

DEMENTIA IN INDIGENOUS RURAL, REMOTE COMMUNITIES

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Acknowledgement

Who are you?

The Journey

- After an interesting mix of options, I was appointed locum general physician to Alice Springs Hospital 1998, then inaugural Chair of Geriatric Medicine in October 1998.
- In 2003 Dr Dina LoGiudice from NARI spent 6 months, sabbatical leave in the Kimberley pioneering work on the KICA. Her work there was only possible with the assistance of the KACS occupational therapist Kate Smith who was generously allowed to do this.

- 2003-2004 NHMRC – Healthy Ageing

Investigators: LoGiudice D, Flicker L, Almeida O, Lautenschlager N, Brown S. The assessment and prevalence of dementia in Aboriginal and Torres Strait Islander people in the Kimberley region

- 2005-2006 NHMRC

Investigators: D LoGiudice, L Flicker, OP Almeida, N Lautenschlager, D Atkinson. Assessing the health needs of older Indigenous Australians living in the Kimberley

- 2007-2009 NHMRC Dementia Research

Investigators: D LoGiudice, L Flicker, K Smith, OP Almeida, NT Lautenschlager, D Atkinson. Models of care to address unmet needs for older Indigenous people with dementia, their families and communities in remote Western Australia

Burden of Chronic Disease In Indigenous People

- In Australia general life expectancy is 78.1 years for men and 83.0 years for women.
- The recent reductions, ie over the last 20 years, have been in the deaths from cardiovascular illnesses.
- The major causes of mortality are cardiovascular illness, including heart disease and stroke, and cancers. Next is respiratory illness and injury.
- Aboriginal life expectancy is much less, 59.4 years for males and 64.8 years for females
- The causes of Aboriginal mortality are very similar as for all Australians, cardiovascular disease, then cancers followed by injury and poisonings

Burden of Chronic Disease In Indigenous People (2)

- The major causes of death are not necessarily the major causes of morbidity
- In non-Aboriginal populations osteoarthritis and mental illness are important causes of reductions in disability free life expectancies and may be as important on this measure as cardiovascular illness and cancer.
- These chronic disabling conditions along with respiratory illness, are probably as important in Aboriginal populations.

How to Control Chronic Diseases?

- It seems clear that chronic disease control will encompass a range of strategies incorporating primary, secondary and tertiary prevention.
- Many of the strategies will be directed at a population level, particularly those that seek to achieve outcomes by primary prevention.
- However, in most of Australia , effective secondary and tertiary preventive strategies are available to reduce the risk for progression of disease and worsening symptoms. Many of these strategies are aimed at individuals.

Risk Factors for Chronic Diseases

- **There is a strong association between Aboriginality and diabetes mellitus, hypertension and premature atherosclerosis.**
- **There is a paucity of data regarding the effect of risk factors on mortality within the Aboriginal population. eg hyperlipidemia and coronary artery disease**
- **There is even less information of the effects of intervention which modify risk factors in the Aboriginal population.**
- **This should not encourage therapeutic nihilism as an extrapolation of a number needed to treat analysis reveals that there may be greater gains realised in an Aboriginal population as opposed to the non-Aboriginal population.**

Primary Prevention

- **Nutrition - Diabetes, ischaemic heart disease, hypertension**
- **Exercise - Diabetes, ischaemic Heart Disease, hypertension**
- **Alcohol - Hypertension, mental illness, respiratory illness**
- **Smoking - Cardiovascular disease, respiratory illness**
- **Alleviate overcrowding - ??Renal Disease, rheumatic fever, respiratory illness.**

Secondary Prevention - 1

- Case detection early in the illness and then an appropriate plan of management **INDIVIDUALISED** for the patient.
- For example the early management of diabetes mellitus focuses on nutrition and exercise for that individual. This is different to the community approach. Diabetes education is usually preformed in small groups with non-threatening individuals as educators.
- Early detection of foot and eye problems can avoid the more disabling complications.
- Tighter metabolic control has been shown to reduce the risk of long term vascular complications.

Secondary Prevention - 2

- For most Australians troubled by lesser levels of chronic illnesses, care is managed by a selection filter through primary care to specialist referral including medical, nursing and allied health.
- In remote communities the availability of specialists is scanty and poorly supported.
- It is an enormous impost to expect stretched primary care services to be providing all levels of this service with essentially a manual as a backup.
- This type of practice is dominated by urgent or acute conditions.
- The necessary focus for chronic conditions will require increased primary and secondary care resources, not just medical but also for all aspects of chronic illnesses.

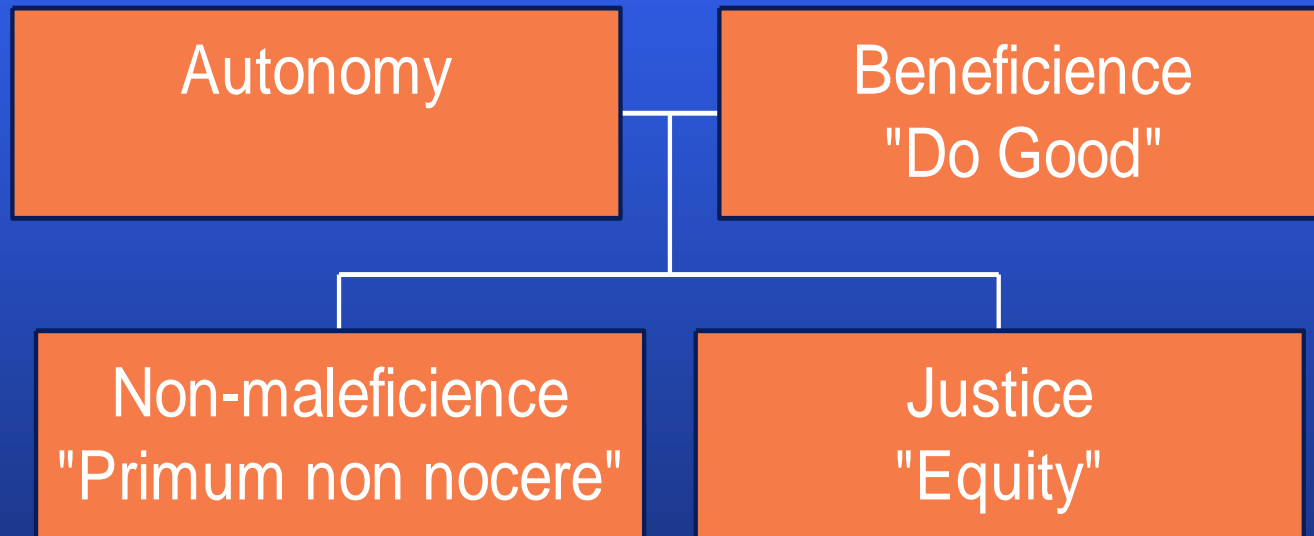
Anecdotal Experience - Diabetes Mellitus 1998

- I reviewed 18 consecutive diabetic patients from 5 separate communities.
 - 10 had Hb A1c ranging from 10-13%
 - 3 with Hb A1c 8-10%
 - 5 with Hb A1c < 8%
 - » 1 with Renal failure
 - » 1 after prolonged hospitalisation
 - » 1 newly diagnosed

Tertiary Prevention

- It has been a feature of my limited personal experience that chronic disabling conditions are common and poorly managed in Aboriginal communities.
- Arthritis secondary to trauma, stroke and limb amputation are particularly prominent.
- More insidious is the high prevalence of chronic cognitive disorders secondary to stroke, trauma, petrol sniffing, alcohol and Alzheimer's Disease
- Residential Care is almost non-existent but there has been some innovative projects commenced.

Medical Ethics - 1



Medical Ethics and Aboriginal Health

- The competing ethical principles are well illustrated in Aboriginal health.
- Autonomy and Non-Maleficence would dictate that we find exactly what Aboriginals want and interfere as little as possible unless requested - hence community control.
- Trouble is who presents the arguments and which Aboriginal voices do we listen to.
- Beneficence and Equity would suggest that we should attempt to provide services that we know benefit the majority of Australians to every segment of the population including marginalised remote Aborigines.

‘Cop-out’ on Aboriginal Health

- **“There is no point doing anything until the major structural problems of the place of Aborigines in society are dealt with first.” THERAPEUTIC NIHILISM**
- **These problems (amongst others) are;**
 - 1) Physical environment - shelter, clean water, sewerage, rubbish removal**
 - 2) Social dislocation - Traditional cultural values and laws versus non-Aboriginal culture and laws**
 - 3) Lifestyle factors - Nutrition, exercise and others including substance abuse alcohol, tobacco, petrol other drugs**
 - 4) Psychological effects of dispossession**

‘Cop-out’ on Aboriginal Health

The Answer

“Preventative services offered in the absence of any provision for treatment of existing and perceived disease are unlikely to be readily accepted by those for whom they are intended” Last JM 1986

- **The provision of medical services to Aborigines provides an opportunity to build bridges between the two cultures. There is every likelihood that the non-Indigenous people concerned will be well meaning and have the interests of their patients at heart.**
- **The provision of treatment services provides an opportunity for education of not only the patient concerned but the entire family. eg the benefits of lifestyle modification in hypertension and diabetes.**
- **As citizens we should advocate for correction of the structural problems but our jobs as health professionals mandate that we focus our energies on providing better health services.**
- **Local supports for health services generates employment.**

Future Progress

- Primary Care health services to remote communities should be increased. Some resources should be decentralised to remote communities.
- These should be supported by appropriate specialists in chronic diseases with a particular focus on diabetes management.
- Culturally appropriate support and rehabilitation services should be developed and evaluated.
- Any service and strategy should have clear and unequivocal clinical goals eg No. of known diabetics and Hb AC levels and the services should be audited against these benchmarks.

Prevalence of dementia in older Indigenous people in the Kimberley

Leon Flicker^{1,2}, Kate Smith^{1,2,3}, Osvaldo Almeida^{1,2,4}, Nicola Lautenschlager^{1,2,4}, David Atkinson^{3,5}, Anna Dwyer^{1,2}, Dina LoGiudice^{1,6}.

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2. School of Medicine and Pharmacology, UWA

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4. School of Psychiatry and Clinical Neurosciences, UWA

5. Kimberley Aboriginal Medical Services Council

6. National Ageing Research Institute, University of Melbourne

Perth Epidemiology Group, Rottnest May 2007

Dementia - ICD 10

- Syndrome due to disease of the brain
- Usually chronic and progressive - at least 6 months for a confident diagnosis
- Involves a decline in multiple higher cortical functions including memory.
- Should attempt to avoid false positive diagnoses, especially depression.
- Decline in intellectual functioning affecting personal activities.
- No clouding of consciousness (delirium)

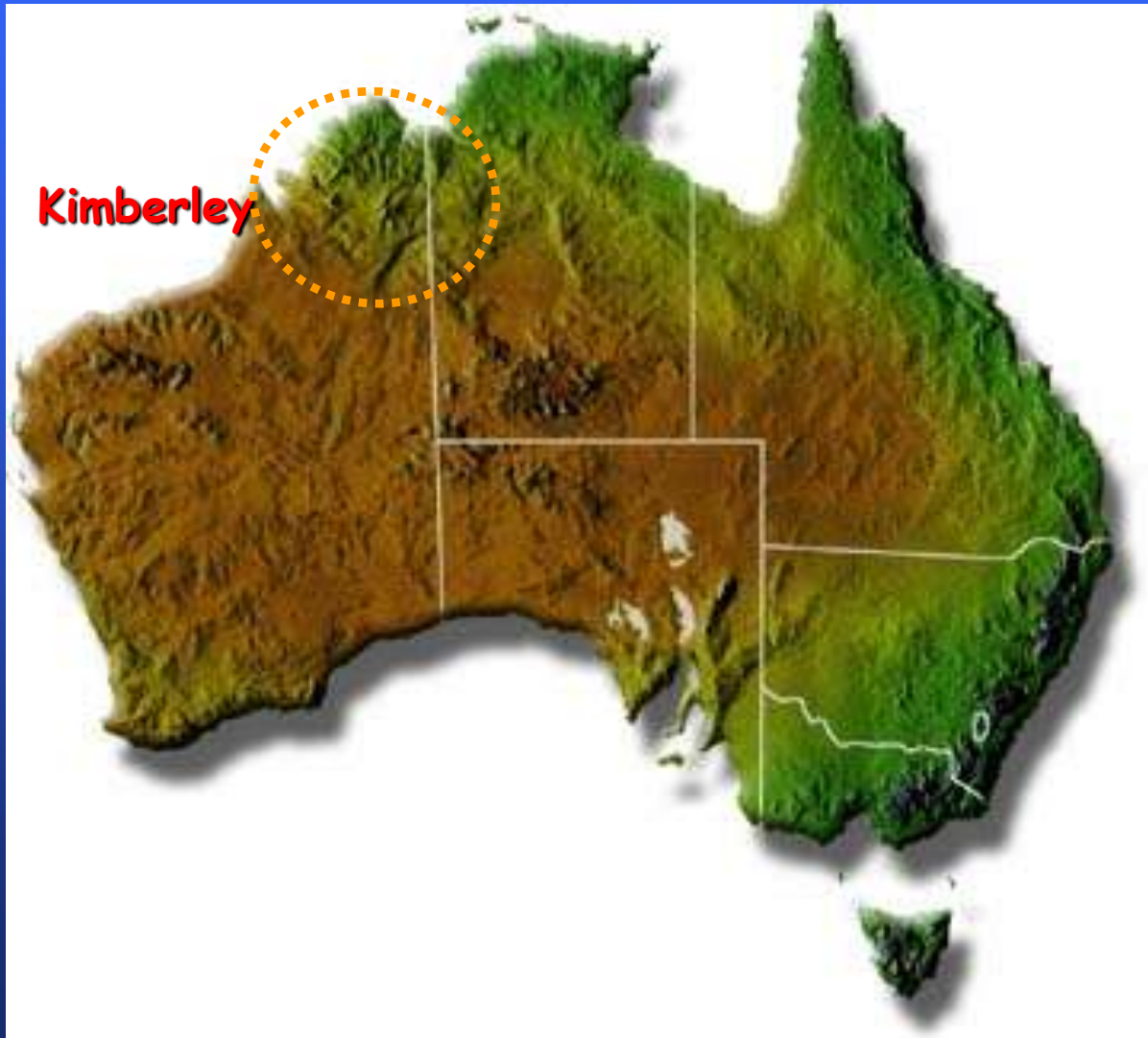
Assessment and Management of Dementia

- Assessment is closely interlinked with management.
- There has been a recent increase in interest in this area because of the cholinesterase inhibitors.
- These symptomatic treatments for Alzheimer's Disease mandate the need for comprehensive assessment of people with Alzheimer's Disease and their carers.
- These assessments have the potential to provide more benefit than the medications themselves though better access to services and general support.

Domains of Assessment

- **Cognition**
- **Functioning**
 - Activities of daily living
 - Instrumental Activities of Daily Living
- **Informant information**
 - Related to cognitive decline
 - BPSD
- **Carer Assessment**
- **(Medical) Type of dementia & medical co-morbidities**

The Kimberley region



Spans 421,451 sq km

**65% of the total
population of 32,625 live
in very remote areas**

**47% of the population are
Indigenous**

**Contains over 200 remote
Indigenous communities
and six larger towns**

Cognitive impairment in Indigenous people

Dementia is usually only diagnosed in late stages (NT Indigenous Dementia Report, 2002)

Reasons for the late diagnosis:

- **missing culturally appropriate assessment instrument**
- **cultural factors – expectations of older people and of health care**
- **high tolerance for unusual behaviour in Aboriginal communities**
- **dementia often not viewed as disease**
- **language**
- **No data Only one study used non-validated instrument, no listed sampling strategy - found 20% in people 65 years and older (Zann, 1994)**

Aim: to develop and validate a cognitive assessment and informant tool for older Aboriginal people which is as much as possible culturally appropriate

Funding:

NHMRC Healthy Ageing
Grant- Development
of the KICA

NHMRC Project Grant

NHMRC Dementia
Research Grant



Participating community members, councils and traditional owners of:

Balgo, Beagle Bay, Bidgydanga, Bililuna, Broome, Derby, Djarindjin, Fitzroy Crossing, Jarlmadangah, Junjuwa, Kalumburu, Kununurra, Lombadina, Looma, Mowanjum, Mulan, One Arm Point, Pandanus Park, Wangkatjungka, Warmun and Wyndham.

Assistance from:

Kimberley Aged and Community Services, Kimberley Aboriginal Medical Services Council, North West Mental Health Services, Community Health Clinics, Derby Health Services, Nindilingarri Cultural Health Service, Kimberley Interpreting Service, Kimberley Language Resource Centre, Kimberley residential care facilities and Home and Community Care providers.

WHO recommendation for development/adaptation of assessment tool for different cultural background.

- **Selection of dimensions to be measured based on diagnostic criteria**
- **Consultation**
- **Independent back translation**
- **Test for acceptability**
- **Revisions**
- **Pilot test comparing to gold standard**
- **Validation**

KICA – Reliability and Validity

Reliability study 14 subjects

- **Inter-Rater**

Validity study 70 subjects

- **1st KICA assessment, followed by clinical assessment (with the help of the CIBIC), blinded for the KICA results.**
- **Medical records**
- **Expert consensus regarding diagnosis in Perth (DSM-IV and ICD-10).**
- **Letter to the GP**
- **Feedback to the “community council”.**

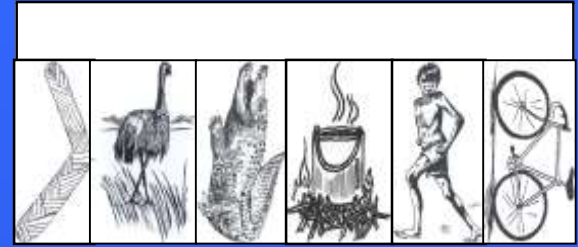
Kimberley Indigenous Cognitive Assessment (KICA)

KICA is divided into a number of sections:

- Medical history
 - Smoking and alcohol history
 - Cognitive assessment
 - Emotional well-being
 - Family report
-
- The cognitive assessment section has been validated with Indigenous Australians aged 45 yrs and above from the Kimberley and Northern Territory. A score of 31/39 or lower indicates possible dementia.
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- The KICA can be downloaded from www.healthykimberley.com.au/chronicdisease.html

KICA- Cog

Cognitive Assessment



- **Orientation** eg. season/ pension week
- **Free and cued recall** eg. objects and pictures
- **Language** eg. naming tasks
- **Verbal fluency** eg. animals to hunt
- **Frontal executive fn** eg. xo
- **Praxis** eg. comb use

Family – cognitive assessment

- *Have you noticed that s/he is forgetting a lot of things?*
- *Does s/he forget the names of his family? His grannies?*
- *Does s/he forget what happened yesterday?*
- *Does s/he forget where he is now?*
- *Does s/he say the same thing over and over?*
- *Can s/he remember which week is pension week?*
- *Does s/he keep walking away and getting lost?*
- *Does s/he say things that are wrong in Aboriginal law?*

Family Report – Daily Living Skills

- *Can s/he still do his own work?*
- *Can s/he still go fishing/hunting?*
- *Can s/he still play cards?*
- *Can s/he look after her/his own money?*
- *Can s/he feed her/himself?*
- *Can s/he put on her/his clothes?*
- *Can s/he shower her/himself?*
- *Does s/he have trouble finding the toilet?*
- *Does s/he make urine in bed in the night?*
- *Does s/he make urine in trousers/dress in the daytime?*
- *Does s/he make bowel motion in her/his dress/trousers?*

Communities involved Ardyaloon, Mowanjum, Junjuwa, Warmun, Derby, Balgo, Looma.



Prevalence study: Methods

- **Cross-sectional, point prevalence**
 - **Target number: n = 400**
 - **Semi-purposeful sampling. Selection of participants (town (1/3), language families, coastal/desert, small versus large communities).**
 - **Approval of communities.**
 - **Community provides list with all community members 45 years or older.**
 - **Selection and training of indigenous health workers**
- **Assessment with KICA.**
 - **Feedback on results to the community clinics.**
 - **Within 3 months: clinical assessment of selected participants (100% with scores <37, 50% of 37 and 5% of subjects with 38-40) by geriatrician or psychogeriatrician not using the KICA. Looks up records.**
 - **Consensus diagnosis by 2 independent experts using info from clinical assessment.**
 - **Feedback on results to the community clinics.**

Out in the field



Independent Validation???

(he looks worried)



Population sample

Kimberley Indigenous > 45 15%,

Non-Indigenous Australians > 45 47%

Refusal rates low: 0% - 9.7% in the 6 small communities and 8.1% in Derby. Reasons for refusals too busy, unwell or not interested.

| Age (yrs) | Kimberley sample | | Australian | |
|-----------|------------------|--------------|------------|--------------|
| | Population | Distribution | Population | Distribution |
| 45-59 | 194 | 0.53 | 3539067 | 0.53 |
| 60-69 | 71 | 0.20 | 1449594 | 0.22 |
| 70-79 | 68 | 0.19 | 1124237 | 0.17 |
| 80+ | 30 | 0.08 | 586054 | 0.09 |
| total | 363 | | 6698952 | |

55% female.

Mean (SD) 60.7 (11.9) years

39% of participants had no formal education

Dementia Prevalence

| Age (yrs) | Dementia numbers (n) | | Dementia prevalence rates | | Dementia prevalence ratio |
|-----------|----------------------|-----------|---------------------------|-----------|---------------------------|
| | Kimberley | Australia | Kimberley | Australia | |
| 45-59 | 4 | 3539 | 0.021 | 0.001 | 21 |
| 60-69 | 12 | 12322 | 0.169 | 0.0085 | 19.88 |
| 70-79 | 12 | 49804 | 0.176 | 0.04 | 3.97 |
| 80+ | 17 | 108713 | 0.567 | 0.19 | 3.06 |
| total | 45 | 174377 | 0.124 | 0.026 | 4.8 |

Types of Dementia

- The prevalence of dementia in this sample was 12.4%
- The prevalence of cognitive impairment not fulfilling criteria for dementia was 7.4%
- Prevalence was higher in males
- 'Dementia not otherwise specified' at 53% of all dementia diagnoses
- Dementia of the Alzheimer's type 24%
- Vascular dementia 13%
- Alcohol induced persisting dementia 4%
- Dementia due to multiple aetiology 4%.

Risk Factors for Dementia and Cognitive Impairment (OR)

■ Besides age other risk factors identified

| | | |
|--------------|-----|-------------|
| Male | 5.9 | [2.3, 15.3] |
| stroke | 6.7 | [2.2, 20.4] |
| Epilepsy | 9.5 | [1.8, 49.7] |
| Head Injury | 4.4 | [1.4, 13.6] |
| (males only) | | |

Other associated variables were

| | | |
|---------------|-----|-------------|
| Falls | 3.2 | [1.4, 7.6] |
| Poor mobility | 5.5 | [2.4, 12.7] |

Limitations

- Risk factors by necessity were elicited by participant and carer report.
- Access to health care was much more restricted for this population than is currently expected by the Australian population as a whole. Investigations such as brain imaging are not able to be performed in the Kimberley region.
- Limited size of the sample
- Younger age group was not completely sampled due to employment and social factors attracting people to towns or stations for long periods
- Only one region of Australia was studied ? generaliseability

Management

- Address risk factors
- Community Supports??
 - Who provides it
 - What accountability
- Awareness raising and is so when?
- Residential care