

Trachoma elimination in remote Indigenous Northern Territory communities: baseline health-promotion study

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Abstract. Identify trachoma knowledge, attitudes and practice of staff in clinics, schools and community workplace settings to optimise trachoma-elimination health-promotion programs in the Katherine West Health Board region of the Northern Territory. Prior to the introduction of a suite of health promotion resources the Indigenous Eye Health Unit and Katherine West Health Board conducted a baseline survey of open, multi-choice and closed questions regarding knowledge, attitudes and practices in relation to trachoma with 72 staff members over a 6-month period in 2010–11. Data were analysed for differences between settings. Two significant barriers and one enabling factor were identified. One in five staff members in clinics and 29% of staff members in schools were unaware they lived and worked in a trachoma-endemic area. One-third of school staff and 38% of clinic staff considered it normal for children to have dirty faces. However, the majority of participants felt comfortable talking about hygiene issues with others. The presence of dirty faces in young Indigenous children underpins the continuing prevalence of trachoma. Increasing the awareness of the health effects of children's nasal and ocular secretions and changing community acceptance of dirty faces as the norm will reduce the risk of trachoma and other childhood infections. Staff in clinics, schools and community work settings can play a role in trachoma elimination by actively encouraging clean faces whenever they are dirty and by including face washing in holistic hygiene and health education. Staff in schools may need additional support. Trachoma-elimination health promotion should increase awareness of trachoma prevalence and encourage all who work and live in remote Indigenous communities to take action to promote facial cleanliness and good hygiene practices.

Additional keywords: facial cleanliness, hygiene.

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Introduction

Trachoma is entirely preventable yet it is the leading infectious cause of blindness worldwide (Wright *et al.* 2008). Trachoma is characterised by episodes of repeated infection with *Chlamydia trachomatis* that begins in early childhood when the bacteria is transmitted from an infected to an uninfected individual by direct contact (Burton 2007). It spreads in poor, overcrowded environments with poor personal and community hygiene (Mariotti *et al.* 2009). Dirty faces, specifically nasal and ocular discharge, spread the infection when children play closely together or share the same sleeping space (Taylor 2008). Improving personal and environmental hygiene will reduce the transmission of trachoma (Rabiu *et al.* 2012). However, in Indigenous communities, crowding and poor economic, social and environmental conditions make personal and community hygiene difficult to maintain (McDonald and Bailie 2010).

Further, housing improvements alone without education and behaviour change will not be sufficient to reduce trachoma (Bailie *et al.* 2012). To compound matters, in some remote Indigenous communities there is an observed tolerance for children to have ocular or nasal discharge, and the concept that dirty faces spread infection does not appear to be recognised (McDonald *et al.* 2010).

Internationally, there are 300 million people living in areas with trachoma and 100 million in need of treatment (International Coalition for Trachoma Control 2011). Australia is the only developed nation among 57 countries with blinding trachoma where it is present almost exclusively in remote Indigenous communities in the Northern Territory, South Australia and Western Australia (Hooshmand *et al.* 2010). Trachoma has recently been found in New South Wales and Queensland where it was previously thought to have been eliminated (Taylor *et al.*

2010). In Australia in 2008, blinding endemic trachoma was found in 60% of remote Indigenous communities and almost 5000 Indigenous children and 16 000 adults were affected nationwide. The later stages of scarring and in-turned eyelashes (trichiasis) affects 1.4% of older Indigenous people across Australia (Taylor *et al.* 2009).

Indigenous Australian children start life with five times less poor vision than non-Indigenous children, yet by adulthood Indigenous Australians have blindness rates six times the rate of other Australians (Taylor *et al.* 2009). Trachoma is responsible for 9% of preventable blindness in Indigenous Australians (Taylor *et al.* 2010).

Australia is a signatory to the Alliance for the Global Elimination of Blinding Trachoma by the year 2020 (World Health Organization 2011). Australia established the National Trachoma Surveillance Reporting Unit in 2006 to improve quality and consistency of data collection and reporting and in 2009 the Australian government provided \$16 million over 4 years through the Improving Eye and Ear Health Services for Indigenous Australians for Better Education and Employment Outcomes (Australian Government and Department of Health and Ageing 2009) in a new, concerted effort to eliminate trachoma by 2020. In the Northern Territory trachoma screening, treatment and health promotion is overseen by the Centre for Disease Control (National Trachoma Surveillance and Reporting Unit *et al.* 2011).

The World Health Organization endorses the SAFE Strategy, which has been shown to be an effective tool in reducing blinding trachoma (Kuper *et al.* 2003; Roba *et al.* 2011). The components of the SAFE strategy are Surgery for trichiasis, Antibiotics to treat active infection, Facial cleanliness and Environmental improvements to sustain reduction of transmission. However, it is known that there are barriers to the uptake of the 'F' and 'E' aspects of the strategy as they involve behaviour change, and sanitation measures and environmental hygiene promotion are generally outside of the health care system (Montgomery and Bartram 2010; Wright *et al.* 2010). In addition, a lack of educational and promotional resources and standardised teaching about trachoma has been observed in Australia (Wright *et al.* 2010).

Lack of facial cleanliness is implicated in trachoma transmission (Lynch *et al.* 1994; West *et al.* 1995; Bailey and Lietman 2001; Schémann *et al.* 2002; Ejere *et al.* 2004; Khandekar *et al.* 2006; Ngondi *et al.* 2008; Bailie *et al.* 2012) and this is the key to its control:

...it is the critical final common pathway for the impact of all the other health environmental parameters on the one hand, and it is the pathway by which infection is spread from one eye to the other. (Taylor 2008, p. 117)

Despite significant environmental limitations such as overcrowding and the poor state of housing infrastructure (McDonald and Bailie 2010), face washing is an action that everyone can engage in to eliminate trachoma and reduce childhood infectious diseases.

The goal of eliminating trachoma through establishing clean faces as the social norm, as well as encouraging good personal, family and community hygiene practices, can be supported with health-promotion resources and strategies based on the SAFE

strategy. To this end a collaboration was formed by the Aboriginal medical service Katherine West Health Board (KWHB), the Centre for Disease Control (CDC) NT Department of Health and the Indigenous Eye Health Unit (IEHU), with funding from private benefactors. An extensive consultation with the Indigenous community and program stakeholders was held and a central role was played by the Ngumpin Reference Group (NRG) at KWHB. The NRG is a consultative group of Aboriginal Health Workers, community elders and members from seven communities who worked for 10 months to advise on the development of components, design and functionality of the resources. The final product was 'The Trachoma Story Kit', a comprehensive suite of clinical training and community health-promotion tools that are culturally appropriate and tailored for specific audiences in remote Indigenous community, clinic and school workplace settings to help locally based communicators promote clear and consistent SAFE strategy messages and services.

The KWHB is a community-controlled Aboriginal Medical Service in the Katherine region of the Northern Territory serving ~3200 Indigenous Australians from nine language groups. The seven main communities range in size from ~40 to 1500 people (Katherine West Health Board Aboriginal Corporation 2011). In 2009 the prevalence of trachoma in children aged 5–15 years in the wider Katherine region was 23%, and KWHB accounts for about half of this area (Taylor *et al.* 2009).

The present study aimed to assess the needs and capacities of staff members in clinics, schools and community workplaces to understand how to optimise health-promotion interventions for specific workplace factors and to establish trachoma elimination within a local context where there is strong engagement with local community members.

Methods

A knowledge, attitudes and practices (KAP) survey was undertaken with staff in three workplace settings of influence in remote communities. This approach was utilised for two purposes: to provide baseline data to compare with post-test data and to inform the developing trachoma-elimination health-promotion campaign using the Trachoma Story Kits in the KWHB region of the Northern Territory.

The IEHU received ethics approval from the Human Ethics Advisory Group at the Melbourne School of Population Health at the University of Melbourne in 2009 and the KWHB approved evaluating the program with paid Indigenous and non-Indigenous staff working in KWHB communities.

The one-page (KAP) survey with two open, two multi-choice and 13 closed questions was designed by the IEHU and approved by KWHB and CDC. Approval was given by KWHB to conduct the survey with Indigenous and non-Indigenous paid staff members in clinics, schools and community groups. The survey was pilot tested in one community and as a result the Likert Scale was changed to 'Yes', 'No' and 'Unsure' options as this was easier to administer in busy workplace settings. An authorisation letter from KWHB was printed on the back of each survey. The participation of staff in clinics was requested by KWHB management, but was not compulsory. Participation from school and community settings was voluntary. Identifying features

such as name, job title, sex, age, Indigenous status or other characteristics were not required. The workplace settings themselves were viewed as the target of the health-promotion intervention as remote community staff members move on from jobs frequently. Staff members of clinics, schools and community groups were selected as survey respondents because they were likely to have some influence in health and well-being issues in their remote Indigenous communities and to have observed everyday life in the communities. In all workplace settings there was a mix of Indigenous and non-Indigenous staff. As is common in remote communities, most staff members in schools, clinics and community workplace settings live in the community.

'Clinic' respondents included doctors, nurses, Aboriginal health workers and allied health, reception and clinic-support staff. 'School' respondents included principals, deputy principals, teachers, teachers' assistants and tutors. 'Community' respondents included allied health workers not based in a clinic and staff in children's services, playgroups and family-support programs, local government, environmental health and recreation programs.

The survey was administered by the KWHB Healthy Skin and Eye Coordinator and IEHU Health Promotion Officer between August 2010 and March 2011 before the roll out of Trachoma Story Kits and before training sessions with the new resources. A summary of the project's aims and objectives was explained to respondents. On two occasions in schools an interpreter translated the questions into the local language. Interpreters were colleagues of the respondents. No one was excluded because of language difficulties. The survey sought quantitative and qualitative data with 13 closed questions, two multi-choice and two open questions. Ten questions related to knowledge, three to attitudes and four to practice. Clinic staff, who undertake trachoma screening and treatment, were asked three additional closed questions.

Data were entered into a Microsoft Excel spreadsheet and categorised by workplace settings and community. Data were checked for accuracy, frequency distributions were used for closed questions and key themes were identified for answers to open questions.

Results

Seventy-two surveys were completed by respondents at the KWHB Katherine office and six remote communities from August 2010 to March 2011, with 67% (48/72) of respondents from clinics, 21% (15/72) from schools and 13% (9/72) from community workplaces.

Most respondents 88% (63/72) correctly defined trachoma, and most respondents had good knowledge in identifying actions to eliminate trachoma, including clinical treatment (25%), environmental (23%) and personal hygiene, and facial cleanliness (37%). Washing faces 'whenever they are dirty' is the behaviour change necessary to eliminate trachoma and this was identified by 75% (36/48) of staff in clinics, 60% (9/15) of staff in schools and 67% (6/9) of staff members in community settings. However, when asked whether 'it's normal for kids to have dirty faces', 38% (18/48) of clinic staff said 'yes', 33% (5/15) of school staff said 'yes' and 13% (1/8) of community staff said 'yes'.

Similarly, when asked whether 'it's normal for old people to have sick eyes or poor vision', 27% (13/48) of clinic staff, 13% (2/15) of school staff and 25% (2/8) of community group respondents said 'yes'.

Attitudes toward hygiene improvement were positive, with 96% (46/48) of clinic staff and 100% (8/8) of community staff stating that they would be comfortable talking to others about hygiene issues. Fewer school staff, only 73% (11/15), were comfortable in doing so. When asked if they were able to teach others about trachoma, 79% (38/48) of clinic staff and 100% (7/7) of community staff agreed they could do so. Only 53% (8/15) of school staff thought they could teach others about trachoma.

Approximately one-fifth of clinic (10/47) and community (2/9) staff members did not know that they worked in a trachoma-endemic region and one-third of school staff (5/15) were unaware of this. Although most clinic (43/48) and community (8/9) staff members knew that trachoma is contagious, only about half of school staff (8/15) knew this fact. Of respondents in the three settings, those in schools had less knowledge of trachoma, its prevalence, how it is transmitted and how to prevent it. These respondents also had less confidence in teaching about hygiene practices and trachoma prevention.

In relation to clinical knowledge and practice, less than half of clinic staff (46%, 21/46) knew enough about trachoma, four-fifths (37/46) could undertake a clinical exam to detect trachoma, and only half (23/46) were able to detect trichiasis.

The results of the closed survey questions are shown in Table 1.

Discussion

This research yields several findings relevant to understanding people's knowledge, attitudes and practice regarding trachoma elimination in remote Indigenous communities. A significant proportion of clinic staff did not know they were living and working in a trachoma-endemic area. Clinics are the most common source of child health information for parents and carers of young children at risk of active trachoma infection. Health clinic staff should know that they are living and working in a trachoma-endemic region. It is clear that clinic staff need greater knowledge of trachoma and increased clinical skills to conduct examinations for trachoma and trichiasis, and to more fully support trachoma-elimination programs. With high levels of clinic staff turnover, there may be a need for ongoing trachoma clinical training in endemic communities.

Trachoma screening is conducted annually in Northern Territory schools as part of the Healthy School Age Kids Check, yet almost one-third of school staff did not know trachoma was common in their community; this low level of awareness of endemic trachoma may have been due to high staff turnover in schools or that trachoma elimination programs are not involving schools in post-screening reporting.

Schools can be very dynamic and sometimes stressful environments, and they contribute to and influence community knowledge greatly. Asking schools to support community education could be invaluable in supporting trachoma-elimination programs as increasing community knowledge and awareness of trachoma in remote Indigenous communities is vital to meaningful engagement by communities in trachoma-elimination programs.

Table 1. Trachoma baseline knowledge attitudes and practice survey results 2011

	Yes (%)	No (%)	Unsure (%)
Is trachoma common in your remote Aboriginal community?			
Clinic (<i>n</i> = 47)	81	13	6
School (<i>n</i> = 14)	71	0	29
Parent/community (<i>n</i> = 9)	78	0	22
Can trachoma be spread from person to person?			
Clinic (<i>n</i> = 48)	90	6	4
School (<i>n</i> = 15)	53	20	27
Parent/community (<i>n</i> = 9)	89	0	11
Can people get trachoma from shared towels or blankets?			
Clinic (<i>n</i> = 47)	77	8	15
School (<i>n</i> = 15)	47	20	33
Parent/community (<i>n</i> = 9)	67	11	22
Can trachoma lead to blindness?			
Clinic (<i>n</i> = 48)	100	0	0
School (<i>n</i> = 15)	87	0	13
Parent/community (<i>n</i> = 9)	100	0	0
Is it true that it is simple to treat trachoma?			
Clinic (<i>n</i> = 48)	90	6	4
School (<i>n</i> = 14)	71	0	29
Parent/community (<i>n</i> = 9)	78	0	22
Would you know if someone has trachoma?			
Clinic (<i>n</i> = 46)	54	31	15
School (<i>n</i> = 14)	21	50	29
Parent/community (<i>n</i> = 9)	22	67	11
It's normal for kids to have dirty faces			
Clinic (<i>n</i> = 48)	38	56	6
School (<i>n</i> = 15)	33	53	14
Parent/community (<i>n</i> = 8)	13	87	0
It's normal for old people to have sick eyes/poor vision			
Clinic (<i>n</i> = 48)	27	73	0
School (<i>n</i> = 15)	13	73	13
Parent/community (<i>n</i> = 8)	25	75	0
I feel comfortable talking about hygiene with others			
Clinic (<i>n</i> = 48)	96	2	2
School (<i>n</i> = 15)	73	20	7
Parent/community (<i>n</i> = 8)	100	0	0
I am able to teach others about trachoma prevention			
Clinic (<i>n</i> = 48)	79	15	6
School (<i>n</i> = 15)	53	14	33
Parent/community (<i>n</i> = 7)	100	0	0
For clinic staff only			
I know enough about trachoma (<i>n</i> = 46)	46	50	4
I can flip eyelids to check for trachoma (<i>n</i> = 46)	80	9	11
I know how to find trichiasis (<i>n</i> = 46)	50	22	28

Encouraging facial cleanliness is at the core of sustainable trachoma elimination (Montgomery and Bartram 2010; Wright *et al.* 2010) and data on the prevalence of clean faces is collected during annual trachoma screening (Communicable Disease Network Australia 2006). Respondents were asked if it is normal for children to have dirty faces, both to elicit their observations of Indigenous children in remote communities and to gauge a general attitude of tolerance or acceptability of visible eye and nose secretions in Indigenous children.

A barrier for trachoma-elimination programs was found to be that many staff members in schools and clinics accepted dirty faces as normal in young children in their remote Indigenous community. Children do get grubby when they play, but it is not normal for a child to have continual eye and nose secretions on

their faces every day. Interestingly, most staff in community workplaces did not consider it normal for children to have dirty faces. This attitude may reflect their different norms on cleanliness, or perhaps they answered in a way they perceived the researchers might desire to gain social approval.

In keeping with the attitude of tolerance to children's dirty faces that was held by many school staff respondents in this study, normalisation of poor facial hygiene in children has been found elsewhere. Research into childhood infectious diseases in remote Indigenous communities has identified that community members consider nasal and purulent ear discharge to be normal (McDonald *et al.* 2009) and a national report on ear health found appropriate action sometimes is not taken by community members about ear discharge as it is often seen just a part of

childhood, especially for Indigenous children (Cultural and Indigenous Research Centre Australia 2010).

Success of the 'F' component of the SAFE strategy depends on behaviour change. People have to register that a child's face is dirty, then understand that nose and eye secretions pose a great risk of spreading trachoma. Finally, they must take action to change the risky behaviour. The normalisation of dirty faces is itself a risk factor for trachoma and other preventable childhood infections.

Teachers and other school staff play a critical role in educating children in good health and hygiene practices to reduce the transmission of trachoma. Many schools use their health and well-being curriculum to address health and social issues vital to remote Indigenous communities. Dental programs (Australian Government 2011) and the Breathe Blow Cough strategy (Western Australia Aboriginal Education Directorate 2002) for ear health are common in many remote schools. The simple inclusion of face and hand washing to prevent the spread of trachoma and other infections is a practical initiative.

An enabling factor for trachoma-elimination programs is that the majority of respondents agreed they could talk to others about hygiene. This indicates a positive attitude from clinic and community staff members toward addressing hygiene practices, although the lower response from school staff suggests they may be less comfortable in directly discussing hygiene issues. This could be due to competing curriculum priorities and time limitations, or staff may not feel adequately trained or experienced to teach hygiene in a remote Indigenous community.

In general, most people would find discussing hygiene improvement a sensitive issue in any setting and doing so in an Indigenous community is likely to have far greater complexity for several reasons. Since colonisation, Indigenous people have experienced great harm from government policies and practice, including being asked to change behaviours for health or social benefits. Not surprisingly, discussing hygiene improvement in remote Indigenous communities could be viewed as 'victim blaming' or disrespectful of local culture (McDonald *et al.* 2009).

Another illustration of the importance of using the right approach is the finding from formative research for the 'No Germs on Me' hand-washing campaign. This found the commonly used small-group and one-to-one methods of health education about infectious disease in Aboriginal children in remote communities may have inadvertently caused embarrassment to individuals, families or households. Consequently, past approaches to try to improve hygiene may have been considered coercive, having the unintended consequence of creating resentment and resistance to health-related behaviour change messages. The research supported use of social marketing to create demand for improved living conditions and to promote hand washing with soap to reduce high rates of infectious disease in remote Indigenous communities (McDonald *et al.* 2011). Personal hygiene has also been addressed directly by the Northern Pride Rugby League Club by utilising the strength and passion for Rugby League in far north Queensland communities. The 'Take Pride in Personal Hygiene' program is based on the 'No Germs on Me' campaign resources, and in partnership with Cairns Public Health Unit, high-profile players are powerful role models working with

locally employed environmental health workers in schools (Take Pride Program 2012).

Despite numerous barriers to good hygiene practice, many Indigenous people in remote communities have been 'found to have a general desire to improve their children's health and for a clean and healthy image among community members' (McDonald *et al.* 2009). Likewise, the enabling attitude of being prepared to talk about hygiene issues found in the KAP study is a positive start. However, community-based motivation and modelling for success (amongst other 'levers' for behaviour change) to promote face washing behaviour change is required (Hill and Dixon 2010).

It must be noted that in remote Indigenous communities overcrowding, poor housing and non-functioning health hardware significantly limit hygiene improvement and affect the spread of infection (McDonald and Bailie 2010). Yet, improved housing infrastructure alone has been found to have limited health benefits, in that it does not significantly reduce crowding or improve the general community environment or health-related behaviours (Bailie *et al.* 2012).

Sustained reduction of trachoma requires behaviour change in personal and community hygiene practices. Hygiene health promotion and social marketing communication strategies could encourage clean faces as the social norm in a similar manner that hand washing with soap to reduce infectious diseases has been promoted in the 'No Germs on Me' multimedia campaign in the Northern Territory (McDonald *et al.* 2011).

Strengths and limitations of the study

The one-page KAP survey was designed for easy participation of staff in busy remote clinics, schools and community workplace settings. Good organisational support that increased the participation of respondents in remote communities was provided by KWHB. There were 72 workforce respondents from a general population of 3200 spread over 162 000 km². This good response was enhanced by delivering surveys in person, flexibility with suddenly changing schedules and limiting demands on staff time.

A limitation of the study is that data were collected from August to March and this extended time may have resulted in some respondents being exposed to the health-promotion resources. However, due to holidays, the December to February work activity in KWHB is quiet, with low staffing levels and a lack of access to communities during the wet season.

There was also the possibility of social desirability bias influencing some respondents for attitude value-laden questions. In particular, the question 'Is it normal for kids to have dirty faces?', which aimed to ascertain if respondents accepted nasal and ocular discharge as an everyday occurrence, may have been influenced in this way. Asking specifically about purulent discharge may have been a clearer question, especially as this concept was central to the study. This issue was not raised during the pilot testing of the KAP study. This question raised much discussion as some respondents struggled with the notion of what was meant by 'normal' and whether it means 'common', 'acceptable' or 'customary'. Some respondents reported that dirty faces including nasal and ocular secretions were the reality in the remote Indigenous community setting but they didn't

judge this to be normal and healthy. This issue could have been further discussed through interviews or focus groups, which were however outside the scope of this phase of the evaluation.

Conclusions

This study has identified several ways to strengthen trachoma health-promotion initiatives in seven remote Indigenous communities in the KWHB region of the Northern Territory. This understanding can contribute to improvements in trachoma health promotion in the KWHB region and may be of value in trachoma elimination across the wider Northern Territory.

In particular, general awareness of trachoma should be increased, plus clean faces and holistic hygiene practices encouraged. Staff based in health, education and community settings indicated they are willing to play a fundamental role in the delivery of hygiene health promotion. Clinic and community staff are able to teach about trachoma elimination, although staff in school settings may require additional support.

Health-promotion approaches for trachoma awareness and elimination based on the strengths of remote Indigenous communities, such as extended family and a strong commitment to community and culture, could be enhanced by social marketing with multimedia such as television, radio and print media. Social marketing uses insight into what motivates the target audience and the benefits and rewards for behaviour change and it has a broad audience reach across remote communities (Griffiths *et al.* 2008). These strategies could enhance the elimination of trachoma by encouraging washing faces whenever they are dirty as a part of holistic hygiene. They illustrate a simple 'call to action' that is within everyone's control.

Conflicts of interest

None declared.

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