A practical framework for culturally safe health care for Indigenous Australians

Scabies + Eye health as models

Artiene Tatian
MBBS, BSc (Adv), MIIndigHlth
MRACI CChem
How Does Aboriginal Culture Work?

- Do not expect to understand all the rules, stories and business in aboriginal culture
  - Most knowledge is only passed to select individuals in aboriginal communities (Crawford & Tantiprasut, 2003)
- Dreamtime stories you will be familiar with are stories for children which may be shared with all (Dean, 1996)
- Gain a knowledge of the overarching ideologies to guide culturally safe practice (Campbell, 2011)
Aboriginal Social Organisation

- **Three-tier system** (Scheffler, 1982)
  1. Physical structuring
     - A tribe or language group - based on geography
  2. Religious structuring
     - Based on Ancestral beings from the Creation Period
     - An individual may belong to be connected to one or more of these - totem
  3. Kinship system

(Rubeli, 2013)
The modern day face of Indigenous Australia

- Why concern ourselves with Indigenous health?
- How to define Indigenous status in health care
The Australian population

Indigenous population was 669,900 (ABS, 2011)

- 3% of the total Australian population in June 2011
- 33% live in capital cities (ABS, 2011)
- Indigenous median age was 21 years (ABS, 2013)

Table 1 - Estimated Indigenous population, by state/territory, Australia, 30 June 2011

<table>
<thead>
<tr>
<th>State/territory</th>
<th>Number of Indigenous people</th>
<th>Proportion (%) of Indigenous population living in that state/territory</th>
<th>Proportion (%) of state/territory population that are Indigenous</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>208,364</td>
<td>31.1</td>
<td>2.9</td>
</tr>
<tr>
<td>Vic</td>
<td>47,327</td>
<td>7.1</td>
<td>0.9</td>
</tr>
<tr>
<td>Qld</td>
<td>188,892</td>
<td>28.2</td>
<td>4.2</td>
</tr>
<tr>
<td>WA</td>
<td>88,277</td>
<td>13.2</td>
<td>3.8</td>
</tr>
<tr>
<td>SA</td>
<td>37,392</td>
<td>5.6</td>
<td>2.3</td>
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<tr>
<td>Tas</td>
<td>24,155</td>
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</tr>
<tr>
<td>ACT</td>
<td>6,167</td>
<td>0.9</td>
<td>1.7</td>
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<tr>
<td>NT</td>
<td>68,901</td>
<td>10.3</td>
<td>29.8</td>
</tr>
<tr>
<td>Australia</td>
<td>669,736</td>
<td>100.0</td>
<td>3.0</td>
</tr>
</tbody>
</table>

(ABS, 2011)
Aboriginal Social Organisation

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(Mechielsen, 2012)
Kinship

- System in Aboriginal culture that dictates: (Yengoyan, 1981)
  - Social organisation
  - Family relationships

- Complex system that determines: (Denham, 1982)
  - How individuals relate
  - Individuals roles in the community
  - Responsibility and relation to one another
  - Ceremonial business and land
  - Culture and knowledge
  - Who may marry who
  - Funeral roles
  - Behaviour patterns with other kin

(Sutor, 2010)  
(Garlingarr, 2013)
Kinship and Identity

Kinship: (Edwards, 2004)

- It provides a person with a spiritual connection to the dreaming
- A connection to kin both past present and future
- A unique self identity and a place in the community
- Allows an individual to show respect for those who carry knowledge and tradition
- Links all Indigenous Australians across boundaries and geography

(McCalman 2014)
Indigenous Definition of Health

“Not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total well-being of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life.” (Wikander, 2002)

(Torzillo, 2014) (Vision Obsession 2012)
Indigenous health is multifactorial

(Whitehead & Dahlgren, 1991)
Naming and Western Terminology

- The Aboriginal/Torres Strait language has a set of reciprocal terms that are used to describe how people are related (Troy & Walsh, 2004).
- English has fewer kin terms than do most Aboriginal languages.
- The kinship system allows naming for up to 70 relationship term in some tribes (NSW Health, 2004).
  - This includes paternal or maternal relations to an individual (Smith, 2003).
Family & Kinship - Link to Western Terminology (Troy & Walsh, 2004)

- Great Grandparents
  - All their brothers and sister are my great grandparents

- Grandparents
  - All their brothers and sister are my grandparents

- Parents
  - All my fathers brother are my fathers
  - All my fathers sisters are my aunties
  - All my mothers brothers are my uncles
  - All my mothers sisters are my mothers

(Armitgæ 2010)
Family & Kinship - Link to Western Terminology (Troy & Walsh, 2004)

- **Me** - (I am male)
  - All my brothers children are my sons/daughters
  - All my sisters children are my nieces/nephews

- **My Children**
  - Relate the same vice versa

- **My Grandchildren**
  - All my sister/brothers children are my grandchildren

(Campbell, 2009)
Tribes or Nations

- These are really language groups (Blake, 1991)
- Comprised of people who share a common language, customs and general laws (Davidson & Akerman, 2011)
  - Governs rules when crossing boundaries - traditional welcome
- People of a tribe share a common bond
- The name of the tribe normally comes from the word “man” in the tribes language (Blake, 1991)
- Tribes were not devised for war making and are not led by a chief (Tindale & Jones, 1974)
  - As such people normally describe themselves based on their moiety or clan name
  - Eg. Larrakeyah Nation - Indigenous people around Darwin
Moieties

(System, 2007)

- System that divides all the members of a tribe into two groups (Tindale & Jones, 1974)
  - Based on a connection with a specific ancestor species, certain animals, plants or other aspects of the environment
  - Kinship has a connection with the environment, nature and culture
- A person from one moiety has to marry a person of the opposite moiety (Berndt & AIAS, 1970)
  - This is an exogamous system - marriage has to be kept external to the group
  - Preventative - birth defects and congenital abnormalities
Sub classes or Skins

- Common in tribes in the central and northern Australia
- Divides people further into group of eight or four
  - Divided based on relation to one another
- Anthropologically = sections if there are four or subsections if there are eight (Berndt & AIAS, 1970)
  - Each has a male and female version
- Precise rules which govern which skins are allowed to marry another (Australia Law Reform Commission 1982)
  - You can never marry someone who is the same skin as your mother or father

(Jagamara, 2012)
Moiety in Practice

- In the northern Kimberley the two moieties are represented by two birds:
  - Wodoi - the spotted Nightjar
  - Djungun - the Owlet Nightjar
- In dreamtime they fought in Lalai
## Skins in practice

**Lardil people of Mornington Island**

<table>
<thead>
<tr>
<th>Eight Subsection groups</th>
<th>Totems</th>
<th>May marry only female skin group</th>
<th>Children will be</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ngarrijbalangi</td>
<td>Rainbird, shooting star, egret</td>
<td>Burrarangi</td>
<td>Bangariny</td>
</tr>
<tr>
<td>Bangariny</td>
<td>Brown shark, turtle</td>
<td>Yakimarr</td>
<td>Ngarrijnalangi</td>
</tr>
<tr>
<td>Buranyl</td>
<td>Crane, salt water, sleeping turtle</td>
<td>Kangai</td>
<td>Balyarriny</td>
</tr>
<tr>
<td>Balyarriny</td>
<td>Black tiger shark, sea turtle</td>
<td>Kamarrangi</td>
<td>Buranyi</td>
</tr>
<tr>
<td>Burrarangi</td>
<td>Lightening, rough sea, black dingo</td>
<td>Ngarrijbalangi</td>
<td>Kamarrangi</td>
</tr>
<tr>
<td>Yakimarr</td>
<td>Seagull, baramundi, grey shark</td>
<td>Bangariny</td>
<td>Kangai</td>
</tr>
<tr>
<td>Kangai</td>
<td>Barramundi, grey shark</td>
<td>Buranyi</td>
<td>Yakimarr</td>
</tr>
<tr>
<td>Kamarrangi</td>
<td>Rock, pelican, brolga, red dingo</td>
<td>Balyarriny</td>
<td>Burrarangi</td>
</tr>
</tbody>
</table>

(Eckermann, 2006)
Totemic Groups

- Allow one to find meaning with the Dreaming (Australian National Commission for Unesco 1973)
- Animal, plant or other object believed to be ancestrally related to a person
- Provide an individual with a cultural and spiritual identity
- Totemic groups may identify the role of individuals in corroboree or ceremonies (Reynolds et al., 2006)
Nangakari

- Nangakari is an Aboriginal Healer (Pattel-Gray, 1996)
  - Methods have been around since time began
  - Still used today
  - Granted the special gift and power of healing
- Only the kin of a Nangakari will inherit this power (Bell, 1999)
  - Kinship can thus define a special role in the community
  - Provide cultural and spiritual healing - something we may be limited by
  - Increase health outcomes and holistic care

(Hammerton, 2013)
Kinship and Indigenous Social and emotion well being

Current Data:

- The prevalence of experiencing high/very high levels of psychological distress was more than twice the rate of non-indigenous people (Kirmayer et al. 2000)

- Rate of hospitalisation of Indigenous Australians for mental health problems was almost twice the non-indigenous rate (The Lancet, 2012)

- Suicide rate is 2.5% higher for indigenous males and 3.4 times higher for indigenous females (ABS, 2012)
Kinship and Good Mental Health

Kinship safe guards against mental health issues by: (Fernandez et al. 2012)

► Providing a support network
► Allows individuals to self actualise and discover and develop their self identity
► Each individual has a role to play in the community and everyone is as important as everyone else
► Involvement with caring adults
► Support at critical times
► Strong cultural identity and pride

► Current government policy - national strategic framework for Aboriginal and Torres Strait Islander mental health
  (Anderson, 2004)
Kinship and Good Mental Health

- The data illustrates that indigenous individuals have good social and community support (strong support networks).
- They are able to access support networks in time of crisis and this is independent of remoteness.

Kinship is doing something right - it promotes good mental health and its presence and the existence of culture should be promoted.

(ABS, 2012)
Scabies Prevalence

- The prevalence of scabies in Indigenous children has been reported to be between 50%-80% (Andrews et al. 2009; Currie & Carapetis, 2000)

- Highest representation in children less than three years.

- This age group is more than twice as likely to acquire scabies compared to older children aged 3 to 14 years (Andrews and Kearns 2009).
Complications

- A major overlooked outcome is the cutaneous and psychosocial morbidity of scabies infections.
- The life limiting sequelae including:
  - APSGN
  - ARF, and RHD
- A literature review of publications in the last century identify that whilst there have been many advances in GAS Infection in terms of pathophysiology, diagnosis and management next to none have been from Australia and its Indigenous communities.
  - ?proof that westernized interventions are effective
  - not acknowledging key issues including psychological squeal.
- This approach fails to recognise the importance of culturally safe practice and the role of the community in health care and prevention.
- Ultimately this is a return to the paternalistic ideal that imposed practices give quality outcomes. Addressing this issue and cultural appropriate research beyond epidemiology is a requirement if change is to occur.
Epidemiology of Complications

- Indigenous Australians aged 5-14 have the highest incidence of ARF and RHD in the world (254 per 100,000)
  - New Zealand (58 per 100,000)
  - Canadian First Nations (126 per 100,000)
  - Native Hawaiian (18 per 100,00)
  - all of whom suffer a higher burden of disease than their non-Indigenous counterparts (Steer & Carapetis, 2009).

- The rate of serious skin infections was also significantly high in Maori children and 3-70 times higher in Pacific children compare to other ethnicities (Steer & Carapetis, 2009).

- This is likely multifactorial including:
  - genetic predisposition
  - climate related factors.

- However, the impact of the prevalence of GAS pyoderma as a consequence of scabies is a major driving factor for the burden of ARF and RHD that needs serious public health attention in Australia.
What about Trachoma?

- Nationally eye and vision health problems were responsible for 11% of the years of life lost to disability for Indigenous Australians.
- Fourth leading cause of the current gap in health, relative to non-indigenous Australians (Taylor et al. 2012).
- Eye and vision health was responsible for at least a two-fold increase in indigenous mortality rates.
- 94% of vision loss however is either treatable or preventable with adequate care (Vos & Taylor, 2013).
- The National Indigenous Eye Health Survey (Taylor et al. 2010) found that 6.2 times more Indigenous adults were blind than their non-Indigenous counterparts.
- Trachoma was the third leading cause of blindness in Indigenous Australians resulting in 9% of all cases, while in the non-indigenous community this value is 0 (Taylor et al. 2010).
Data Collection Methodologies

- The national prevalence of trachoma in children was 3.8% (Taylor et al. 2010).

- 1977 where it was reported by the National Trachoma and Eye Health Program [NTEHP] (Hollows, 1977) to be 9.5%.

- The National Indigenous Eye Health Survey [NIEHS] (Taylor et al. 2010) identified trachoma as endemic in regions of the Northern Territory, Western Australia and South Australia.
Data Collection Methodologies

- In 2006 Australia established The Nation Trachoma and Surveillance and Reporting Unit.

- Subsequently the organisation has released seven reports documenting the data for the years - 2006 (Tellis et al. 2007), 2007 (Tellis et al. 2008), 2008 (Tellis et al. 2009), 2009 (Adams et al. 2010), 2010 (Cowling et al. 2012) and final report for 2011 (Cowling et al. 2013).

- The data presented when analysed is completely negligible and statistically unreliable.
The reports present combined statistics from ‘at risk’ communities for trachoma.

The definition for inclusion was a prevalence of 5% or greater among children.

Previous identified endemic location and failed to assess any new or at risk communities of developing endemic levels.

The inclusion criteria also neglects to use the validated Trachoma Rapid Assessment tool (Negrel & Mariotti, 1999) and Acceptance Sampling Trachoma Rapid Assessment protocols (Lansingh & Carter, 2008) to identify at risk communities even though they are validated and reliable tools.

Completely neglects Queensland and NSW communities with known trachoma (Taylor et al. 2010).
Disregards the Communicable Disease Network Australia’s (CDNA) requirements that at risk communities be screened until <5% prevalence is seen for 5 consecutive years (Black et al. 2006).

An analysis of the screening methodology highlights that coverage rates are as low as 9% and are unlikely to represent the true prevalence.

- Fails to screen children not attending school who are statistically more likely to experience social, housing and environmental issues associated with trachoma.

It is important that research is not guided by proving a hypothesis or point but to represent the scientific value Indigenous health represents.

What is the true value? Likely around 8% prevalence
Why are they good models to compare?

- Similar risk factors and Distribution
  - Young age
  - Overcrowding
  - Hygiene
  - Socioeconomic status
  - Resource-poor communities
  - Intrinsic environmental and climactic issues may be unavoidable in Northern Australia.
So What is Needed?

- A systematic approach to issues with:
  - Identification of scabies and pyodema
  - Access to care in resource poor communities
  - Community education
  - Provision of treatment
  - Recognising psychological stigmatism and sequelae

- These are issues compounding the ongoing propagation of these infestations
Our mission is to eliminate disease from remote Indigenous communities, one disease at a time.

First on the hit list is scabies, which affects 7 in 10 children before they turn 1.

What presents as an innocent itch can lead to heart and kidney failure and ultimately premature death.
We will disrupt the status quo and implement innovative, culturally respectful treatment programs that are not thrust upon, but built together with the Indigenous communities in which we work.
We believe no Australian should die of a preventable disease.

Pitting our will against scabies and its devastating effects will not only eliminate the disease, but also create a stronger partnership with Indigenous Australians and begin to heal a much older wound.
HEALTHY SKIN
PROGRAM GOALS

Our program is a multifaceted and effective partnership with Indigenous Australia to eliminate crusted scabies and scabies as a public health issue. It consists of five key goals with multiple strategies under each. Here we review our progress over the past 6 months relating to each goal.

TREAT CORE TRANSMITTERS
- Crusted scabies case management
- Supporting families with recurrent scabies

SUSTAINED REDUCTION
- Community surveillance for early treatment
- Social marketing for early treatment and compliance
- Development of next generation scabies cream

POINT IN TIME PREVALENCE REDUCTION
- Healthy Skin, Healthy Homes events
- Ivermectin mass drug administration

OPERATIONAL ENHANCERS AND ENABLERS
- Building community workforces
- Education tools for clinical staff and patients
- Sustainable washing machines
- Monitoring and evaluation
- Targeted operational research

SCALING-UP IMPACT
- Advocacy and systems-wide change
- Developing systems for national-roll out

CRUSTED SCABIES
A NEGLECTED AND MISUNDERSTOOD DISEASE

Crusted scabies is a far more severe form of simple scabies. It is a highly infectious condition that occurs when an individual’s immune system is not able to control scabies mite reproduction. The disease is disfiguring and can impact life expectancy due to complications from secondary bacterial infections. Family members often suffer recurrent scabies, skin sores and complications.
Goals

With a greater understanding of the spectrum of disease that is scabies, our vision remains the same and our goals are clearer.

- Encourage and support patient self-management as a method to eliminate crusted scabies as a public health concern in the Northern Territory.
- Develop an effective community engagement model to reduce the disease burden of scabies in two focus regions of Maningrida and Gove Peninsula.
- Encourage and support patient self-management as a method to eliminate crusted scabies as a public health concern in Australia.
- Reduce the disease burden of scabies among children in their first year of life across remote Indigenous communities in Australia.
Simple Scabies Vs Crusted Scabies
Skin Sores

Group A Strep
Rheumatic Fever
Glomerulonephritis
IMPACTS OF SCABIES AND CRUSTED SCABIES

Scabies

Itch and scratch

Skin infection

Severe infection (sepsis)
5-10% mortality rate

Severe and chronic kidney disease
5% mortality rate

Rheumatic fever & heart disease
2-5% mortality rate

Crusted Scabies

1.6% annual death rate

Adapted from Engelman et al., 2013
SNAPSHOT OF THE HEALTHY SKIN PROGRAM ACTIVITY

**GALIWINKU**
(1890 COMMUNITY MEMBERS)
- Washing machine audit and repairs made as a part of the 'Spin Project'.

**GAPUWIYAK**
(925 COMMUNITY MEMBERS)
- Washing machine audit and repairs made as a part of the 'Spin Project'.
- Two trips to community to initiate work on crusted scabies, in partnership with local health worker Teresia Gulyula.
- Early identification and management of one crusted scabies patient.
- One in-service update and education session at local health clinic.

**MILINGIMBI**
(1817 COMMUNITY MEMBERS)
- Washing machine audit and repairs made as a part of the 'Spin Project'.

**YIRRKALA**
(1250 COMMUNITY MEMBERS)
- Frequent ongoing monitoring and support of 6 crusted scabies patients – no serious relapses since August 2011.
- Brief hospitalization of two patients in Dec.
- Early detection meant relapse was not serious.
- Continuing general monitoring of scabies in community through local Community Health workers (Wwayawanga, Bamunya, Bandyal, Ritiili).
- Two in-service updates and education sessions with Yirrkala Health Centre and Gove District Hospital.
- Partnering with key influential families and elders to plan Healthy Skin event (June 2013) and secured support from Gunuwatu/Milk Mala group (community nominated leaders).
- Scabies education session with expectant mothers from the Frangipani Unit from the local maternity ward (first of a series).
- Washing machine audit and repairs made as a part of the 'Spin Project'.

**RAMINGINING**
(326 COMMUNITY MEMBERS)
- Washing machine audit and repairs made as a part of the 'Spin Project'.

**GUNYANGARA, GALUPA & BIRRITJIWI**
(350 COMMUNITY MEMBERS)
- Scabies rates continue to be very low.
- Monitoring and support for one crusted scabies patient.
- Assisting Miwatj with identification of a new crusted scabies patient and offering light touch support for Miwatj to manage the case.
- Mini skin and child health education sessions.
- Local community worker Sharyl Yawupungu, working in her community to monitor scabies rates and assist with treatment.
- Local Community Coordinator Wwayawanga Marika working in her community to monitor rates of scabies and assist with treatment.
- Washing machine audit and repairs made as a part of the 'Spin Project'.
- One in-service update and education session at local health clinic.
- Case conferencing commencing with Miwatj Health to ensure shared care of Crusted Scabies clients.
What Do Our Community Based Health Workers and Healthy Skin Clinicians Do?

**Crusted Scabies**
- Long-term relationships
- Liaison point
- Case management
- Improve understanding & self management
- Decrease reinfestation & transmission
- Patient, family, clinic, hospitals, housing, public health

**Kids 0-5 years**
- Household visits
- Screening
- Case management
- FAFT
- Childcare
- School
- Logistics
- Clinic education
Community Collaboration

Six Community based health workers across North East Arnhem Land
  x2 in Gove
  x4 in Maningrida
Mentorship, support, personal & community empowerment
Development of skin health & education expertise
Professional development
  further study preparation & support during HW training
Patient & community education

Developing an effective & sustainable community model
Reduction of disease burden over time
Case Study: Milingimbi

Approx 700 people on Milingimbi

98 children in the target group of 0-5 years

103 young people screened

73% of the target age group were screened
Results

Point prevalence of 26% scabies, 18% skin sores

Over 200 tubes of Lyclear provided

Community education

x5 LAB injections

Incidental findings of three cases of APSGN

Clinic and text follow-up reminders
Case Study: Milingimbi

Scabies
One year later…

0-5 year olds
12% scabies
16% skin sores
Keen to know more?

In the GP Setting Always think about:

- Population mobility and appropriate follow up care (region wide approach)
- Culturally safe practice and the stigma of western medicine
- Community engagement in program development and implementation
- Adequate supplies and CTG Scripts
- The role of aboriginal health workers and doctors in providing culturally appropriate care
- Indigenous ideal of childhood personality development and decision making
  - Kinship and support
Acknowledgements to the communities of Maningrida and Milingimbi, the One Disease crew, and Dr Dana Slape