therefore interpretation is difficult in the absence of further research into dementia incidence and prevalence
2. 5 Demographics of the Australian Indigenous population

Trovato identifies two important demographic features of Indigenous populations, namely their relatively disadvantaged socio-economic status and their delayed epidemiological transition, compared with the rest of their respective populations (Trovato 2001). Aboriginal people in Australia have an overall life expectancy 17 years less than for the rest of the Australian population, with life expectancy at birth for Indigenous males 59 years and for Indigenous females 65 years, compared with 77 and 82 years for non-Indigenous males and females respectively (Steering Committee for the Review of Government Service Provision 2007).


<table>
<thead>
<tr>
<th>Indicator</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life expectancy</td>
<td>17 years less than non-Indigenous</td>
</tr>
<tr>
<td>Death rates</td>
<td>2 to 4 times higher than rates for rest of population and 6 times higher for those aged 35-54</td>
</tr>
<tr>
<td>Disability</td>
<td>Twice as likely as rest of population for Indigenous adults in non-remote areas</td>
</tr>
<tr>
<td>Daily smokers</td>
<td>Twice as likely as non-Indigenous population</td>
</tr>
<tr>
<td>Low birth weight</td>
<td>More than twice as likely compared with non-Indigenous population</td>
</tr>
<tr>
<td>Abuse or neglect</td>
<td>Substantiations nearly four times as likely as rest of population</td>
</tr>
<tr>
<td>Unemployment rate</td>
<td>Three times the non-Indigenous rate</td>
</tr>
<tr>
<td>Suicide death rates</td>
<td>Between 19 and 45 per 100 000 population compared to 11 and 16 per 100 000 for non-Indigenous population</td>
</tr>
<tr>
<td>Educational level</td>
<td>Indigenous students half as likely to continue to year 12 as compared with non-Indigenous students</td>
</tr>
<tr>
<td>Literacy and numeracy</td>
<td>Not achieved in reading by 22% of Indigenous children compared with 7% of non-Indigenous Y3 children; Not achieved in writing by 26% of Indigenous children compared with 7% of non-Indigenous Y3 children; Not achieved in numeracy by 20% of Indigenous students compared with 6% of non-Indigenous children. Similar results for Yrs 5 &amp; 7</td>
</tr>
<tr>
<td>Homicide rate</td>
<td>5 to 15 times the rate in non-Indigenous population</td>
</tr>
<tr>
<td>Imprisonment</td>
<td>Incarceration 13 times greater than for non-Indigenous population</td>
</tr>
</tbody>
</table>
2.5.1 Australian population by Indigenous status and location

In the latest population census, the 2006 Census, 455,028 Australians were identified as being of Aboriginal and Torres Strait Islander origin, representing 2.3 percent of the total Australian population (Australian Bureau of Statistics 2008). The overwhelming majority were of Aboriginal origin only (90%), with 6 percent of Torres Strait Islander origin and 4 percent of mixed Aboriginal and Torres Strait ancestry. The majority of the Torres Strait Islander population (64%) live in Queensland.

The state of Victoria, followed by New South Wales and Queensland, recorded the largest proportional increases in the Indigenous population, with 20 percent, 15 percent and 13 percent respectively. Almost a third of the resident Indigenous population live in Major Cities, with 21 percent in Inner Regional Areas; 22 percent in Outer Regional areas; 10 percent in Remote areas and 16 percent in Very Remote Areas. The non-Indigenous population is more highly concentrated in Major Cities (69%) and underrepresented in Remote and Very Remote Australia (2%). While the majority of Indigenous people in Australia reside in cities and smaller urban centres, as compared to Remote and Very Remote Areas, their proportional representation increases with geographic remoteness.

New South Wales has the largest Indigenous population of all the States and Territories, yet this population comprises only 2 percent of the total New South Wales population. By contrast, the Northern Territory has the largest proportion of Indigenous people in the population (32 percent), with the majority of these living in Remote and Very Remote Areas of the Territory (79%). States with a relatively high proportion of Indigenous people living in Major Cities, include South Australia (48% of the total State Indigenous usual residence count), Victoria (48%) and New South Wales (42%) (Australian Bureau of Statistics 2007b).

Social demographers point to the substantial undercounting of the Indigenous population occurring in the census. Taylor and Biddle utilised 2006 Census data to explore what they describe as, “the geography of spatial change in Indigenous population counts” (Taylor and Biddle 2008). Their modelling and analysis show that in some remote locations, the Census functions more “like a sample survey”, while in other locations, there are higher counts than expected with, “Indigenous people comprises(ing) a steadily rising share of local town and country populations across almost all of regional Australia” (Taylor and Biddle 2008). These spatial changes need to be taken into account when reading estimates of the resident Indigenous population, and understanding their impact on policy and program resourcing.

Table 2 shows the estimated resident population by Indigenous status and by State and Territory based on data from the 2001 and preliminary 2006 censuses (Australian Bureau of Statistics 2007b).

*) According to the ABS, the census count of Indigenous people has doubled over the past two decades due to natural increases (births minus deaths) and non-demographic factors (improvements in census collection and increased identification of people as being of Indigenous origin); ii) The information on population characteristics in this section is drawn from the ABS (2008) document, unless otherwise referenced.
Table 2: Estimated resident population, Indigenous status – 2001 and preliminary 2006

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Indigenous '000</th>
<th>Total '000</th>
<th>Proportion of total Indigenous population %</th>
<th>Proportion of state/territory population %</th>
<th>Inter-censal change 2001-2006 %</th>
</tr>
</thead>
<tbody>
<tr>
<td>New South Wales</td>
<td>148.2</td>
<td>6 817.2</td>
<td>28.7</td>
<td>2.2</td>
<td>9.9</td>
</tr>
<tr>
<td>Victoria</td>
<td>30.8</td>
<td>5 128.3</td>
<td>6.0</td>
<td>0.6</td>
<td>10.7</td>
</tr>
<tr>
<td>Queensland</td>
<td>146.4</td>
<td>4 091.5</td>
<td>28.3</td>
<td>3.6</td>
<td>16.3</td>
</tr>
<tr>
<td>South Australia</td>
<td>26.0</td>
<td>1 568.2</td>
<td>5.0</td>
<td>1.7</td>
<td>2.0</td>
</tr>
<tr>
<td>Western Australia</td>
<td>77.9</td>
<td>2 059.0</td>
<td>15.1</td>
<td>3.8</td>
<td>18.2</td>
</tr>
<tr>
<td>Tasmania</td>
<td>16.9</td>
<td>489.9</td>
<td>3.3</td>
<td>3.4</td>
<td>-2.8</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>66.6</td>
<td>210.7</td>
<td>12.9</td>
<td>31.6</td>
<td>17.1</td>
</tr>
<tr>
<td>ACT</td>
<td>4.0</td>
<td>334.2</td>
<td>0.8</td>
<td>1.2</td>
<td>3.4</td>
</tr>
<tr>
<td>Australia</td>
<td>517.2</td>
<td>20 701.5</td>
<td>100.0</td>
<td>2.5</td>
<td>12.8</td>
</tr>
</tbody>
</table>


The Census also showed that the vast majority of Indigenous people spoke English only at home, similar to that reported by non-Indigenous Australians (Australian Bureau of Statistics 2008). One in eight Indigenous people (12%) speak an Australian Indigenous language at home, increasing by a small margin in speakers aged 45 years and over. Remoteness was the key indicator of the vernacular being spoken at home, with almost three-quarters (74%) of Indigenous people who spoke an Indigenous language at home, living in Very Remote Australia, by comparison to 14 percent in Remote Australia and 4 percent in Major Cities. Over half of all Indigenous language speakers live in the Northern Territory. Similarly, affiliation with a traditional Indigenous religion was highest in Very Remote Areas (6%) by comparison to all other areas (less than 1%).

A feature of the Indigenous population aged 55 years and older, was their greater likelihood than those in other age groups to report recognition of homelands or traditional country, identification with a clan, tribal or language group (60%), or to speak an Indigenous language (26%) (ABS 2007a).

Figure 1 shows the numbers of Indigenous people and their proportions in the total Australian population between the years 1991 to 2006. This data demonstrates that the Indigenous population is not growing at the same rate relative to the general population, with figures for declining fertility amongst Indigenous women supporting this. This is beginning to mirror the trend in the non-Indigenous population, with population growth in this latter population attributable to migration.
Figure 1. Numbers of indigenous peoples and their proportion in the total Australian population, 1991 - 2006

![Graph showing numbers of indigenous peoples and their proportion in the total Australian population, 1991 - 2006](image)


2.5.2 Age structure of the Indigenous population

The Indigenous population has a markedly different age structure to the rest of the Australian population. About 39.3 per cent of the Indigenous population are under 14 years of age compared to 20.4 per cent for the non-Indigenous population (Steering Committee for the Review of Government Service Provision 2007). In a number of older age groupings, the estimated resident population by Age and Indigenous Status, as at 30 June 2006, show stark differences in number and percentage between Indigenous and non-Indigenous populations (Australian Bureau of Statistics 2008).

Table 3: Numbers and percentages of Indigenous and non-Indigenous population by age group, 30 June 2006

<table>
<thead>
<tr>
<th>Age groupings</th>
<th>No.s in population</th>
<th>% in population</th>
</tr>
</thead>
<tbody>
<tr>
<td>45-49</td>
<td>25 216 (1 470 072)</td>
<td>4.9 (7.3)</td>
</tr>
<tr>
<td>50-54</td>
<td>20 041 (1 343 639)</td>
<td>3.9 (6.7)</td>
</tr>
<tr>
<td>55-59</td>
<td>14 541 (1 257 018)</td>
<td>2.8 (6.2)</td>
</tr>
<tr>
<td>60-64</td>
<td>9 773 (978 074)</td>
<td>1.9 (4.8)</td>
</tr>
<tr>
<td>65-69</td>
<td>6 541 (772 628)</td>
<td>1.3 (3.8)</td>
</tr>
<tr>
<td>70-74</td>
<td>4 345 (624 793)</td>
<td>0.8 (3.1)</td>
</tr>
<tr>
<td>75+</td>
<td>5 163 (1 273 644)</td>
<td>1.0 (6.3)</td>
</tr>
<tr>
<td><strong>Total population</strong></td>
<td>517 174 (20 184 314)</td>
<td><strong>2.6 (100.0)</strong></td>
</tr>
<tr>
<td><strong>Median age</strong></td>
<td><strong>21.1 (37.0)</strong></td>
<td></td>
</tr>
</tbody>
</table>

10 Table 3 is drawn from the data in section 2.3.17, Estimated Resident Population (a), Sex by Age - 30 June 2006, data for Indigenous Persons and Non-Indigenous Persons. ABS 2008
The following figure shows the Age Structure of the Australian population as a whole, with the juxtaposition of the Indigenous population against the non-Indigenous population highlighting stark differences in the age composition of these respective populations. This figure comes from the ABS publication, “Population Characteristics, Aboriginal and Torres Strait Islander Australians” (Australian Bureau of Statistics 2008).11

Figure 2: Estimated resident population by age, 2006

![Age Structure Chart]

11 Figure 2 in the ABS publication can be found in chapter 2, Population Distribution and Structure, on page 15.

2.5.3 Population distribution: Aboriginal and Torres Strait Islander Australians aged 45 and over

What do we know about the composition of the older Indigenous population in Australia?

The Australian Bureau of Statistics provides latest figures for the numbers of Indigenous people aged 45 and over by State and Territory. These are shown in Table 4 below.

In figure 4, the numbers of Indigenous people 45 years and over, and 75 and over, are shown for the Census periods from 1991 to 2006.

A number of observations can be gleaned from the data of the over 45s in the Indigenous population:

- There has been a three-fold increase in the numbers of Indigenous people over the age of 45 identified in the Census periods, 1991 to 2006.

- The age distributions across each five yearly age category remain remarkably stable. This is true both over time and across States. There are no appreciable differences in the distribution of age for Indigenous Australians aged 45 years and over.

- Victoria is the only State which is slightly underrepresented in the “younger-old” age group and somewhat overrepresented in the “older-old” age group. Victoria would appear to be a more integrated Aboriginal community.
Table 4: 2006 Census counts Indigenous persons by State and Territory and age group

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>45-49 years</th>
<th>50-54 years</th>
<th>55-59 years</th>
<th>60-64 years</th>
<th>65-69 years</th>
<th>70-74 years</th>
<th>75-79 years</th>
<th>80-84 years</th>
<th>85+ years</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>New South Wales</td>
<td>7059</td>
<td>5640</td>
<td>4314</td>
<td>2949</td>
<td>2025</td>
<td>1390</td>
<td>809</td>
<td>379</td>
<td>300</td>
<td>24 865</td>
</tr>
<tr>
<td>Victoria</td>
<td>1484</td>
<td>1235</td>
<td>952</td>
<td>627</td>
<td>465</td>
<td>1028</td>
<td>231</td>
<td>126</td>
<td>119</td>
<td>5 511</td>
</tr>
<tr>
<td>Queensland</td>
<td>6018</td>
<td>4804</td>
<td>3621</td>
<td>2359</td>
<td>1531</td>
<td>233</td>
<td>632</td>
<td>365</td>
<td>273</td>
<td>20 631</td>
</tr>
<tr>
<td>South Australia</td>
<td>1267</td>
<td>1028</td>
<td>690</td>
<td>503</td>
<td>351</td>
<td>233</td>
<td>167</td>
<td>79</td>
<td>78</td>
<td>4 396</td>
</tr>
<tr>
<td>Western Australia</td>
<td>2942</td>
<td>2317</td>
<td>1606</td>
<td>1082</td>
<td>738</td>
<td>499</td>
<td>317</td>
<td>182</td>
<td>178</td>
<td>9 861</td>
</tr>
<tr>
<td>Tasmania</td>
<td>934</td>
<td>701</td>
<td>571</td>
<td>359</td>
<td>229</td>
<td>160</td>
<td>99</td>
<td>56</td>
<td>22</td>
<td>3 131</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>2620</td>
<td>2073</td>
<td>1358</td>
<td>1032</td>
<td>654</td>
<td>491</td>
<td>254</td>
<td>156</td>
<td>155</td>
<td>8 793</td>
</tr>
<tr>
<td>ACT</td>
<td>191</td>
<td>172</td>
<td>94</td>
<td>56</td>
<td>30</td>
<td>16</td>
<td>14(b)</td>
<td></td>
<td></td>
<td>573</td>
</tr>
<tr>
<td>Total</td>
<td>22515</td>
<td>17970</td>
<td>13206</td>
<td>8967</td>
<td>6023</td>
<td>4089</td>
<td>2509</td>
<td>1343</td>
<td>1125</td>
<td>77 761</td>
</tr>
</tbody>
</table>

Source: Information to build this table is drawn from ABS data from the 2006 Census.

Figure 3: Age distribution by percentage for Indigenous population 45 years and over by State and Territory, 2006

Figure 5: Age distribution of the Indigenous Population 45 years and over by Indigenous Region: all States, 2006
2.6 Indigenous health indicators

The health of the last generation begins well before conception (Pollard 2005). This intergenerational and trans generational perspective to the cycle of ill-health within a given population, goes a long way towards explaining the disparities found between Indigenous and non-Indigenous populations in the, “differential allocation of [health] risks and benefits (Pollard 2005). Similarly, the body of research by Michael Morrissey and colleagues on the social determinants of health within the Indigenous Australian population, exposes the “complex aetiology and pathways of chronic disease” (Morrissey 2003). Other researchers point to the limitations of epidemiological approaches focusing on individual level risk factors for ill-health (Thompson and Gifford 2000). Further, the legacy of prejudice and discrimination, as a consequence of colonialism and government policy, continues to impact on Aboriginal ‘well-being’ (Zubrick, Lawrence et al. 2004; Bishop, Colquhoun et al. 2005).

The concept of well-being is integral to an Indigenous understanding and perception of health, defined in a landmark document by the National Aboriginal Health Strategy Working Party as encompassing, “Not just the physical well-being of the individual but the social, emotional and cultural well-being of the whole community...This is a whole of life view and it includes the cyclical concept of life-death-life” (National Aboriginal Health Strategy Working Party 1989).

The following Indigenous health indicators across the life span are presented. A number of these are implicated in the general literature as potential risk factors for the development of dementia in later life. Much of the data are drawn from a government review of key indicators of Indigenous disadvantage, unless otherwise referenced (Steering Committee for the Review of Government Service Provision 2007).
Indigenous health indicators: A snapshot of key findings

Three recurring reasons for paediatric consultations of 40 separate diseases/health problems reviewed were, chronic suppurative otitis media, suspected child abuse and neglect; and failure to thrive. In the paediatric population of Aboriginal communities, the prevalence of foetal alcohol spectrum disorder was at least 1.5%, and in Torres Strait Islander children, rheumatic heart disease prevalence was at least 0.6%

Source: (Rothstein, Heazlewood et al. 2007)

Low birth weight

Live births to Indigenous mothers (13%) compared to non-Indigenous (6%) Source: (Steering Committee for the Review of Government Service Provision 2007)

Proportion of live births with very low and extremely low birth weights were: 2.4 and 1.1 per cent respectively; and 1.0 and 0.4 percent respectively for Indigenous compared with non-Indigenous mothers Source: (Rothstein, Heazlewood et al. 2007)

Low birth weight predisposes to renal disease and other chronic diseases in a high risk environment Source: (Hoy, Rees et al. 1998)

Preventable diseases and injuries

251. 0 Indigenous children per 1000 under 4 years hospitalised compared with 122. 6 per 1000 in non-Indigenous children Source: (Steering Committee for the Review of Government Service Provision 2007)

Infections and diseases

Recurring skin infections affected 8.5 per cent of Indigenous children, particularly for the age group 4 to 11. Prevalence of skin infections was 17.6 per cent in isolated areas;

18.1 per cent of Indigenous children affected with ear infections, with those aged 0 - 3 and 4 - 11 most affected;

Prevalence of hearing conditions, including total/partial hearing loss and otitis media, higher for Indigenous children aged 0 - 14 (9.5%) than for non-Indigenous children (3.0%);

No association found between primary carer’s educational attainment and recurring infections or ear infections; but the estimated rate of more than one type of recurring infection, where the primary carer reported financial difficulty, was about double (16.3%) that of the prevalence in households where the primary carer reported being able to save occasionally or fairly frequently (8.4 %)

Source: (Steering Committee for the Review of Government Service Provision 2007)

Children in remote living Aboriginal communities found to be almost all affected by otitis media Source: (Morris, Leach et al. 2005)

Hearing loss

Source: (Steering Committee for the Review of Government Service Provision 2007)

Higher rates among Indigenous people than non-Indigenous people in all age groups up to 55 years of age, with the greatest disparity between Indigenous and non-Indigenous children aged 0 - 14 years.
Prevalence of hearing conditions for Indigenous children three times as high as for non-Indigenous children;

The prevalence of hearing conditions in the Indigenous population (all ages) did not vary with remoteness (comparison to the Morris et al 2006 study of otitis media in remote NT children);

Tooth decay

Indigenous children had higher numbers of both infant and adult teeth with decay than non-Indigenous children in both metropolitan and rural areas;

Indigenous children aged less than five years had the highest dental hospitalisation rate of any age group, almost one and a half times the rate for non-Indigenous children of that age group
Source: (Jamieson, Armfield et al. 2007)

The Western Australian Aboriginal Child Health Survey found 38 percent of children had experienced tooth decay, tooth removals or fillings
Source: (Zubrick, Lawrence et al. 2004)

Psycho social stress and chronic disease

Health outcomes associated with Stress - Psychological stress, anxiety, depression, suicidal thoughts, hypertension, reduced immune function, diabetes, hyperglycaemia, heart disease, cholesterol levels, artery thickness, pre-term birth, substance misuse Source: (Paradies 2006)

Emotional or behavioural difficulties - Almost a quarter of Aboriginal children aged 4 - 17 years assessed at high risk compared with 15 percent of children in the non-Aboriginal population
Source: (Zubrick, Lawrence et al. 2004)

Major life stressors

About 22 percent of Aboriginal children were living in families where 7 or more stressful life events had occurred in the previous 12 months
Source: (Zubrick, Lawrence et al. 2004)

Parenting

A quarter of Aboriginal children were living in families with, “poor quality of parenting”. Around one in five, were living in families that “functioned poorly”
Source: (Zubrick, Lawrence et al. 2004)

Suicide and suicide ideation

Over one in six young people aged 12 - 17 years had seriously thought about ending their own life in the 12 months prior to the West Australian Child Health Survey. Of these, 39 percent had attempted suicide
Source: (Zubrick, Lawrence et al. 2004)

The age adjusted suicide rate in the Northern Territory increased significantly between 1981 and 2002. Indigenous males under the age of 45 years most at risk. These rates are strongly associated with a history of diagnosed mental illness (49%) and misuse of alcohol or other drugs (72%)
Source: (Measey, Li et al. 2006)
<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Imprisonment</td>
<td>The age standardised imprisonment rate for Aboriginal and Torres Strait Islander people (1.668 per 100,000) is currently 13 times the rate for non-Aboriginal and Torres Strait Islander people. The majority of prisoners suffer from psychiatric, mental health and substance use disorders. Source: (Belcher and Al-Yaman 2007)</td>
<td></td>
</tr>
<tr>
<td>Impact of “Stolen Generations” and removal from families</td>
<td>Children of Aboriginal carers who had been forcibly separated from their natural family were 2.3 times more likely to be at high risk of clinically significant emotional or behavioural difficulties after adjusting for age, sex, Level of Remoteness Index (LRI) and irrespective of whether the primary carer was the birth mother of the child. These same children also had levels of alcohol and other drug use that were approximately twice as high as children whose Aboriginal primary carer had not been forcibly separated from their natural family. Source: (Zubrick, Lawrence et al. 2004)</td>
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</tr>
<tr>
<td>Health risk behaviours</td>
<td>Of Indigenous people who had been removed from their natural family, 54 percent had a disability or long-term health condition, including 14 percent with a profound or severe core activity limitation compared with 36 percent and 8 percent of all Indigenous people. Source: (Australian Bureau of Statistics and Australian Institute of Health and Welfare 2005)</td>
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</tr>
<tr>
<td>Smoking and alcohol</td>
<td>Over one third of young people (35 percent) smoked regularly, with over half of those aged 17 years smoking regularly. At 17 years of age, 61 percent of males and 43 percent of females were drinking alcohol. Almost one in five young people had been in a car with a drunk driver in the six months prior to the survey. Source: (Zubrick, Lawrence et al. 2004)</td>
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</tr>
<tr>
<td>Substance abuse</td>
<td>Cognitive deficits in the areas of visual attention, visual recognition memory and visual paired associate learning were found amongst chronic petrol sniffers in Indigenous inner-urban and remote rural communities. Source: (Maruff, Burns et al. 1998)</td>
<td></td>
</tr>
<tr>
<td>Injury</td>
<td>Rates of death from injury higher for all age groups in the Indigenous population, except people older than 65 years; Indigenous people aged 25 - 44 years twice as likely to be hospitalised as their non-Indigenous counterparts and five times as likely to be hospitalised for interpersonal violence. Source: (Clapham, Stevenson et al. 2006)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Violence and falls were the two most common mechanisms of injury leading to hospitalisation for Aboriginal men and women. Source: (You and Guthridge 2005)</td>
<td></td>
</tr>
</tbody>
</table>
Acquired brain injury

Standardised rates for Indigenous people 343 per 100,000 substantially higher than for the non-Indigenous population rate for ABI of 142 per 100,000 Source: (Fortune and Wen 1999)

Chronic disease indicators

Circulatory system diseases: 11 percent of Indigenous Australians reported a long-term health condition associated with the circulatory system, most commonly hypertension;

Rheumatic heart disease: 94 percent of rheumatic heart disease in Central Australia occurs in Aboriginal populations, with a prevalence rate of 13 per 1,000 among Indigenous Australians, compared with less than one per 1,000 among other Australians; In the Top End of the Northern Territory, the figures are 92 percent for Aboriginal Australians, of which two thirds were Indigenous women. The highest incidence rates for Rheumatic fever were found among Aboriginal and Torres Strait Islander children aged 5 - 15 yrs, at 346 per 1000, 000 in the Top End and 365 per 1000,000 in Central Australia

Diabetes: The prevalence of diabetes among Indigenous Australians (mainly type 11 diabetes) aged 35 - 44 years was almost as high as among non-Indigenous Australians aged 55 years or over. Hospitalisation rates for Type 11 diabetes in Indigenous males and females eight and ten times than those for total Australian males and females

End-stage renal disease: Aboriginal Australians comprised 6.5 percent of those registered with the ANZDATA, despite a 2.4% Indigenous representation in the total population; About two thirds of those registered were less than 55 years old

Standardised end stage renal disease incidence among Indigenous Australians highest in remote regions, where it is up to 30 times the national incidence for all Australians; in urban regions the incidence is much lower but nevertheless significantly higher than the national incidence
Source: (Cass, Cunningham et al. 2001)

The raft of chronic diseases – heart disease, stroke, diabetes and renal failure – share a number of common risk factors: poor quality diet; physical inactivity, smoking, central obesity; these often occur in the same people and amplify mortality risk Source: (O’Dea 2005). O’Dea, citing the Cass et al study (2001), notes the 20-fold gradient in ESRD among Indigenous people between the least and most disadvantaged ATSIC regions (by comparison to a three-fold gradient for the non-Indigenous population)

A rapid upsurge in “lifestyle” diseases with associated complications and co-morbidities observed in the last few decades including, overweight and obesity; cardiovascular disease, type 11 diabetes mellitus and chronic renal disease. Specifically, The prevalence of overweight or obesity in Aboriginal adults approx. 40 - 45%. The incidence and prevalence of diabetes in Indigenous people 2 to 4 times higher on average than in other Australians. Rates of newly diagnosed childhood diabetes in WA about 18 times higher in Indigenous children. Cardiovascular disease the leading cause of death in Indigenous Australians, with relative mortality rates 3 to 4 times higher than in the non-Indigenous population. Aboriginal people suffer disproportionately high rates of chronic renal disease and renal failure
Source: (Gracey 2007)
Cardiovascular risk among urban Aboriginal people showed 84 percent of study group fell within the National Heart Foundation’s “high risk” or “highest risk” categories for cardiovascular disease; A high proportion of this group reported diabetes, hypertension, smoking, overweight and obesity, with obesity and smoking twice as prevalent as in the general population Source: (Thompson, Bradshaw et al. 2003)

Very high prevalence of the metabolic syndrome in Aboriginal and Torres Strait Islander Australians Source: (Schutte, Shemesh et al. 2005)

Hospital admissions (Ishak 1998)

Disease categories, specifically Service Related Group (SRG) data with the highest Indigenous hospital admission rates for New South Wales include: Drugs and Alcohol; Endocrinology, Respiratory Medicine, Nephrology, Neurology and Dermatology (Neurology featured in the top five for males; and Nephrology for females).

Annual admission rate for Neurology SRG per 1000 population in NSW between 1989 to 1995 show 14.61 and 8.47 for males and females respectively in the Indigenous NSW population, and 6.44 and 6.42 for males and females respectively in the non-Indigenous population; the Indigenous/non-Indigenous percentage difference for males is 226.92 and 133.58 for females.

Data for Service Related Groups (SRG) by age and the related Indigenous/non-Indigenous differentials in NSW show:

Indigenous admission rate due to Respiratory Medicine for children in the age category 0 - 4 years three times the rate for non-Indigenous children; From the age of 30 onwards the gap increases again with the Indigenous admission rate for some age categories approximately seven times the non-Indigenous rate. Indigenous rates in relation to admission rates for Drugs and Alcohol are much higher in most age categories, up to 15 times the non-Indigenous rate in some age groups. The Indigenous hospital admission rate peaks around the ages of the mid-thirties and then again around the mid-fifties as the main cause of admission.

The high rate of Indigenous admissions for Endocrinology is more than 10 times the non-Indigenous rate in some age groups, with the greatest differentials being observed from the age of 45 upwards. Data on Dermatological admissions shows great variations in the childhood age spans, particularly between 0 and 4 years of age; and again in the group over 60 years.

Admission rates by age due to the Nephrology SRG increase more rapidly than the rate for non-Indigenous admissions after the age of 20 and then most visibly from age 50 onwards.

Area of residence is one of the important factors in the considerable variation observed between Indigenous and non-Indigenous hospital admission rates by Service Related Group, with the more remote areas of the State contributing to the greatest differentials Source: (Ishak 1998)

The treatment for chronic kidney disease accounts for one third of all hospital admissions for Indigenous people

The search strategy entailed both a broad brush approach to searching the literature on dementia or Alzheimer’s disease combined with targeted searches mapped to risk factors and areas of key focus. The first part of the search scoured the literature on cognitive impairment and dementia and related risk factors. This was followed by a search of the above in the Aboriginal and Torres Strait Islander Population as well as other Indigenous populations in comparative countries. This was extended to a search for studies addressing narrative, experience and meaning of dementia and other illnesses in Indigenous populations.

Given the vast literature on dementia and the substantial literature on health, welfare and chronic disease in Indigenous populations, relevance was defined for the purposes of this review as, research which would illuminate cognitive health and decline across the life-span and its relevance to Aboriginal and Torres Strait Islander populations, with special reference to Alzheimer’s disease and the common dementias.

The first electronic data base searches occurred over the period, November 2006 to April 2007. Searches through Google and organisational websites continued throughout the review period (Nov 2006 to Nov 2008). The following is an outline of the process and rationale behind the search strategy.

3.1 Mapping of subject areas

During this phase the search was clearly delineated into subject areas. These terms were then mapped into subject headings as defined by the electronic data bases being searched.

3.2 Search of electronic data-base

The following data-bases were searched for both peer-reviewed and non-peer reviewed material:

- Pre-Medline (OVID)
- Sociological Abstracts (CSA)
- Cinahl (OVID)
- Medline (OVID)
- Embase (OVID)
- Informit (APAIS)
- HEALTH and other related databases
- PsycInfo (OVID)
- Cochrane Library
- Global Health

The following combinations of search and related MESH terms were used:
- Aborigin* or Indigen* or Torres Strait Islander or First Nations
- Alzheimer or dementia or neurodegenerative diseases
- Cognition or cognitive impairment
- Ag(e)ing or aged
- Ag(e)ing Well or Successful Ag(e)ing
- Carers or Caregivers
- Intervention research or intervention studies and dementia or cognitive decline
- Qualitative or Subjective or Identity or Narrative or Stories or Perceptions or Meaning and Dementia
- Health Transition or epidemiological transition
- Risk factors (Related terms mapped to different data bases; searches mapped to Diseases and/or Subjects)
- (Abuse or physical abuse or child abuse or partner abuse)
- (brain development or neural development or brain function or cognitive development)
- (systemic diseases or chronic diseases)
- (substance misuse or alcohol misuse or drug abuse)
- (cognition)/or trauma/ or exp birth trauma/or exp emotional trauma/or exp emotional trauma/or exp traumatic brain injury/ or exp posttraumatic stress disorder
- (Childhood separations or stolen generation)
- Exp childhood development
- (low birth weight or maternal health)
- Exp cognitive processes/ or exp Brain/ or exp At Risk Populations/Poverty/or exp social issues/ or exp disadvantaged/ or exp lower income level/ or exp socioeconomic status/ or exp poverty areas
<table>
<thead>
<tr>
<th>Aboriginal or Indigenous or Torres Strait Islander or First Nations</th>
<th>Dementia or Alzheimer’s disease or Neuro-degenerative diseases</th>
<th>Cognitive impairment or Cognition</th>
<th>Chronic disease/systemic disease/Metabolic syndrome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abuse (child/partner/physical/sexual)</td>
<td>Substance use/misuse</td>
<td>Drugs</td>
<td>Alcohol</td>
</tr>
<tr>
<td>Childhood separations</td>
<td>Stolen generation</td>
<td>Trauma</td>
<td>Family trauma</td>
</tr>
<tr>
<td>Head trauma</td>
<td>Low birth weight</td>
<td>Maternal health/maternal nutrition</td>
<td>Foetal development</td>
</tr>
<tr>
<td>Poverty</td>
<td>Socio-economic determinants</td>
<td>Education</td>
<td>Educational intervention</td>
</tr>
<tr>
<td>Nutrition</td>
<td>Epidemiological transition</td>
<td>Health transition</td>
<td></td>
</tr>
</tbody>
</table>
3.3 Creation of Endnote Library and Subject Libraries

An Endnote Master Library was set up to capture relevant literature searched for the broader study. Following this, subject libraries were created from within the Endnote library to search for references with a common theme. Common themes were derived through the use of keywords attributed to each entry in the Master Library. In addition to the Master End Note Library, thematic Endnote Subject Libraries were created. Appendix 2 shows the key words for the subject libraries, with the number of references corresponding to each; and with the number of references in the main endnote library.

3.4. Search of Google and Google Scholar search engines

The following additional search phrasing to search Google and Google Scholar were used:

“Subjective experience of illness”
“Subjective experience and meaning of dementia”
“Aboriginal or Indigenous or First Nations subjective experience of illness”
“Indigenous Psychology and Ageing”
“Palliative care and Indigenous communities”
“End of life care and Indigenous communities”
“Qualitative or Subjective or Identity or Narrative or Stories and Dementia”

3.5 Citation searching

Articles were also located from research references considered highly relevant to the study.

3.6 Organisational website search

The following organisation’s websites were searched for relevant material:

* Australian Bureau of Statistics
* Australian Institute of Health and Welfare
* Australian Government Department of Health and Ageing
* Alzheimer’s Disease International (ADI)
* Alzheimer’s Australia and State Branches
* Australian Indigenous healthInfoNet
* Centre for Aboriginal Economic Policy Research, Australian National University

3.7 Criteria for inclusion of references in study

Each member of the research team (4 people) independently rated the relevance of references in the Endnote library - based on initial abstract. An independent member of the team then summarised the consistency of the scores attributed by team members for relevance to the study. References were scored with the following ratings: A - highly relevant; B - some application; C - no relevance.
4. Health and psycho-social determinants of dementia: A global picture

4.1 Risk and protective factors for cognitive decline

Much has been written about risk factors known to be implicated in the development of dementia. Increasing age, female gender and low educational levels have been found in a number of studies to be highly significant and independent risk factors (Herrera, Caramelli et al. 2002; Zhang, Katzman et al. 2004; Zhang M 2004). In the case of the two most common forms of dementia, Alzheimer’s disease (AD) and vascular disease (VaD), the known risk factors are somewhat different, but are nevertheless implicated with each other (White and Launer 2006). In the case of AD, age, family history of dementia, female gender and presence of the ApoE 4 allele are the key significant risk factors (Suh and Shah 2001; Welsh-Bohmer, Breitner et al. 2006). In the case of VaD, the known risk factors are similar to those for cerebro vascular disease (CVD), and include CVD itself, hypertension, arrhythmia, hyperlipidaemia, alcohol-related disorders, smoking and diabetes mellitus (Suh and Shah 2001). Similarly, other studies report age, hypertension, electrocardiographic abnormalities and high hematocrit as significant and independent risk factors associated with the occurrence of VaD or a dementia syndrome (Ueda, Kawano et al. 1992; Ueda K 1992; Skoog 2003). Stroke and ischemic heart disease, correlated with VaD, is strongly implicated in the development of dementia in the elderly (Roman 2002). Obesity is a further independent risk factor for dementia, with one longitudinal study finding a 74 per cent and 35 percent increased risk of dementia for obese and overweight people respectively (Whitmer, Gunderson et al. 2005), and with other studies confirming this independent association (Gorospe and Dave 2007). Metabolic cardiovascular risk factors also increase the risk of dementia, notably of vascular origin ([Kalmijn, White et al. 2000). In particular, the presence of risk factors for heart disease in mid-life – high cholesterol, hypertension, diabetes and smoking – are associated with a 20 to 40 percent increased risk of dementia in later life, which increases exponentially if more than one risk factor is present (Whitmer, Sidney et al. 2005).

Exposure to inflammation early in life, including a history of tooth loss before age 35, increases one’s risk of developing Alzheimer’s disease later in life (Gatz, Mortimer et al. 2006b). Data from the Nun Study, found participants with the fewest teeth had the highest risk of prevalence and incidence of dementia (Stein, Desrosiers et al. 2007). While the strength of the association between age at, and amount of, tooth loss and risk of late life dementia is yet to be established, these findings do add weight to the role of vascular burden in the risk for dementia.

The concept of a “cohort morbidity phenotype”, developed by Finch and Crimmins to describe, “common epidemiological environments that are experienced by a given cohort in the earlier part of their lives regardless of changed location later on”, may explain how infectious and inflammatory causes found in the external environment in early childhood relate to different morbidity and mortality outcomes (Finch and Crimmins 2004). The association between viral, bacterial and other less common infections (eg. prion diseases) and compromised cognitive functioning, which can lead to the development of a dementia syndrome, have also been noted (Almeida and Lautenschlager 2005).

Population studies have gone some way towards mapping out the terrain between genetic and environmental risks for dementia, particularly when comparing dementia prevalence in populations of the same origin but in differing environmental contexts. As the Indianapolis-Ibadan Dementia Project has demonstrated, genetic markers of Alzheimer’s disease – presence of the e4 allele of APOE - increases risk marginally in Yoruba peoples in a North American context but not for those in an African context (Hendrie, Murrell et al. 2006). As Gatz et al observe, the story is not just about the genes (Gatz, Prescott et al. 2006a).

The mapping of this genetic-environmental terrain is important, as explanations are needed as to why certain groups are at greater risk than others and what other genetic and environmental factors reduce or increase the risks. Female gender as an independent risk factor for dementia, for example, presents differently in different population studies: no gender differences were found regarding the prevalence of different dementia types amongst an elderly urban population in Stockholm, Sweden (Fratiglioni, Grut et al. 1991), nor in the incidence of dementia and of AD in the Sydney Older Person’s
Increasing evidence is also emerging of the importance of looking to early childhood and its relationship to the development of dementia and Alzheimer’s disease in later life (Borenstein, Copenhaver et al. 2006). The work of Finch and Crimmins demonstrates the importance of a trans generational lifecycle perspective, which links suboptimal adult female health and nutrition to compromised fetal growth and lowered resistance to inflammation and environmental pathogens, as the main link between childhood conditions and adult morbidity (Finch and Crimmins 2004; Crimmins and Finch 2006). Numerous epidemiological studies have pointed to the relationship between a deficient or over abundant foetal nutritional environment and increasing susceptibility to insulin resistance, to glucose intolerance and to diabetes in later life (Reusens, Ozanne et al. 2007). In both human and animal models, an adverse in utero environment predisposes to, what some researchers describe as, “gestational programming” of offspring for diseases such as obesity, diabetes and hypertension (Ross, Desai et al. 2007). Gatz and colleagues in their study of the Swedish twin registry, point to poor nutrition or childhood diseases as the “presumed mechanisms” for compromising brain maturation; and further, that early exposure to inflammatory disease, including periodontal disease, multiplies the risk of developing Alzheimer’s disease (Borenstein, Copenhaver et al. 2006; Gatz, Prescott et al. 2006a; Gatz, Mortimer et al. 2006b). Low birth weight and maternal malnutrition are linked to higher morbidity at later life from cardiovascular disease, hypertension and type 2 diabetes (Finch and Crimmins 2004), all diseases implicated in a higher risk of developing dementia (Haan, Mungas et al. 2003). Both low birth weight and social disadvantage, as measured by deficits in relation to IQ, have been found to be consistent across social environments and birth weight groups respectively (Breslau, Dickens et al. 2006).

In relation to early childhood, a substantial research literature around child maltreatment and stress is addressing its impact on brain development (Glaser 2000; De Bellis 2002; De Bellis 2005; DeBellis and Kuchibhatla 2006; Watts-English, Fortson et al. 2006), as well as, to risk taking behaviours and health problems in adulthood (Felitti, Anda et al. 1998; Middlebrooks and Audage 2008). This includes a strong correlation between adverse childhood experiences and the burden of adult mental illness.
Further, the effects of childhood abuse have been demonstrated to impact well into late life health outcomes (Draper, Pfaff et al. 2008). Studies have linked chronic stress or abuse in childhood to the region of the brain involved in learning and memory, and in extreme situations of stress, to abnormal brain development and a decrease in cognitive functioning (Noble, Tottenham et al. 2005). Severe childhood stress is increasingly linked to cognitive, language and academic deficit and to a variety of maladaptive behavioural outcomes (Watts-English, Fortson et al. 2006). These factors, usually in tandem with poor socio-economic environments, constitute contextual risk factors for crime, and subsequent imprisonment (Weatherburn, Lind et al. 1997).

Heavy long term drinking and smoking are also associated with increased risk of cognitive impairment (Hulse, Lautenschlager et al. 2005). Yet as researchers point out, determining the specific link to neuro-cognitive damage requires addressing multiple and related factors, including family history of substance abuse, alcohol exposure in utero, multiple substance abuse and head injury (Tapert and Schweinsburg 2006). Both moderate and severe head injury in early adulthood have been found to be associated with increased risk of developing Alzheimer’s disease in later life, with a stronger association between AD and head injury in those with more e4 alleles (Plassman, Havlik et al. 2000).

The relationship between psycho-social stressors and social and environmental determinants to the development of chronic disease is well established (Morrissey 2003; Brown, Morrissey et al. 2006; Paradies 2006), and studies are increasingly demonstrating the links between chronic disease and the development of different types of dementia (Sastre and Evans 2003).

The role of stress across the lifespan and its relationship to a dementia diagnosis was explored in a longitudinal prospective study of 70 year olds followed for nine years (Persson and Skoog 1998). In this study, stressors, found to be independent contributors to the prediction of dementia (with similar outcomes for AD and VaD), included death of a parent before the age of sixteen, heavy manual labour and serious illness in a spouse or child after the age of 65.

A review of early life risk factors and childhood exposures for Alzheimer’s disease over the past twenty years - peri natal conditions, early life brain development, early life body growth, early life socio-economic conditions, environmental enrichment and “cognitive reserve” - suggests the interplay between genetic and environmental exposures throughout the life course (Borenstein, Copenhaver et al. 2006).

Protective factors

Findings from the Cache County Memory Study suggest the importance of “heart-smart” lifestyles in mid and late life to continued cognitive health and reduction of dementia risk (Welsh-Bohmer, Breitner et al. 2006). Individual and population level interventions in areas such as type 2 diabetes, hypertension, dietary fat, cholesterol and obesity could, it is argued, go a long way to reduce the risk of both vascular and Alzheimer’s dementia (Haan and Wallace 2004; Skoog and Gustafson 2006). This is the basis for the research and education work of the International Society for Vascular Behavioural and Cognitive Disorders (Vas-Cog), addressing the vascular causes of various brain disorders, including Alzheimer’s disease, vascular dementia, mild cognitive impairment and other behavioural disorders 13.

A review of factors that demonstrate a positive relationship to the maintenance of brain health, identifies regular physical activity, reduction of risk for vascular disease, stroke and diabetes as well as social engagement and cognitive stimulation as likely to decrease dementia risk (Cherry and Reed 2007). The National Institute of Health (NIH), U.S. Department of Health and Human Services’ Cognitive and Emotional Health Project: The Healthy Brain, summarises the epidemiologic findings, both established and newly emerging, that link cardiovascular disease to cognitive decline and dementia 14. Diet and high levels of self-reported physical activity and cardio respiratory fitness in particular, emerge as protective factors against cognitive decline from recent observational studies, although as noted by the NIH, clinical trials are lacking.

13 Information can be found at the following web address : http://www.vas-cog.org/

Other critical assessments of the literature consistently reveal several potentially protective factors for cognitive health in adults, including higher education levels, higher socioeconomic status, emotional support, better baseline cognitive function, better lung capacity, more physical exercise, moderate alcohol use, and use of vitamin supplements (Morrison-Borgorad, Cahan et al. 2007). In the U.S. to-date, there have been no clinical trials testing the long-term effects of any type of exercise on maintenance of brain health or slowing onset of AD, although a limited number of short-term clinical trials provide some evidence for effects of aerobic exercise on cognitive tasks, notably executive function, and a positive relationship between aerobic training and the volume of several brain regions important for learning and memory (Morrison-Borgorad, Cahan et al. 2007). Studies analysing the relationship between cardiovascular disease and cognitive changes related to AD pathology, mild cognitive impairment (MCI) and dementia, are highly suggestive but as yet, inconsistent.

Demonstrated associations between factors such as emotional health and cognition as well as social engagement, mental stimulation and decline in risk for AD are also emerging, and it is argued that these additional lifestyle factors are worthy of further investigation (Hendrie, Albert et al. 2006; Martin, Clare et al. 2006; Morrison-Borgorad, Cahan et al. 2007). Other research shows, “connectivity to neighbourhood and community and strength of family and social networks” as positively related to maintenance of cognitive function up until about 80 years of age (Beland, Zunzunegui et al. 2005). It is now recognised that early childhood intervention is a protective factor for disadvantaged children, with particular scope for success if the timing and duration of the intervention occur early enough and if support continues over a period of time (Reynolds and Ou 2003). In this context, interventions aimed at “enriching” children’s learning environments include, scholastic and social programs aimed at pre-school and school aged children, and their families, who are otherwise at risk of poor outcomes developmentally due to environmental disadvantages or developmental disabilities or delays. Reynolds and Ou (2003) reviewed the key outcomes of a number of programs which showed improved cognitive development, school achievement, and ultimately educational attainment (Reynolds and Ou 2003). Their review of the literature also found that children who attended pre-school programs in the poorest neighbourhoods benefitted more than children from less poor neighbourhoods, particularly in the areas of maths and reading (Reynolds and Ou 2003). The World Health Organisation acknowledges the role that children’s early environment has on the brain and the subsequent influence this has on health and social outcomes across the life course, including, mental health problems, obesity and stunting, heart disease, criminality, competence in literacy and numeracy and related consequences (Irwin, Siddiqi et al. 2007). Other research points to the period of transition to adulthood as a window of opportunity for the role of providing positive contexts and strategies to positively influence the direction young adults will take: through rites of passage and the role of communal organisations, to opportunities for higher education, apprenticeships and various forms of ‘national service’ (Masten, Burt et al. 2004).

The vast body of literature on childhood maltreatment and stress demonstrates the interplay of experience and neurobiological development (Glaser 2000; Cicchetti 2007). Therefore, active early intervention for the most vulnerable children gives them a chance, by producing changes in the internal (neurological stress systems) and external (care giving) environments, to cope with subsequent life experiences despite significant childhood adversity. The nature of such interventions include, the training of caregivers (whether birth, adoptive or foster parents) in establishing secure attachment relationships to children and in effective behaviour management techniques to combat both difficult child behaviours and caregivers’ own responses and interpretations of these (Gunnar and Fisher 2006). Yet, understanding and promoting resiliency and the developmental processes showing positive adaptation despite significant life stresses, needs to take account of both ‘cellular’ and ‘cultural’ factors leading to positive outcomes in terms of brain development and growth, thus moving beyond psychological and social indices of resilience (Cicchetti and Blender 2006).
Resiliency research documents clearly the characteristics required by families, schools and community environments to foster ‘natural resiliency’ in children. These protective factors have been shown to alter, reverse or transform adverse outcomes into the development of resilience despite risk and include, caring relationships, high expectation messages and opportunities for meaningful participation and contribution to society or community (Benard 1991; Benard 2004). In this sense, human and social capacity can be effectively developed.

4.2 Risk and protective factors for cognitive decline in fourth world Indigenous populations

Studies of dementia in Indigenous American and Alaskan populations have given rise to a hypothesis that AD may be less common among some Indigenous groups (Jervis and Manson 2002). There is some evidence that genetic Cherokee ancestry may have a protective effect, particularly in younger age groups, although whether this is attributable to genetics or environment remains unexplored (Jervis and Manson 2002). As Jervis and Manson (2002) point out, this may be due to greater immersion in Native health or cultural practices, some of which could provide protection against AD. Other studies of dementia prevalence among Cree Indians over 65 years of age, found a 0.5 percent rate of AD by comparison to 3.5 percent in a non-Indigenous non-literate population, with most demented Cree Indian’s exhibiting multi-infarct and alcohol-related dementias (Jervis and Manson 2002). The lower rate of AD in these populations may well be due, as Jervis and Manson point out, to “competing epidemiologic risks” for early mortality, which contribute to the reduced population who would otherwise be vulnerable to a diagnosis of AD. The high rates of health risk factors for dementias of other aetiologies however, especially those of vascular origin, make it highly likely that Indigenous populations bear a disproportionate burden of these types of dementias. These risk factors for dementia include, high rates of the metabolic syndrome in first Nations communities in Aboriginal Canadians, (Kaler, Ralph-Campbell et al. 2006; Pollex, Hanley et al. 2006), as well as of diabetes, hypertension and heart disease amongst Indigenous Americans (Weiner, Rosenberg et al. 2003; Weiner, Rosenberg et al. 2006) and include the problem of childhood obesity and its complications (Retnakaran, Hanley et al. 2006). The Alzheimer Society of Ontario, Canada cites the high prevalence of diabetes and increased life expectancy observed in Canadian Aboriginal populations, as two key risk factors for dementia15.

Fourth world Indigenous populations share much history in common. The experience of colonization, and the repercussions of prejudice, discrimination and social and economic marginalization, continue to impact on the well-being of individuals, families and communities. Thus, history and social processes, as Pollard argues, are central to understanding the differential patterns of risk and uneven distribution of chronic disease across population groups, such as, Aboriginal populations (Pollard 2005). As Pollard states, “chronic physical and psychological stress is recognised as an important etiological factor in many lifestyle diseases of the cardiovascular, immune and reproductive systems. Diseases of adaptation are further advanced by non-adaptive lifestyle choices, depression, alcoholism and other drug dependencies” (Pollard 2005). Further, these and related risk factors such as child abuse, neglect, unemployment and poverty constitute risk factors for crime, and taken together, encompass what has been described as the “neurobiology of offenders” (Bennet and Broe 2008). It is no coincidence that Indigenous offenders in fourth world populations, such as Australia, New Zealand and North America, are disproportionately represented in their respective prison populations. Further, there is evidence to suggest that the lifetime prevalence rates of mild to severe traumatic brain injury in Maori prisoners is much higher than for the rest of the prison population, and that similar findings are very likely for Indigenous prison populations in comparable countries, like Australia and Canada (Ogden 2001).

Brown, Morrissey and colleagues provide a methodological framework for addressing the, “complex and interactive hierarchy of biomedical, social and political processes”, to unpack the
determinants of cardiovascular disease among Indigenous people, providing a useful template for research into cognitive health and decline (Brown, Morrissey et al. 2006). Of particular relevance within their methodological framework is the “valuing and positioning” of Indigenous knowledge in order to chart the complex and interacting aetiological pathways to chronic ill-health (Brown, Morrissey et al. 2006). This methodology has been applied in a number of studies exploring the experiences and meaning of living with diabetes as a way of understanding why there is such disproportionate burden across Indigenous fourth world communities (Thompson and Gifford 2000; Iwasaki, Bartlett et al. 2004; Retnakaran, Hanley et al. 2006). The notion of ‘social suffering’ is a key component and explained thus: “Social organization and cultural norms contribute significantly to the average sweetness of blood at any given time within various populations. And systems of appropriation, exploitation, and exchange - in other words, political economy - have helped shape the genetic composition of human bodies, social organization, and cultural norms” (Iwasaki, Bartlett et al. 2004).

In an urban Indigenous Australian context, diabetes was seen as, “life out of balance, a life lost, or severed connections with land and kin; little control over past, present, or future (Thompson and Gifford 2000). This is echoed by North American research into diabetes in the Cree Nation, Manitoba, where changes caused by, “devastation of their living environments destroying their traditional way of life”, and “the loss of power, control and cultural identity experienced in peoples’ contemporary lives”, points to the collective and historical aspect to illness (Iwasaki, Bartlett et al. 2004).

The relevance of this perspective to impairment in the working of the brain revolves around the concept of “historical grief” or “historical trauma”. Wasserman has explored historical trauma in the context of Indigenous Americans, who like Indigenous Australians, “may represent the most traumatized segment of the [mainstream] population” (Wasserman 2005). In the Wasserman report, historical trauma is defined by two key Native respondents as, “cumulative emotional and psychological wounding, over the lifespan and across generations, emanating from massive group trauma experiences” (Wasserman 2005). Damage to the brain occurs on a number of indicators: exposure to traumatic events and the witnessing of violence, the experience of personal violence and abuse, the experience of separations from primary caregivers, exposure to maternal drinking and smoking with impacts on the growth and health of the foetus, and what has been described as, “historical grief” (BraveHeart and YellowHorse 2003; Wasserman 2005).

Measurements of this damage are drawn from the scientific literature demonstrating abnormal neuronal development and major changes in biological stress systems as a result of overstimulation of certain areas of the brain due to childhood trauma; the physiological changes related to the experience of fear (located in the hypothalamo-pituitary-adrenocortical axis); and the specific impacts of stress and trauma on brain development involving the hippocampus, a part of the limbic system, involved in memory and emotion (Wasserman 2005).

Lack of appropriate stimulation and opportunities for bonding with an appropriate caregiver have also been implicated in smaller brains, lower IQ and lack of social skills (Perry 2002; DeBellis and Kuchibhatla 2006). Child neglect and abuse are considered to have neurobiological sequelae well beyond the circumscribed hypothalamic “stress response” causing hippocampal damage. Child neglect and abuse may also cause generalised inhibited neurobiological development, and more extensive biochemical, functional, and structural changes of the brain, particularly in the frontal lobes and frontal networks subserving attention, planning and executive brain functions. “These findings provide hard neuroscientific evidence for the notion that parenting and childcare and education are not secondary or soft “social” factors to be lightly considered in economic and health planning, but factors that have a direct and primary impact upon the neurobiological development of the individual” (Bennet and Broe 2008).
Protective factors

The importance of early therapeutic interventions and supportive experiences with carers is essential to lessen the impact of childhood trauma. In tribal communities, Wasserman points to the numerous traditional activities to assist children learn alternative ways of coping: story-telling, purification and healing ceremonies and engaging children in traditional craft activities. Specific interventions have been developed, such as the Historical Trauma & Unresolved Grief Intervention (HTUG) based on the experiences of the Lakota, Sioux (Wasserman 2005). The cornerstones of this approaches include educating the community about the impact of traumatic ‘tribal’ history on current trauma, using visual stimuli to facilitate processing of trauma; and fostering a re-connection to traditional tribal cultural values and rituals that can serve as protective and healing factors (Ibid).

4.3 Risk factors and protective factors for cognitive growth and decline in Australian Aboriginal people

Many of the factors contributing to high mortality in Australian Aboriginal and Torres Strait Islander communities (as indeed in other comparable Indigenous populations) - high rates of diabetes, cardiovascular disease, hypertension, head injury, alcohol abuse and suicide – are also risk factors for dementia for those who do survive to old age (Pollitt 1997). O'Dea’s review of chronic disease among Indigenous Australians, views colonisation and the epidemiological transition as both contextual and explanatory variables of the heavy burden of infectious disease in this population, and the emerging view that these factors amplify the risk and/or severity of chronic disease, including vascular disease (O'Dea 2005). The INTERHEART study, which O'Dea cites in her review, found that nine modifiable risk factors, explained more than 90 percent of heart disease risk in all populations, with smoking the most important risk factor globally (O'Dea 2005). The interaction of lifestyle and biological factors, point to very high levels of risk for ill-health in the Aboriginal population, but also, as O'Dea notes, the potential for reducing some of the burden of chronic disease (O'Dea 2005). Given the links then between the endemic chronic diseases disproportionately borne by the Aboriginal population, and their emerging association with cognitive decline and dementia, preventative public health promotion and intervention can draw on effective Indigenous specific community-based interventions aimed at improving cardiovascular and other health indicators. A number of successful interventions have been trialled within the context of remote-living Aboriginal populations. An intervention involving temporary reversion to a hunter gatherer lifestyle on a group of middle-aged, diabetic Aborigines from the West Kimberley region of WA, showed dramatic improvements in the health profile of respondents (O'Dea 2005). These results included:

- The loss of an average 7kg’s weight
- Greatly improved metabolic abnormalities with half the group no longer diabetic
- Marked improvements in risk factors for heart disease (blood pressure, blood cholesterol and triglycerides, bleeding time)
- Increase in daily physical activity routines
- Consumption of “Bush tucker” and selection of Western foods with nutritional value of bush foods
- Building a greater sense of mastery and control.

Within the same paradigm, O’Dea and colleagues report the outcomes of a decade long follow-up of morbidity and mortality from all causes and from cardiovascular disease in a remote living Aboriginal community in the Northern Territory (Rowley, O'Dea et al. 2008). As a result of primary health care services providing regular outreach to far-flung communities and a decentralised mode of more traditional living, including opportunities for greater physical activity and the consumption of unprocessed foods, mortality in the study cohort was significantly lower than that for the rest of the Northern Territory population, with hospitalisation for CVD, 13 per 1000 compared with 33 per 1000 for the Northern Territory Indigenous population as a whole. The authors also concluded that social factors such as, connectedness to culture, family and land, and opportunities for self-determination and control, were important contributors to the successful nature of the intervention. Other successful community
based outreach programs have significantly reduced morbidity and mortality in patients with kidney and cardiovascular disease (Katz, Hoy et al. 2006). Adherence to traditional culture and way of life, has also been found to be protective against emotional and behavioural problems, with findings from the Western Australian Child Health Survey, showing better emotional health and behaviours in children who live in areas of extreme isolation in Western Australia compared with their urban and regional counterparts (Zubrick, Lawrence et al. 2004).

A collaborative study conducted in the Top End of the Northern Territory, where the communities’ health problems were overwhelmingly attributed to the, “consequences of cultural change”, led to the implementation of a community led model of change, whereby the solutions to the breakdown in Yolnu systems of law, relationship and education and the loss of Yolnu knowledge and practices related to health (most particularly nutrition and hygiene), were to strengthen Yolnu systems, knowledge and practices which promote health through education, “rather than education about specific diseases and medical interventions” (Lowell, Maypilama et al. 2003). As an outcome of this study, a local concept “Marngithinyaraw Yalu” model commenced a pilot phase where the essential aspects included establishing a, “community nurturing or learning centre”, based on Yolnu management structures to strengthen Yolnu systems, practices and knowledge related to health, into which relevant Western knowledge and practices can be integrated\(^{17}\).

While the intervention studies cited in this section of the report provide some idea of what this might mean for more traditional living remote communities, vis a vis strengthening traditional culture and practices, there is little, if any, research material to draw on regarding how this translates in an urban, peri-urban or regional Indigenous context. There are however, some lessons to be learned in relation to future programs or interventions in Indigenous contexts relevant to strengthening families and communities (Scougall, Rogers et al. 2008). Ultimately, these programs and interventions are aimed at longer term resiliency outcomes. Some of the key lessons reported by Scougall and colleagues (2008) include:

- The importance of sustained long-term interventions
- Linking capacity-building activities to project activities as opposed to isolated interventions
- Healing the effects of trauma, attitudinal and behavioural change and rebuilding of confidence and self-belief
- Facilitating greater networking for projects to learn from each other
- Finding the appropriate balance between capacity building in organisations and with families and communities themselves
- Employing strategies of engagement that connect with Indigenous people in meaningful ways
- Strategies to repair or reinforce familial bonds: between mothers and babies; youth and Elders; teenage mothers and women Elders; parents and school children
- Putting at the forefront issues of cultural security and confidentiality and the creation of ‘safe’ spaces for ‘marginalised’ people

Inhibiting factors to the success of Indigenous programs are equally salutary: unsupportive social environments; complex Indigenous family and community issues; lack of basic infrastructure and accessible services, especially in remote regions; and, human resource pressures (Scougall, Rogers et al. 2008).

The importance of underlying belief systems in relation to perceptions of risk for dementia, as opposed to ‘scientific evidence per se’, have been explored in a mainstream Australian context (Low and Anstey 2007). Successful health promotion, the authors argue, “has to be based on pre-existing beliefs, or even the knowledge that brain health and function are related to other health and social factors” (Low and Anstey 2007). This view is reflected in the National Framework of Action to address dementia in the Indigenous population, with stakeholders pointing to the importance of community awareness and prevention programs prioritising the

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belief systems or concepts of what constitutes healthy ageing for Indigenous communities (Alzheimer's Australia 2006).

The concept of “Brain health” is emerging as an important paradigm on the neuroscience and public health agenda, but is yet to be incorporated into broader health promotion campaigns. Evidence has been presented in this section of the review demonstrating increasing awareness of associations between brain health, childhood experiences and later physical activity and vascular health. More research, including clinical trials, are needed to establish causal pathways to disease and the nature and efficacy of interventions in different population groups (Morrison-Borgorad, Cahan et al. 2007).

Interventions targeting cognitive growth and development across the lifespan draw on evidence demonstrating the relationship between education and health and wellbeing. In the Australian Indigenous context, these encompass opportunities for formal schooling, vocational education and life-long learning as well as models for traditional learning of cultural practices and ‘tribal’ law (Lowell, Maypilama et al. 2003; Stanwick, Ong et al. 2006). In other contexts, early interventions with children who have experienced high levels of stress in childhood, offer scope for influencing brain - behaviour interactions. There are however, very few intervention studies in many areas of maternal and children’s health, including tobacco, alcohol and other substance use in pregnancy, mental health, social health, childhood injury and sudden infant death syndrome (Hercog 2005). Interventions addressing broader social determinants and with a preventative orientation, such as the ‘Best Start’ program, require, “widespread implementation and continued commitment to a preventative rather than surveillance paradigm” (Leggat 2004).

In relation to mild to moderate Alzheimer’s disease, a number of techniques have been used effectively on older adults with mild to moderate Alzheimer’s disease, such as interventions designed to improve recall of information, activation of aspects of motor memory and support for retrieving and encoding learning and memory processes (Acevedo and Loewenstein 2007). There is a paucity of information on cognitive interventions for dementia within heterogeneous populations. Within a cultural context of Indigenous experience and identity, there is a need to establish the appropriate methodological and conceptual issues relevant to any proposed interventions aimed at improving cognitive capacity for Aboriginal and Torres Strait Islander people with dementia and for engaging members of families and communities in this process.

What is clear is that interventions in terms of brain health need to occur across the life cycle and before cognitive decline commences.
5. Dementia and cognitive impairment in Indigenous populations

Within the Indigenous population, there is a paucity of research into ageing or diseases of ageing. Studies of dementia prevalence and its sub-types, both in Australia and other comparable countries, are in their infancy (Pollitt 1997; Ranzijn and Bin-Sallik 2001; Jervis and Manson 2002). What is virtually non-existent is information about how the experience of dementia is lived and understood, and how this translates into care giving and care seeking by Indigenous communities across urban, rural and remote settings. Anecdotal accounts provide fragmented but compelling glimpses into some of the significant challenges experienced by older Indigenous people, their families and service providers (Alzheimer's Australia 2006; Sutherland 2007). These challenges encompass understanding the impact of literacy, socioeconomic factors, residential location and cultural affiliation and beliefs, on the diagnosis of dementia, its experience for sufferers, families, communities and services, as well as, its impact on the roles and responsibilities of older Aboriginal and Torres Strait Islander Australians and the special place of Elders in the community.

5.1 The Indigenous elderly: differential life experiences

Few data are available on the experiences and needs of the Indigenous elderly. Ranzijn and Bin-Sallik identify the following markers differentiating the experiences of Aboriginal Elders as a group from the rest of the elderly Australian population (Ranzijn and Bin-Sallik 2001):

- Life expectancy
- Proportion of the population
- Health and functional ability
- Percentage of ‘old-old’
- The ‘Stolen Generations’
- Work life experience
- Income and financial security
- Family and social life
- Housing
- Bereavements
- ‘Citizenship’, racism and prejudice
- Mental health

These differential life experiences provide the context for understanding different notions of what it means to age ‘successfully’ and how notions of well-being are understood. It also raises questions concerning the status of older Indigenous people in the community as well as the community’s own resources for caring for the elderly and those who are functionally impaired.

Older Indigenous Australians, despite a backdrop of disadvantage, continue to play an integral role in culture and community as highlighted by a recent review of their lived experiences (Warburton and Chambers 2007). The review described the various ways older Indigenous Australians contribute to their societies as, “custodians of kinship rights, responsibilities and obligations”; as “purveyors of cultural continuity, identity and knowledge”; and, as “practical providers of child care”. Successful ageing is tied up with the roles and responsibilities of becoming Elders in the community. As noted in the report, Beginning the Conversation, “these roles and responsibilities require Elders to provide guidance and support to the community, participate in decision making, cultural activities or ceremonial events; share stories, proffer advice, and pass on key information about their heritage”. In short, “to look after country” (Alzheimer's Australia 2006). The corollary of this for care of older members of the community is that, removal from families to institutions may have major implications, “for peoples’ relationship with country, their dreaming, their totems, their capacity to care for country and fulfil cultural rights, responsibilities and obligations” (Alzheimer's Australia 2006).

The special place of older Indigenous Australians is integral to ‘Sense of Community’ and Indigenous psychological well-being (Bishop, Colquhoun et al. 2005). In turn, the link between sense of community and psychological wellbeing in Indigenous society is integral to cultural survival and continuity. A number of important issues flow from this:

- The role of Elders in the generational transfer of knowledge and cultural maintenance
- The sense of ‘connectedness’ based on family and geographical ties that underpin the meaning of ‘Aboriginal community’
The importance of kinship, as rules governing culturally acceptable behaviour. Conversely, rules governing violations of these protocols

The importance of spiritual links with the land that tie in with notions of kinship

The sharing of associated rights, responsibilities, and ‘dreamings’ (Bishop, Colquhoun et al. 2005)

The loss of language as more than loss of communication as, “…also the loss of cultural tradition and [one which] threatens Sense of Community” (Bishop, Colquhoun et al. 2005)

The extent to which these issues are still pertinent to the experience of Indigenous people growing older in metropolitan and urban centres

The legacy of colonialism and dispossession continues to threaten ‘sense of community’, in the sense defined by Bishop and colleagues. However, despite cultural and community breakdown, as well as, variations in territorial and cultural heritage due to rural-urban, language, regional and cultural affiliations, Pollitt argues that, “kinship networks are strong and links with homelands and significant sites are maintained” (Pollitt 1997). A survey of older Indigenous Australians by the Australian Bureau of Statistics found that most older Indigenous Australians reported recognising homelands or traditional country, or identifying with a clan, tribal or language group or speaking an Indigenous language (Australian Bureau of Statistics 2007a). In this self-reported survey, residential location is not specified and therefore its relationship to aspects of cultural identification cannot be teased out. Other research has highlighted the important role played by Indigenous elders within their communities supporting ‘troubled’ younger people and maintaining and promoting their culture (Warburton and McLaughlin 2007). It is through reliance on memory that Indigenous people pass on education in traditional law, land and language (Smith, LoGiudice et al. 2007). In light of the integral role played by many Elders in Indigenous society, as well as, the significance of ‘surviving’ to older age, it is worth reflecting on the emerging impact dementia is likely to have amongst older Indigenous Australians and their communities.

5.2 Dementia in Australian Aboriginal and Torres Strait Islander populations: a snapshot of Australian research

A small number of studies constitute an embryonic literature on dementia and cognitive decline in Indigenous Australian communities. Unfortunately, not all of these earlier research reports have remained available in the public domain. There is also the problem of no comprehensive source of data on dementia in Aboriginal and Torres Strait Islander communities, and, a problem of Indigenous invisibility due to under-representation or lack of representation in data collections (and hence data sources) for national reportage on dementia in Australia (Australian Institute of Health and Welfare 2006). Consequently, what we know about dementia in Australian Indigenous communities is drawn from a very small number of localised, largely community based studies, from information provided by key stakeholders to Indigenous specific workshops, or information extrapolated from mainstream documentation.

Zann’s (1987) study of six urban, rural and isolated Aboriginal and Islander Communities in North Queensland revealed a prevalence of around 20 percent of diagnosed or suspected dementia in a population 65 years and over, contrasting with the Australian national average of 5.4 percent (Zann 1994). It also revealed a majority of those diagnosed had alcohol related dementia or Korsakoff’s disease, of whom, most were in institutional care. The word dementia in Zann’s study was found to have no meaning in Aboriginal and Islander culture. In a North American Indigenous context, Jervis and Manson note the difficulty of assessing where normal ageing ends and cognitive decline begins, especially in relation to mild cognitive impairment, given their observation that cultural values and differential lifestyle activities, “are deeply embedded in determinations of “functionality” (Jervis and Manson 2002). Mahajani and McDougall’s work on cognitive testing and differential diagnosis in people of Aboriginal and Torres Strait Islander background
A Review of the Literature

(cited in Pollitt’s 1997 review), suggests the need for a typology to group the differential circumstances, experiences and needs of Indigenous people with cognitive decline. Firstly, those over seventy considered ‘old old’, who “have generally lived a more traditional lifestyle and not been exposed to lifestyle diseases nor [have they] been consumers of alcohol until later in their life”; secondly, those aged 50 to 70 or ‘the old’, who are becoming increasingly dependent and needing assistance with daily living and complex medical problems; and finally, a third and younger age group who have sustained cognitive decline primarily from alcohol and drug abuse, and head trauma from violent behaviour (Pollitt 1997).

Problems of diagnosis and assessment - related to the lack of appropriate assessment tools for indigenous people or lack of access to appropriate assessment - was a recurring theme in a report on ‘Indigenous’ dementia in the Northern Territory (AANT 2002). Variation between urban and remote living communities, diversity within remote living communities, low levels of literacy and differences in language, culture and education as well as variations in the daily living activities between urban and remote communities, were some of the challenges identified in the Northern Territory report (Alzheimer’s Australia Northern Territory 2002).

More recently, research by LoGiudice and colleagues (2006) in the Kimberley region of Western Australia, has refined a culturally sensitive cognitive assessment tool – the KICA-COG - for older Indigenous Australians that demonstrates the importance of linguistic and cultural concept translation for accurate and successful diagnosis of dementia (LoGiudice, Smith et al. 2006; Smith, LoGiudice et al. 2007). Their observation that, “more sophisticated ways of assessing executive function in this community” will be needed, echo the recognition by Mahajani and McDougall (quoted in Pollitt’s 1997 review) a decade earlier, that assessment of dementia in Indigenous communities will need to address the diversity of individual risk factors and life circumstances across different aged cohorts in the Indigenous population. Currently, information on the rates of dementia in the Aboriginal population is fragmented and incomplete, with the most detailed picture to-date emerging from remote living communities in the Kimberley region of Western Australia. Accepting that the sample size is small, the study found that dementia prevalence is almost five times greater than for the general Australian population, that males, rather than females, are more greatly affected, and that dementia affects a much greater proportion of the ‘younger-old’ in the Indigenous population (LoGiudice, Smith et al. 2006; Smith, Flicker et al. 2008). Table 5 shows dementia numbers, dementia prevalence rates and the dementia prevalence ratio for the ages 45+ in the Indigenous sample as compared with the rest of the Australian population 18.

A further research initiative has been the successful validation of the cognitive screening tool used in the Kimberley studies - known as the KICA-COG - on participants and carers in the Northern Territory (Marsh, Inglis et al. 2006).
Data for acquired brain injury in Australia present prevalence figures for the total population as a whole and do not include Indigenous specific data (Fortune and Wen 1999). However, the prevalence in the Northern Territory, where the Indigenous population is disproportionately represented by comparison to the other States, is much higher than in other states and territories.

Head injury due to assault is 21 times more prevalent in the Indigenous population compared with the non-Indigenous population, with Indigenous females experiencing 69 times the injury rate experienced by non-Indigenous females (Jamieson, Harrison et al. 2008). This has serious implications for the care requirements of younger Aboriginal Australians with cognitive, behavioural and mood disorders given the peak incidence of head injury due to assault in the 30-34 year age group (Jamieson, Harrison et al. 2008).

The following is a snapshot of Australian studies on dementia in Indigenous populations.

<table>
<thead>
<tr>
<th>Age (yrs)</th>
<th>Sample</th>
<th>Dementia numbers</th>
<th>Dementia prevalence rates</th>
<th>Dementia prevalence ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>45 - 59</td>
<td>5</td>
<td>3539</td>
<td>0.026</td>
<td>26.00</td>
</tr>
<tr>
<td>60 - 69</td>
<td>12</td>
<td>12322</td>
<td>0.169</td>
<td>19.88</td>
</tr>
<tr>
<td>70 - 79</td>
<td>11</td>
<td>49804</td>
<td>0.164</td>
<td>4.10</td>
</tr>
<tr>
<td>80+</td>
<td>17</td>
<td>108713</td>
<td>0.567</td>
<td>2.98</td>
</tr>
<tr>
<td>Total</td>
<td>45</td>
<td>174377</td>
<td>0.124</td>
<td>4.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>State/ Territory</th>
<th>NSW</th>
<th>VIC</th>
<th>QLD</th>
<th>WA</th>
<th>SA</th>
<th>TAS</th>
<th>ACT</th>
<th>NT</th>
</tr>
</thead>
<tbody>
<tr>
<td>% with acquired brain injury</td>
<td>1.8</td>
<td>1.9</td>
<td>2.6</td>
<td>2.0</td>
<td>2.2</td>
<td>1.8</td>
<td>2.3</td>
<td>3.6</td>
</tr>
</tbody>
</table>

*This table is drawn from the following source: “Dementia: A Major Health Problem for Indigenous People”. Briefing prepared for Parliamentary Friends of Dementia, Paper number 12; August 2007 Alzheimer’s Australia.*
<table>
<thead>
<tr>
<th>Study Authors</th>
<th>Date</th>
<th>Population</th>
<th>Assessment instruments</th>
<th>Key findings</th>
<th>Suitability of tool (Authors’ assessment)</th>
<th>Author’s comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zann</td>
<td>1994</td>
<td>North QLD</td>
<td>Modified Version of the Psychogeriatric Assessment Scales</td>
<td>Dementia identified in approx. 20% of subjects over 65 yrs of age (compared with 5% in non-Indigenous subjects)</td>
<td>Non-validated instrument ‘reasonably satisfactory’</td>
<td>More cultural and linguistically sensitive tool required</td>
</tr>
<tr>
<td>Bruce, Baird, Saddler, Goldswain</td>
<td>1998</td>
<td>Kimberly</td>
<td>A retrospective review of ‘the first’ 119 cases assessed by members of the Kimberley Aged Care Assessment Team, Western Australia</td>
<td>Chronic dementia (40%); moderate degrees of physical impairment (55%); longstanding urinary incontinence (43%); Aborigines on average a decade younger than other referred patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Australia NT Indigenous Dementia Project Report</td>
<td>2002</td>
<td>Northern Territory Indigenous people living with dementia, their families and carers</td>
<td>Community Consultation (Interviews, surveys, workshop)</td>
<td>Lack of appropriate assessment tool or lack of access to appropriate assessment; Need for early detection; major management needs such as medication, incontinence, insomnia and wandering; lack of access to specialist services; Need for culturally appropriate services, respite care; Indigenous specific activities required; education, training and information needed in the community by carers, professional staff, family and friends etc.</td>
<td>Good inter-rater reliability and consistency with clinical raters</td>
<td></td>
</tr>
<tr>
<td>LoGiudice et al</td>
<td>2006</td>
<td>Kimberley, North-west Australia Coastal, river and desert communities with different languages and cultural traditions</td>
<td></td>
<td>Prevalence of dementia for those 45+ was 12.4%, compared to a rate of 2.6% in the Australian population; prevalence higher among males; AD was most common followed by VaD</td>
<td>Good inter-rater reliability and consistency with clinical raters</td>
<td></td>
</tr>
<tr>
<td>Study Authors</td>
<td>Date</td>
<td>Population</td>
<td>Assessment instruments</td>
<td>Key findings</td>
<td>Suitability of tool (Authors’ assessment)</td>
<td>Author’s comments</td>
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</tr>
<tr>
<td>Alzheimer’s Australia Paper No 12</td>
<td>2007</td>
<td>Reporting on the WA studies</td>
<td>KICA-COG (cognitive assessment section) tested in 70 Indigenous subjects over 45 yrs of age. Interview followed by independent clinical assessment</td>
<td>The Kimberley region: 2100 Indigenous people over 45 years Six remote Indigenous communities took part and one town</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Australia Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities</td>
<td>2006</td>
<td>National Indigenous Dementia Workshop participants</td>
<td>Consultation with participants; survey data from key stakeholder participants;</td>
<td>Recommended six key action areas to be included in a National Framework of Action to address dementia: * community awareness and prevention * Care and Support * Research * Diagnosis, Referral and Treatment * Workforce Issues * Partnerships and Collaboration</td>
<td></td>
<td>A ‘Wellness Approach’ seen as necessary to address the issue of dementia with other health conditions</td>
</tr>
</tbody>
</table>
5.2.1 Systems of care and support for those with dementia within their communities

Information about Indigenous peoples’ use of dementia services and other aged care programs is currently limited by the following deficiencies in data capture common across service domains: firstly, under disclosure of Indigenous status by Indigenous clients; secondly, inadequate capturing of Indigenous data where it is disclosed by some program data collection sets, with inconsistent data capture both within and across systems; and thirdly, limited data on dementia prevalence, and lack of data on dementia incidence, to inform rates of dementia in the Indigenous population. Given these problems and the fact that the diagnosis of dementia in the Indigenous Australian population is still in its infancy, we are unable to ascertain the real extent to which Indigenous people are accessing dementia services.

The latest published review of dementia in Australia, provides some data on the users of government community programs by Indigenous status, where this information is collected and/or identified (Australian Institute of Health and Welfare 2006). However, the picture provided in this overview is difficult to interpret in light of the difficulties in data capture as well as the absence of denominator data as outlined above. Therefore, the data cannot be meaningfully interpreted as an indicator of need, but may in the future be used to model service use by Indigenous clients.

With these limitations in mind, the most recently published figures show the following for users of government community programs and services for people with dementia, by Indigenous status: (Australian Institute of Health and Welfare 2006).

- One percent of Aged Care Assessment Program (ACAP) clients with dementia are identified as Aboriginal or Torres Strait Islander. [A similar proportion of ACAP clients without dementia identified as Aboriginal and/or Torres Strait Islander]
- Data from the National Respite for Carers Program (NCRP) show that 1.8 percent of care recipients with dementia registered with a Commonwealth Carer Respite Centre (CCRC) were Aboriginal or Torres Strait Islander. [The percentage of all care recipients registered with a CCRC who were Indigenous was 3.6 percent]
- Similarly, almost all clients of the Community Aged Care Packages (CACPs) with dementia were non-Indigenous with around 3 percent of clients identified as Aboriginal or Torres Strait Islander background. [Similar (but slightly higher) proportions of CACP clients without dementia were identified as Aboriginal and/or Torres Strait Islander]
- No Extended Aged Care at Home (EACH) clients were identified as being of Aboriginal or Torres Strait Islander background
- 1.8 percent of carers of people with dementia assisted by a CCRC were Aboriginal or Torres Strait Islander, with the percentage of all Indigenous carers assisted by a CCRC, 3.3 percent (Australian Institute of Health and Welfare 2006).

From this data, there appears to be mostly an under representation of Indigenous people with dementia using government services - given what is known about dementia prevalence in remote living Aboriginal communities and given that Indigenous Australians comprise about 2.6% of the total Australian population. In some programs, there may be a possible over representation of Indigenous clients with a dementia, but we do not currently have the population level data to provide an accurate picture of service use by Indigenous people. Since the research for this literature review took place, emergent data on aged care services from the Productivity Commission’s Indigenous Compendium (2009) confirms this pattern of mainly under utilisation of aged care service provision (non dementia specific) by Indigenous Australians, with some above average representation in mainly, non-residential programs providing in situ support.

A potential area for further investigation is the need to: (a) model Aboriginal service utilisation numbers against Aboriginal population data more effectively and; (b) to model Aboriginal utilisation patterns against non-Aboriginal patterns, including factors such as disease, severity and disability rates. Together, these two approaches would help to construct a better picture of how effective Aboriginal access to services such as, HACC, CACP and EACH are, relative to need.
Pollitt’s overview of dementia in Australian Aboriginal and Torres Strait Islander communities just over a decade ago, noted problems of access, availability and appropriateness of service provision, and the responsibility borne by families in caring for people, “manifesting markedly abnormal behaviour” (Pollitt 1997). Similarly, Bruce and colleagues noted the need for health programs for Aboriginal people and their families struggling to cope with the chronic cognitive and physical impairments common in elderly Aboriginals in the Kimberley region (Bruce, Baird et al. 1998).

In the Northern Territory, where the greatest proportions of Indigenous people live, the hospitalisation rate for dementia in Aboriginal people was less than half that for non-Aboriginal people, in the period between 1993 and 1997 (AANT 2002). In the same period, dementia was the most common reason for hospitalisation for mental illness for Territorians aged over 55 years; while for Aboriginal people it was ranked as the fourth highest reason for admission by principal diagnosis (AANT 2002).

From November 1999 to 30 June 2001, ACAT (Aged Care Assessment Team) managed assessments for a total of 130 clients, of whom 43 were Indigenous. In the Northern Territory, the highest concentrations of people living with dementia are in Darwin, followed by Alice Springs, Barkley region, East Arnhem and Katherine (Alzheimer's Australia Northern Territory 2002). While data specific to Indigenous dementia status are not provided, what we know about the population profile of remote Northern Territory areas, means that most of the assessments outside of Darwin and Alice Springs, are for Indigenous clients.

In New South Wales, a report outlining future directions for dementia care and support, noted the preference for Aboriginal elders to be cared for in their own communities, close to family and kin and to die on their own land (Department of Ageing Disability and Home Care 2002). The lack of respite services and facilities, in particular for those in remote areas, has been articulated in a number of reports. The report into dementia in the Northern Territory listed the following contributory factors as contributing to this lack of services (Alzheimer's Australia Northern Territory 2002):

- lack of appropriate infrastructure in communities (such as hostel type accommodation or visitor accommodation)
- difficulties attracting workers due to conditions in some communities
- difficulties with the need to quantify and justify the need for dementia respite
- difficulties due to ‘cultural protocols’ that influence who can care for whom
- A possible lack of acceptability of out-of-home care within remote communities
- The concept of respite being not widely understood

In addition to the lack of availability of services and facilities (particularly in relation to remote living Indigenous communities), respondents also noted the need for community based support, for assistance with providing ‘safe’ environments and access to comprehensive HACC programs to assist with daily living tasks (Alzheimer's Australia Northern Territory 2002). Language and culture were found to be less important in the accessing of services in urban settings, with other reasons such as, lifestyle factors, personal and health reasons influencing decisions around access (Alzheimer's Australia Northern Territory 2002). The recording of individuals’ social histories was identified as a potential enabler of individually tailored service provision.

The report, “Beginning the Conversation”, identified the importance of developing localised information specific to communities, regions, circumstances and language groups to feed into service planning, as well as, the importance of providing respite and other services to carers of people with dementia (Alzheimers Australia 2006). Challenges identified by currently operating regional HACC programs for older Aboriginal people include, the need for transport to address the social isolation experienced by many of the residents, and importantly, the concerns raised by Elders relating to the erosion of their local culture and measures to reverse the trend of social and cultural erosion (Alzheimers Australia 2006). We know little about the impact of social and cultural erosion on families’ care arrangements.

The following are some of the dementia specific resources that have been developed for Aboriginal and Torres Strait Islander populations:

19 While Indigenous dementia status was not available for this report, most of the assessments in remote areas would be for Indigenous clients given the population profile of the NT.
<table>
<thead>
<tr>
<th>Title</th>
<th>Funded by</th>
<th>Date</th>
<th>Content</th>
</tr>
</thead>
<tbody>
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<td>Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities</td>
<td>Australian Department of Health and Ageing and Alzheimer’s Australia Government</td>
<td>2007</td>
<td>A Facilitator’s Guide; Assessment Items; Participant Materials; Related Information Pack</td>
</tr>
<tr>
<td>Meet Dementia The Bad Hawk That Steals</td>
<td>Aboriginal Drug and Alcohol Council (SA) and Alzheimer’s Australia SA</td>
<td>1993</td>
<td>Information resource</td>
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<tr>
<td>Dementia Training for Indigenous People</td>
<td>Australian Government Department of Health and Ageing</td>
<td>1997</td>
<td>Training and Information Resource</td>
</tr>
</tbody>
</table>

5.3. The dementia experience in Indigenous populations

What is the ‘talk’ about dementia? How do populations respond to ‘new sicknesses’? How congruent are these perceptions between patients, their families and carers as well as providers of health care and services? These questions have been posed in the context of how dementia is understood and described in a North American Indian tribe (Henderson and Henderson 2002). As the authors point out, while old age and cognitive confusion is not a new phenomenon, the magnitude of prevalence and incidence are relatively new.

Pollitt (1997) describes the concept of dementia in old age in Australian Aboriginal and Torres Strait Islander communities as, “intrinsically paradoxical”. The first relates to the relatively small numbers of Indigenous people reaching old age, whilst the second relates to the fact that for many Aboriginal people, dementia is unrecognised as a medical condition. Disruptive behavioural manifestations of cognitive impairment are often attributed to, ‘madness’ (Ibid, 1997:155). Pollitt’s (1997) review of cognitive decline in Aborigines and Torres Strait Islanders, draws on a number of studies to examine some of the meanings attached to concepts and behaviours associated with, ‘old age’, ‘abnormal old age’, ‘mental disorder’, ‘sickness’, and ‘dementia’. A common thread in studies examining ageing in Indigenous populations, is the perception that being an ‘elderly person’ is less about chronological age, and more about an individual’s functional and social capacity and standing in the community (Pollitt 1997; Jervis and Manson 2002).

In the research reviewed by Pollitt (1997), distinctions in the range of behaviours characteristic of cognitive decline are drawn between behaviours seen as ‘sick’ or ‘disturbed’, and behaviours characterised as ‘madness’. Pollitt draws on the work of two earlier studies in identifying what behaviours associated with cognitive decline cannot be tolerated within the community’s normative functioning (cf Maharajani and McDougall, 1995; Rafael 1995, quoted in (Pollitt 1997)). These include, “[W]hen an individual is no longer able to recall ceremony business, identify kinships and skin groups, no longer knows what the taboos are...then the community will seek help” (Ibid:158). Other studies addressing dementia in Indigenous communities have confirmed this “threshold”, in relation to, what Pollitt (1997:158) has described as the, “flouting of cultural norms” and other disruptive behaviours. Descriptions of people with more severe manifestations of cognitive decline as, “not a person anymore”, or as, “a reason for sorrowing”, reflect both the grief experienced by family and community members as well as the social ostracism that can occur when confronted with the effects of cognitive decline on the family and wider community. At the other end of the spectrum, behaviours characteristic of mild or moderate dementia are viewed through a more benign lens as, ‘childlike’ or as, ‘tiredness’ (Ibid).
Studies also report a widely held view that Aboriginal and Torres Strait Islander people have little or no knowledge of what dementia is and of how the potential risk of dementia might be reduced. Lack of understanding of dementia as a disease and its link to tensions within family networks have been raised in a study of dementia amongst Indigenous people in the Northern Territory (Alzheimer's Australia Northern Territory 2002). Some of these tensions revolve around the ‘blaming’ of individuals for ‘inappropriate behaviour’ and reluctance to become part of their care, particularly when cultural protocols are breached. Further, early interventions are often bypassed by Indigenous communities, since early behavioural changes caused by dementia are often perceived as an inevitable decline in functioning due to ageing and not cause for medical attention. The findings of fairly widespread lack of understanding by Indigenous carers and families of the causes of dementia, unfamiliarity with associated medical concepts and the fear of being involved, in addition to language and cultural barriers, may explain, at least in part, why the hospitalisation rate for dementia in Aboriginal people was less than half that in non-Aboriginal people during the period 1993 to 1997 in the Northern Territory (Alzheimer's Australia Northern Territory 2002). Workshop discussions confirmed the widespread view that dementia is not often perceived as a medical issue, but as a ‘natural part of the cycle of life and death’ (Ibid:17).

Ariotti’s research on disability amongst the Anangu peoples in the cross-border region of Western Australia, South Australia and the Northern Territory, suggests important parallels in the evolution of a community’s understanding of, and engagement with, unfamiliar bio-medical concepts (Ariotti 1999). Ariotti examined the role that history, culture and language played, in what he describes as, “the social construction of disability”, and the Anangu’s evolving engagement in dealing with it. In the first phase, ‘disability’ as a concept did not exist (Zann makes the same finding with respect to dementia). In the second, disability was constructed for the Anangu by, “the powerful Piranpa (Whitefellas)”. During the third phase, the Anangu are in the process of, “(re)constructing this phenomenon” through local community involvement (Ariotti 1999).

In Ariotti’s conceptualisation, the phase where the concept of disability is developed in the post-colonisation era occurs at a number of levels. Cognitively, new words and concepts are introduced, “which challenge their own language and the way they think about people who are physically impaired” (Ibid: 219). At the behavioural level, ambivalence by the community can be experienced as, ‘acceptance’ of the condition as defined for Indigenous people and result in consequent passivity. On the other hand, identification and naming of the disease (or ‘category’ in the case of disability), is required for the use of government services and benefits but can also be felt as a stigmatising experience. At the social level, loss of control on how best to respond to the ‘new concept’ can impact profoundly on the spiritual, cultural and psychological health of the family and community. In the case of Ariotti’s research, this had much to do with the “distressing initiation” into the world of treatment and services, where, “the practice of removing children with severe impairments from their families was one of the earliest factors in the construction of the Anangu understanding of disability” (Ibid:220). This can be experienced as a “cultural threat” in that children removed cannot, “learn my culture or law” or, “the Dreaming places of our grandparents” (Ibid).

The process of removal has major implications for peoples’ relationship with country; their dreaming, their totems, and their capacity to care for country and fulfil cultural rights, responsibilities and obligations. In a different context, the removal of Elders from remote South Australia for dialysis treatment was described by the community as, “a social trauma” (Shepard, Allen et al. 2003).

It is in this context, as noted by Jervis and Manson (2002) writing of the North American Indigenous experience, that any socio-cultural impacts of dementia need to be considered, together with the “clinical, epidemiological and diagnostic” aspects. As the authors writing of Native elders in the North American context ask, “how [do] Native people reconcile cognitive decline with the idealization of elders that is so often a core cultural value in their culture” (Jervis and Manson 2002). While idealisation of Elders within society is a common phenomenon across many cultures, what does need teasing out in the Indigenous context is the role that Elders play
within Aboriginal society and the impact of a dementia diagnosis in light of this.

Perceptions of dementia amongst American Indians and Native Americans differ in their accounts of how dementia is understood. These perceptions range from perspectives viewing dementia in both lay and biomedical terms, as part of ‘normal ageing’, and as a transitory phase of an elder’s journey to the afterlife (Jervis and Manson 2002). Jervis and Manson’s review of dementia in American Indian and Alaska Native communities reveals little information on the socio-cultural impact of dementia, that is, information on how dementia is understood and coped with. In Pueblo Indian communities, caregivers experience significant personal and interpersonal strain but also a reluctance to express negative feelings about this role (Jervis and Manson 2002). As the authors note, “Burden, for Pueblo caregivers, revolved around limitations on the caregiver’s ability to fulfil valued family and tribal role activities”.

The issues of elder abuse (both physical and financial), distress caused by the removal of older people from their communities for care and of people being sent back to communities without the requisite support or acceptance needed, have been recorded as concerns for people living with dementia (Alzheimer’s Australia Northern Territory 2002). Further research is necessary to understand how the experience of ‘community care’ and ‘community burden’, to borrow from Jervis and Manson’s terms, is experienced and articulated in a diverse range of Australian Indigenous populations and residential settings.

5.4. End-of-Life Care for Indigenous Australians

Indigenous understandings of the causes of disease with its emphasis on social and spiritual dysfunction; the importance of appropriate involvement of family members with its emphasis on kinship networks and relationships; and, of ceremonies after death and the importance of dying on traditional lands, point to key cultural considerations in the provision of palliative care for Indigenous communities (Maher 1999; Maddocks and Rayner 2003). Recent research addressing the impact of language differences on the provision of palliative care for Aboriginal people in remote areas of Australia, found widespread experiences of fear, particularly amongst the elderly and those who speak little or no English, in their dealings with the health system (McGrath and Holewa 2007). Aboriginal people from rural and remote areas articulate a wish to die at home connected with land and community. In McGrath’s words, “strong cultural reasons were given for this preference, including the strong connection with land and community, a belief in ‘death country’, the importance of passing on sacred knowledge to the appropriate family member, the significance of ensuring that the dying individual’s ‘animal spirit’ is able to return to the land, and the imperative that the ‘right person’ in the family network is available to provide the care” (McGrath 2007).

Findings on end-of-life care for Indigenous people in remote and other areas of the Northern Territory indicate a lack of respite services, whether community based or inpatient - other than limited accessing of hospital based respite linked with acute management of symptoms - and in a minority of cases, access to respite centres (McGrath, Patton et al. 2006).

While a cultural gap between Indigenous and non-Indigenous Australian beliefs and perceptions concerning health, and especially, death and dying, has been documented in the literature, there is also no single ‘Aboriginal experience’ of death and dying. This finding is the outcome of a Commonwealth Report into culturally appropriate palliative care for Indigenous Australians which draws on a sizeable anthropological literature on death and dying and which notes, “huge geographical imbalances in research activity”20

The Review does however identify a number of key themes in the literature that are relevant to the experiences of Indigenous families around death and dying. The most salient being:

- the centrality of place in peoples’ lives
- the importance of kin and family
- the life-death-life continuity; and
- the significance of Spirit, soul, place and time

The vast ‘geographical imbalances’ in research activity so characteristic of Australian Aboriginal research, leave open a number of worthy avenues for inquiry. In particular, the extent to which more urbanised Aboriginal communities draw on a deeper Indigenous connection to place, to kin, and to a uniquely ‘Indigenous’ spirituality\(^\text{21}\), and, to how this translates to their use of care and support services, to their experience of dementia and its implications for their end of life care.

\(^{21}\)The Co-operative Research Centre for Aboriginal Health (CRCAH) has recently commissioned two literature reviews on Aboriginal spirituality and resilience. For more information about these reviews please see the CRCAH website: http://www.crcah.org.au/
6. Conclusion

The experience of colonisation and its aftermath is the overarching point of commonality for Indigenous Australians and their counterparts in comparable fourth world countries. The political, social and health consequences of this - as evidenced in the health and demographic profile of Indigenous Australians - suggests that there is something “other” about the Indigenous experience that transcends a considerable diversity (Lee 2006).

On almost every social, educational and health indicator, as evidenced in the literature reviewed for this Report, Indigenous Australians do worse than non-Indigenous Australians. This is a reflection of the current health transition status of Australia’s Indigenous population, but emerging trends in fertility patterns, degree of urbanisation, increasing life expectancy and changing disease patterns, have implications for the manner in which the community will age, with implications for “brain health” and the development of dementia syndromes.

The social and health profile of Indigenous Australians, well documented in the literature, show many of the risks associated with a greater chance of developing dementia in later life in non-Indigenous populations. These risks presage the development of higher rates of dementia as well as its manifestation at a younger age than in the non-Indigenous community. This pattern has already emerged in studies of dementia prevalence amongst Indigenous Australians in remote living communities (Smith, Flicker et al. 2008). While dementia prevalence in urban and regional communities has yet to be established, it is reasonable to hypothesise, based on what we know about the health and welfare of Aboriginal Australians, that urban populations are both a high risk and an at risk population for dementia in at least equal measure to that of remote living Indigenous Australians.

Research also shows that social connectivity, good vascular health and other life style factors are protective, and more knowledge is needed about these factors relative to the Indigenous population.

The conceptual framework for addressing dementia in the Indigenous population needs to take account of the impact of history, context and culture in understanding the potential risk factors that this population faces, in both the development of dementia syndromes, and, of the approaches required to ameliorate and address these at a community health, public health and service provision level.

An important part of the research terrain around dementia, are differences in socioeconomic, language and health literacy status across residential locations in shaping how people perceive and experience dementia. This includes research into care giving and care seeking arrangements. We know very little about how families in diverse locations and circumstances navigate their own capacity to provide care for family members affected by dementia and balance this with their own needs for support.

It is also not clear how Indigenous culture, identity and spirituality, that is, attachment to ‘Country’, community ties and kinship relationships, influences the dementia experience, including, use of treatments, approaches and services in remote and non-remote settings.
6.1 Main messages

The main messages to emerge from this Review are:

* **Prevalence of dementia**

The prevalence of dementia amongst Indigenous Australians is almost five times the rate as that in the general Australian population and differs in two other key respects: currently more Indigenous males than females are affected and the Indigenous dementia rate is higher in the 45 - 69 year age group compared with the non-Indigenous population. Prevalence rates of dementia are based on recent research conducted in the remote Kimberley region of Western Australia and research is currently underway to determine the prevalence of dementia in urban and regional New South Wales.\(^{22}\)

* **Description of dementia**

‘Dementia’ in Indigenous communities has been described in the literature in a number of different ways: as “childlike” (benign behaviours); “madness” (aggressive or inappropriate behaviours) or, as “a sick spirit”, in suffering from the consequences of colonization and loss of connection to Land and traditional relationships. Dementia is not always recognised as a medical condition. Solutions to the problem of dementia need to take account of cultural perspectives and approaches to wellness.

* **Demographic change**

The Indigenous Australian population is beginning to age in a manner consistent with Indigenous populations in comparative countries and non-Indigenous populations in Australia. These trends toward population ageing include: increases in longevity (notably in the age group 45 - 64), different patterning in causes of death, reduction of chronic disease mortality in selected jurisdictions, and declining fertility rates and increased age at first birth.

* **Risk profile**

The social and health profile of Indigenous Australians show many of the risks associated with a greater chance of developing dementia in later life in non-Indigenous populations. The high level of multiple and confounding risk factors for cognitive decline and dementia across the life-cycle include: early-life risk factors such as, exposure to inflammation, low educational attainment, adverse childhood experiences, known risk behaviours (smoking, substance abuse, violence & brain injury); and mid-life vascular and metabolic risk factors such as, high cholesterol, obesity, hypertension, inactivity, and the presence of diseases such as cardiovascular disease and diabetes.

* **Interventions**

Interventions in terms of brain health need to address factors across the life cycle which ‘grow’ or impair brains, before cognitive decline begins. This is because ageing, health and the absence or presence of chronic disease is a whole of life process, with interaction of social and biological determinants, both proximal (early life) and distal (mid to later life) impacting on late-life risk for dementia.

* **Access to services**

From the limited data we have available, Indigenous people with dementia appear to be under represented in most - but not all - government services and programs in comparison to non-Indigenous people with dementia. Without reliable data on dementia rates (and sub-types) in Australia’s Indigenous population in urban, regional and remote areas, we are unable to ascertain the real extent to which Indigenous people have access to dementia services or the extent to which services are meeting the needs of the Indigenous population. Information about Indigenous peoples’ use of dementia services and other aged care programs is currently limited by the following deficiencies in data capture common across service domains: firstly, the reticence of workers to ask the question about a person’s Indigenous status; secondly, lack of disclosure of Indigenous status by some Indigenous clients; thirdly, inadequate capturing of Indigenous data where it is disclosed by some program data collection sets, with inconsistent data capture both within and across systems; and finally, limited data on dementia prevalence, and lack of data on dementia incidence, to inform rates of dementia in the Indigenous population. Given these problems and the fact that the diagnosis of dementia in the Indigenous Australian population is still in its infancy,
we are unable to ascertain the real extent to which Indigenous people are accessing dementia services. What the literature tells us is that many Indigenous Australians in rural and remote areas can’t access needed services due to transport difficulties and the unavailability of staff and services capable of delivering care adapted to local languages, culture and circumstances. In urban areas, many Indigenous people experience problems accessing services due to social isolation, personal and health problems, and because services are not experienced as being culture-friendly. Other reasons for non-access, relate to the fact that dementia is not always recognised as a medical condition, is not yet diagnosed, and because some families may fear the medical system

* Care arrangements

The literature on palliative care tells us that Aboriginal Elders wish to be cared for in their communities where they are close to family and kin and where they can die on their Land. We know that many older Indigenous people are greatly concerned about the erosion of their local culture and wish to reverse this trend. We know little about the impact of this on families and their care arrangements
6.2 Recommendations

In light of significant knowledge gaps we make the following recommendations:

<table>
<thead>
<tr>
<th>Research gaps</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>What understanding do Indigenous people from different backgrounds have about dementia from a socio-cultural perspective? What is their dementia literacy?</td>
<td>Research is required about Indigenous understandings of ageing, spirituality and dementia in a number of contexts - different cultural groups, traditional and non-traditional lifestyles, urban and rural.</td>
</tr>
<tr>
<td>What is the meaning, experience and impact of caring for a person with dementia for immediate and extended family groups? How do factors such as family, older person's status, age, gender and residential history influence this experience?</td>
<td>Research is required to examine the role, impact and effects of being a carer for an indigenous person with dementia in different socio-cultural contexts.</td>
</tr>
<tr>
<td>What is best practice for the identification and assessment of indigenous persons with suspected cognitive impairment – in remote and rural, regional and urban locations?</td>
<td>Research is required on case identification and assessment of cognitive impairment in Indigenous people across diverse locations to establish best practice models. Communities' own perceptions of what dementia means is an important part of this knowledge.</td>
</tr>
<tr>
<td>What is best practice for the provision of formal healthcare in both community and residential settings for indigenous persons with dementia from different backgrounds?</td>
<td>Research is required to establish best practice models of care and service for indigenous people in diverse locations. This includes knowledge about individuals' social histories and localised information about communities to inform individually tailored service provision and appropriate service planning at community level.</td>
</tr>
<tr>
<td>What is a reasonable estimate of formal service use by Indigenous Australians with dementia, relative to need?</td>
<td>We recommend modelling Aboriginal service utilisation numbers against Aboriginal population data and against non-Aboriginal patterns of service utilisation to construct a better picture of how effective Aboriginal access to programs such as HACC, CACP and EACH services are, relative to need.</td>
</tr>
</tbody>
</table>
6.3 Guides for clinicians

The following guides for clinicians arising from the information may be useful as background information, and are not intended to be exhaustive or prescriptive.

1. Cognitive assessments

The patient’s level of formal education, English language skills, and degree of acculturation, are all important factors to bear in mind when thinking about doing a cognitive assessment. Standard screening instruments may need to be adapted for patients whose language, education and degree of acculturation is not the same as the ‘mainstream’.

2. Impact of a dementia diagnosis

Clinicians need to be aware of the impact of a dementia diagnosis for Indigenous people. The diagnosis of dementia as a disease is a recent phenomenon for Australia’s Indigenous population, and there is a real problem of fear and stigma around this. Secondly, in light of the important role played by so many older Indigenous Australians in the life of their communities, especially caring for grandchildren, a diagnosis of dementia needs to sensitively take into account both the safety and wellbeing of the Elder and those around them and in their care.

3. Role and status of the Aboriginal Elder in community

Sensitivity is required to negotiate discrepancies that may arise if an Elder is regarded as functioning competently in the community and the clinician knows there is cognitive impairment. It will be important to involve the older person in the community in appropriate ways and involve carer support in sensitive ways.

4. Medical examination

A preventative approach to chronic disease management needs to be borne in mind, given the very high rates of chronic disease in mid and later life in the Indigenous population, and the association between cerebro-vascular, cardiovascular disease and diabetes and increased risk of dementia. Clinicians may consider the need for early screening of Indigenous patients for these chronic diseases.

5. Families

It is important to be aware that members of the immediate family may not be the only family members involved in the care of an older Indigenous person with dementia. Extended family may also be involved. There may also be proscribed ways of dealing with family obligations.

6. Cultural awareness

Clinicians need to be aware that for many Indigenous patients and their families, a diagnosis of dementia is likely to be associated with mistrust or fear of an unfamiliar medical system as well as the fear of possible removal from the community to a residential institution. This is especially pertinent to members of the ‘Stolen Generation’ and their families. Indigenous peoples’ preferences for care are most likely to be for the older person to be managed in community, with appropriate support, which might include both mainstream and indigenous specific services.

As with all patients, building a relationship of trust and confidence is important to Indigenous families. The history of mistrust between Indigenous people and the ‘system’ means that careful attention needs to be given to building this relationship. It may be useful for practitioners to consult with Aboriginal health workers and form partnerships with appropriate community networks, to assist in addressing complex issues in culturally sensitive ways.
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## Appendix 1: Literature database search results summary

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A Review of the Literature
### Appendix 1 continued

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