

Understanding lived experiences of Aboriginal people with type 2 diabetes living in remote Kimberley communities: diabetes, it don't come and go, it stays!

Why was this study done?

Aboriginal people have been living with type 2 diabetes (T2D) for a number of years, but what does this mean for Kimberley remote communities? We wanted to talk with Aboriginal people from remote communities, to listen to their stories about what it is really like to live with diabetes. This included exploring: How do they manage their diabetes? What kind of medicines they take? Who supports them? What is needed to assist them to look after their diabetes better?

How was this study done?

Two Kimberley Aboriginal Medical Services (KAMS) remote community clinics were part of this study. The team were Aboriginal Health Workers/Practitioners (AHW/P) and doctors from both clinics, KAMS research staff (including the KAMS Aboriginal Research Officer), and WA Country Health Service Physicians. Everyone worked together on what questions would be asked, and how to ask these questions.

In total, 13 Aboriginal adults agreed to be part of this study and chose to be interviewed at the clinic, in the community or at their home. The AHW/P yarning with patients, the non-Indigenous clinicians listened, recorded the interview and wrote the story down. Patient medical records were also looked at to see what diabetes medicines they were prescribed, and to find out how many adults in the communities had T2D.

What did we find out?

Three (3) out of 10 adults in the communities had T2D.



The 13 patients interviewed had lived with T2D from 9 to 33 years. Key areas from the interviews included: the need for culturally appropriate education and resources that use pictures; importance of relationships with healthcare staff; lifestyle management advice that takes into account local and cultural factors; and the involvement of Aboriginal community members and families in support roles.

These stories helped us to make recommendations for the clinics, family, community and other service providers to come together to improve the care of patients living with T2D. The study team also gained skills from working with each other and yarning with patients.

Recommendations for action

Improve clinic based education: AHW/P should be the first point of care for patients with T2D to provide ongoing support, to work with patients to assist them to better understand what diabetes is, to be there when a patient is first told they have diabetes, to ensure they know what medicines they need to take and why, and any potential side-effects, and to explain any medicine changes. Resources that use pictures were requested to explain medicines, symptoms and how to care for themselves i.e. wound/foot care.

“felt a bit of a shock. ‘Cos I have always been active ... that sort of knocked the wind out of my sock” (patient).

“It didn't really hit me ‘til I started watching them pictures” (patient).

Improved clinic support: ensure everyone has access to point of care HbA_{1c} testing (measures sugar levels over a long period). Similar to what we found when interviewing young Aboriginal people in Derby, patients valued good communication and relationships with clinicians, and identified that long term, gender matched staff were best placed to provide this support. Clinicians should yarn with patients before discussing medical information, and in some cases they should do home visits to increase patient comfort and communication. AHW/P should have on-going meetings with clinicians to discuss how to provide patient support and advice; each patient should have an individualised management plan.

“We need someone who will sit with us on a weekly basis to talk to us. Not just fly in and fly out” (patient).

“Shocked at how differently the participants responded to the AHW-led yarning approach to interviews compared with clinic consultations. They were so open and honest” (non-Indigenous doctor).

Clinic-based intervention to improve use of diabetes medication: patients should be able to have clinic staff assist them with their weekly diabetes injection preparations (eg exenatide); and encourage culturally safe yarning for patients to share their story of how they are feeling and how their body is coping with their medication.

“There have been a lot of changes in my medications from month to month... it’s just tiring me out” (patient).

Clinic and community interventions to improve lifestyle modifications and self-management: provide a place for patients to check their own blood sugar levels. The council, community and local store should work together to provide fresh affordable food that is appropriate for people with diabetes. AHW/P should take patients to the local store to show which foods are good for people with T2D. Diabetes cooking classes should use food that is available locally. Elders and AHW/P should work together to assist patients to be active: go walking, hunting, fishing and share knowledge of traditional healthy living.

“People tell us what you’re supposed to eat and what you’re not supposed to eat but you gotta try and go and find it. There’s nothing there in the shop” (patient).

“I’m also learning off the old people how they do it” (patient).

Improved family and community support: when a patient first finds out that they have T2D, their family should be provided with information (if the patient asks for this) about diabetes, medicines and a care plan. Elders and AHW/P should run male and female diabetes support groups, where everyone can share information and stories, and cook diabetes group meals. There should be whole community information sharing on diabetes.

“There’s no support, there’s nothing. . . no programs here for well-being” (patient).

“Sometimes when you talk to family and friends they think that diabetes is just an ordinary little thing that comes and goes and I like to tell them it don’t come and go, it stays!” (patient).

“I was not supportive of it like I could have been. Diabetes isn’t a quick fix. It’s an ongoing daily struggle” (AHW/P).

“Gets you more understanding. You learn a lot from asking them questions” (AHW/P).

Further collaborative research: research projects should make sure that Aboriginal people are involved in the interviews (preferably female to female and male to male), which can be done at the participant’s home or another place around the community, not just at the clinic. Local Aboriginal people should be investigators on research projects that involve their community, to assist with all the stages of the research (eg overall design, developing questions, meeting and yarning with participants and looking at what stories were collected, and what they mean), to fully understand what community members’ needs are and what they are saying.

“...while we were experts in our own field, we were not the experts in the room . . . We had to challenge our own ways of knowing and understanding” (non-Indigenous researcher).

We will continue to work with communities, patients and clinics to help improve the experience of Aboriginal people living with diabetes.

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