

★ Understanding eye care through the experiences of Aboriginal people in the NT

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Background

Issues around accessibility of primary and tertiary eye care, continue to support eye health inequity between Indigenous and non-Indigenous Australians. Structural factors concerning accessibility of eye health are well researched. However little is known about the factors that influence patient agency and decision making in eye health, how these factors determine accessibility, and the different social determinants which shape them. We present some of the findings from the Patient Experience in Eye care study which aims to understand issues around accessibility and equity of eye care for Indigenous people living in remote locations in the Northern Territory, from their own perspectives.

Methods

We collaborated with Aboriginal Community Controlled Health Services (ACCHS) in two Top End communities in the Northern Territory, to undertake semi-structured interviews with patients living with diabetes about their experiences accessing eye care. Interviews were conducted by Community Based Researchers (CBRs) (RS, FH, GB). Interviews conducted in Aboriginal languages were translated by a trained interpreter (GB). All participants were current ACCHS patients (>40 years), with a recorded diagnosis of diabetes. The first author (AY) conducted a preliminary analysis in tandem with data collection, to determine theoretical saturation using grounded theory and qualitative analysis software NVivo 10. The results of these analyses were discussed among the authors including the linkages to social determinants, and how barriers could be overcome and enablers strengthened within the existing health system context.

Results

Our findings are focused on **a)** the barriers which prevent good eye health and the social determinants that shape them, and **b)** key enablers that assist and enhance good eye health outcomes. The barriers we have identified and will discuss include: poor knowledge of diabetes related eye diseases and prevention, fear of surgery, distrust of mainstream services, poor diabetes management, access to comprehensive chronic disease care, individual responsibility of health and healing, social and cultural obligations, and mobility/patient management. The enablers we have identified include: accessible and regular primary eye care delivered by ACCHSs, strong patient support services (including transport), enhancing preventative eye health knowledge among the community through **a)** accessible and understandable health promotion materials and **b)** accessible and comprehensive chronic disease care, and spreading positive eye surgery stories through community outreach.

Recommendations

- Health promotion materials targeting knowledge of diabetic eye disease is needed in both communities. Materials should be visual (pictures or videos) and targeted at whole family groups as well as the individual. In Community B materials should be in the local language of Kriol.
- Preventative primary eye checks should be incorporated into routine chronic disease care, to reduce the number of appointments and clinics a patient has to attend. Chronic care consultations should include a patient education component around diabetic eye disease, to help bridge the gaps identified in our study.
- Address issues of access to chronic disease care for men, including providing chronic disease care at a location where men feel comfortable such as the men's only Primary Health Clinic.

- Provide an opportunity for patients who have undergone successful cataract surgery to share their experiences with those who need surgery. This could be facilitated as a community focus group. Spreading positive stories will help reduce fear and distrust.
- Further research needed: (a) diabetes management and access to affordable fresh fruit and vegetables, (b) indirect costs of travel and available support systems for patients accessing care outside their communities.

Presenters

Aryati Yashadhana is a PhD candidate at the University of New South Wales through the Vision CRC, and a Research Assistant with the Brien Holden Vision Institute, Public Health Division. Her PhD study is exploring how Aboriginal patients experience eye health care in the Northern Territory (Katherine & South East Arnhem Land) and New South Wales (Western), and how this is linked to clinical outcomes, social determinants and health equity. Aryati has a background in international development studies, with experience working in cross-cultural, participatory and qualitative research with marginalised communities in Australia and abroad.

Ruby Stanley is a Wakka Wakka woman from the Dawson Valley Region in Queensland. For the last 50-odd years she's lived and worked around different communities in the Top End of the Northern Territory—as an Aboriginal Liaison Officer and Aged Care Coordinator. Ruby has been involved with improving health services, including education and knowledge of nutrition among the elderly. She helped establish aged care hostels in several communities in the Top End. Ruby currently sits on the board of Wurli-Wurlinjang Health Service, and the North Australian Aboriginal Justice Agency. She continues giving back to the community by working towards improving the lives of Aboriginal people for a better future.