Remote Indigenous Australians with cataracts: they are blind and still can't see

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ABSTRACT

- Aboriginal and Torres Strait Islander people are three times more likely than non-Indigenous Australians to report vision loss due to cataracts, but are four times less likely to have cataract surgery.
- To increase access for Aboriginal and Torres Strait Islander people to cataract surgery, we need to identify the barriers to current services and trial strategies to overcome these barriers.
- Barriers to cataract surgery exist at the health service, community and individual level.
- Health service factors include infrastructure, cost, and provision of interpreters, escorts and transport.
- Community factors include social support, perceptions about the success of surgery, and beliefs about the causes of cataracts.
- Individual factors include ignorance that cataracts can be cured, fear of surgery or poor outcome, and comorbidity.
- Strategies proven to increase uptake of cataract surgery in other countries could be trialled in remote Australia.

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Aboriginal and Torres Strait Islander people are three times more likely than non-Indigenous Australians to report vision loss due to cataracts, but are four times less likely to have cataract surgery.[1] This is despite evidence that cataract surgery has a beneficial effect on visual acuity and quality of life.[2]

The reason for the increased prevalence of cataracts in Indigenous Australians is not known for certain. Relevant risk factors are trauma, age-dependent relationships between cataract (and subsequent mortality) and lower socioeconomic group, smoking, alcohol consumption and increased exposure to sunlight and ultraviolet light.[3-5] Impaired glucose tolerance and diabetes[6] are risk factors for cataracts, and cataract extraction may be required so that diabetic retinopathy can be treated. The high incidence of diabetes in remote Indigenous people,[7] and recent gains in life expectancy[8] mean that cataract surgery is an increasing issue in remote Australia.

More services are urgently needed, but the reasons for Indigenous Australians' low rates of cataract surgery are complex. In this review I discuss the barriers to cataract surgery and make recommendations for action.

Methods

Two researchers searched the electronic database MEDLINE 1966–2006 using the medical subject headings *eye*, *cataract*, *ophthalmology*, *vision*, *Oceanic ancestry group*, *qualitative research*, *health services accessibility*, and *delivery of health care*, and the key words *Indigenous*, *Aborigin$*, and *blind*. We searched the Australian Government website, the Australian Indigenous Health*InfoNet*, the *Medical Journal of Australia*, the *Australian and New Zealand Journal of Ophthalmology*, *Clinical and Experimental Ophthalmology* and the *Community Eye Health Journal* for relevant articles. Each researcher independently read the titles and available abstracts. The resulting articles were read and assessed for their relevance. The reference lists of these articles were hand searched for further relevant articles.

Most articles on the barriers to cataract surgery come from large surveys in developing countries. This literature is relevant to remote Indigenous Australians whose morbidity and mortality statistics and access to health services resemble those experienced in developing countries. Indigenous Australians live in a developed country, but have blindness rates of 1% (compared with 0.1% blindness for non-Indigenous Australians), similar to rates in the populations of Indonesia, Nepal and Zimbabwe.[9] Similarly, Indigenous Australians in remote communities maintain their cultural values of responsibility to family and community, rather than focus on the individual. Combining the literature from Australia and developing countries may reveal clues about the uptake of cataract surgery in Indigenous Australians.

The barriers to cataract surgery relate to health services, the community and the individual.

Health services barriers

Infrastructure and systems

The Australian health ministers have agreed that "All Australians should have equitable access to appropriate eye health care when required".[10] To ensure equity, waiting lists are created. But lists work against those for whom access to communication and transport is unreliable. Being put on a waiting list can mean that other life priorities take precedence on the eventual date of surgery. Many allocated theatre slots are wasted. Conversely, waiting lists mean that care cannot be provided opportunistically when patients are in a regional centre for other reasons.

The primary and secondary care systems and government bureaucracy designed to assist eye health can inadvertently become a barrier to its delivery. In a discussion paper from the Koori Health Research and Community Development Unit, Kaplan-Myrth criticised Aboriginal blindness prevention policy as echoing colonial practice; she argued that Indigenous Australians should shape their health services, not westernised specialists.[11]

In New South Wales, collaboration between the Aboriginal community, researchers, health care funders, health care providers and educators has increased access and uptake of eye services in Aboriginal Medical Services.[12] This service is well used, but cannot provide surgery.

Cost

In developing countries, cost is the major barrier to cataract surgery.[13-16] Cataract surgery is free in public hospitals in Aus-

tralia, but the indirect costs of surgery, including the carers' cost of food, transport and loss of income,[17,18] are not. How much cost deters remote Indigenous Australians needing cataract surgery is not known.

Transport and distance from a cataract centre

The utilisation of eye care services is lower in rural Victoria than in metropolitan Victoria,[19] but there is no difference in cataract surgery rates.[20] The distances involved in remote Australia exceed those experienced by rural Victorians.

International experience is that uptake of cataract surgery is lower in rural and remote areas than in urban areas.[18] Geographical distance and transport[18] are cited as barriers for patients and their families;[16] if surgery is performed, distance remains an issue for accessing follow-up.[21]

Interpreters, escorts and transport

In Victoria, non-English speakers used eye services less.[19] Interpreter services for Indigenous patients are patchy, despite English being the fourth or fifth language for many. Evidence shows that communication problems with Indigenous people extend beyond simple language issues.[22]

In central Australia, patient travel services only pay for transport if travel is more than 200 km and an escort depending on the clinical condition. Is this reasonable for a person who cannot see?

Consent issues

Patients, families and staff all reported a lack of information as a barrier to cataract surgery in The Gambia.[16] The effect of information about cataract surgery is mixed. In most patients, information leads to a reduction in fear,[23] but some prefer not to know.[24] Increasing knowledge does not necessarily increase uptake of cataract surgery: "Physicians walk a tightrope between informing patients sufficiently and frightening them".[25] We need to find the optimum level of information to aid remote Indigenous Australians in making informed decisions about cataract surgery.

Ophthalmologist

Health professionals said African Americans' knowledge and attitudes were barriers to cataract surgery. In contrast, the patients rated vision and eye care as important and their perceived barriers were trusting and communicating with the doctor, and cost.[13] Not being comfortable with the eye doctor can be a barrier,[21] and counselling by the ophthalmologist affects satisfaction with quality of care more than other eye health education.[26]

Community: role in society and expectations

Family influence

Social support is an important precondition to surgery.[18] Fears of cataract surgery expressed by the family and community[15,16] are barriers to cataract surgery, as are family dynamics[27] if the dominant member does not see the need for eye care.[19] We need to find out what the relevant family dynamics are for Indigenous Australians facing surgery.

Community influence

Remote Aboriginal Australians have a 28% chance of posterior capsule opacification within 5 years of cataract surgery.[28] Seeing others "going blind" again following surgery — albeit from a treatable cause — may affect fellow community member's enthusiasm. In India, the community misperceived continued poor vision after an operation as an operative failure, when the real cause was macular degeneration or glaucoma.[15]

Culture and beliefs

The key to health and wellbeing is a balance and harmony with one's culture. Indigenous people have told me that the dust and environment or people "being sung" cause eye problems. It may be hard to trust that an operation can cure a problem created by these causes.

Similarly, societal beliefs that cataract is just part of old age or God's will act as barriers to cataract surgery.[15,21] A mix of alignment of several factors is needed for surgery to go ahead.[29]

Individual

Ignorance

Estimates from India are that about 50% of those blind from cataracts did not know they could be cured,[18] and many did not know where they could get treatment.[21] It is not known how many Indigenous Australians are in a similar situation.

Stoicism

Cataracts grow slowly. Gradual loss in vision is less noticeable than sudden loss. People adapt and manage despite poor vision and literally do not see the need for surgery.[15,16,21,28] Surgery becomes a more acceptable option as blindness from cataract worsens.[14]

Fear

Fear is a significant barrier to cataract surgery. There can be fear of the operation,[30] fear of a poor outcome (ie, that the operation will damage the eye),[15] fear that a check-up would show a real problem,[21] and fear of death.[15,27]

In some instances, this fear is justified from having seen a bad outcome.[15] The Western Australian data on endophthalmitis show a higher incidence for remote community people.[31] Watching the experience of others[28] affects the level of personal fear.[16]

Beliefs

Personal beliefs are often intertwined with societal beliefs and so barriers noted at the community level also affect the individual. The effect on individuals of isolation from their land when having cataract surgery is assumed,[32] but needs further exploration.

Demographics

In Victoria, there were no differences in cataract surgery rates according to age, ethnicity, health insurance status, occupation or education level.[20] Similarly, the Blue Mountains Eye Study showed no statistically significant difference in the incidence of cataract surgery for 5 years for any of the occupational categories.[33] However, more recent data from Western Australia showed increased surgery rates for female and older patients, and lower rates for socioeconomically disadvantaged people and rural resi-

dents.[34] The most advantaged underwent 9% more surgery than the most disadvantaged. These differences demonstrate the increasingly two-tiered Australian health system, with more privately provided cataract surgery in urban areas.

Other illness

Experience from overseas is that some patients want eye check-ups, but other medical problems prevent them from going.[21] The high morbidity experienced by remote Indigenous Australians creates similar dilemmas, and the waiting list system means that patients accessing care in a regional centre for a comorbid condition cannot opportunistically seek cataract removal.

Useful interventions

There are two overseas initiatives to increase the rate of cataract surgery that may work in remote Australia: supported, opportunistic surgery, and aphakic motivators.

In eastern Africa,[35] surgery rates increased when:

- the decision to do surgery was made on the community site;
- the examiner on site had enough training to differentiate causes of visual impairment;
- the patient was transported to hospital on the day of diagnosis;
- the patient was transported to and from hospital;
- the team included a dedicated counsellor and program manager;
- there were no hidden charges;
- there was no fee for examination at the site;
- fixed sites were visited regularly and advertised, and never cancelled; and
- the community program was closely coordinated with hospital services.

A study in Aravind, India, compared the cost-effectiveness of strategies to reduce the barriers to cataract surgery in 10 villages with 10 control villages.[36] The interventions were an aphakic motivator (a person who had had a successful cataract operation), a basic eye health worker, a screening van, or a mass media campaign, and either fully funded or partially funded (excluding costs of transport or food) surgery. The most effective, but more costly, intervention was fully funded surgery and an aphakic motivator. Second best, and less expensive, was a mobile screening van. Aphakic motivators have subsequently proved effective in rural Malawi.[37]

The higher risk of endophthalmitis in remote Australians[31] and high morbidity from other illnesses demand that surgery be performed in a sterile hospital environment. Cataract camps work effectively in developing countries, but anecdotal evidence is that this model had mixed results in central Australia.

Conclusion

Cataracts are a significant cause of preventable blindness in the remote Indigenous population. A comprehensive strategy is needed,[38] and the National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss is welcome. Our approach must be comprehensive from the patients' perspective as well as the providers'. The Box summarises the recommendations for action. The Fred Hollows Foundation is trialling the second recommendation of a fully funded and supported model of care in partnership with the Northern Territory and Commonwealth governments in central Australia.

Recommendations for action

- Patient-centred hospital service: designated slots for cataract surgery for Indigenous patients. Slots allocated according to community eye visits, people available for opportunistic care, and the waiting list.
- Fully funded and supported services: this includes transport, food for the patient and carer, interpreter, counselling/liaison services, program management, and a visionary.*
- Research, grounded in Aboriginal and Torres Strait Islander communities, into the best ways to overcome the information, fear and health belief barriers to allow Indigenous Australians to make informed decisions about cataract surgery.

*Visionary: a modern equivalent of an aphakic motivator. Cataract surgery no longer leaves people aphakic. ◆

Removal of external barriers by the provision of accessible and affordable surgery reveals other fundamental attitudinal barriers among the blind population.[27] "People who do not use eye services know why they do not seek treatment. It is therefore critical that providers ask and listen to the views of their community".[39]

Eye services in Australia could trial models that have been successful in developing countries. The literature suggests factors that could explain the underutilisation of cataract surgery in the Indigenous population. Research is needed to explore these factors to reduce the preventable burden of blindness of Aboriginal Australians.

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Competing interests

None identified.

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