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


AKimberley Regional Physician Team, Western Australia Country Health Service, PO Box 62, Broome, WA 6725, Australia.
BKimberley Aboriginal Medical Services Ltd, PO Box 1377, Broome, WA 6725, Australia.
CThe Rural Clinical School of Western Australia, The University of Western Australia, PO Box 1377, Broome, WA 6725, Australia.
DCorresponding author. Email: sarah.straw@health.wa.gov.au

Abstract. This study aimed to explore the lived experiences of Kimberley Aboriginal people with type 2 diabetes managed by remote Aboriginal Community Controlled Health Services using phenomenological analysis. Semi-structured interviews formulated by Aboriginal Health Workers, researchers and other clinicians were used to obtain qualitative data from 13 adult Aboriginal patients with type 2 diabetes managed in two remote communities in the Kimberley. Together with expert opinion from local Aboriginal Health Workers and clinicians, the information was used to develop strategies to improve diabetes management. Of 915 regular adult patients in the two communities, 27% had type 2 diabetes; 83% with glycated haemoglobin A1c >10%. Key qualitative themes included: the need for culturally relevant education and pictorial resources; importance of continuous therapeutic 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. Recommendations to improve diabetes management in the remote communities have been made collaboratively with community input. This study provides a framework for culturally relevant recommendations to assist patients with diabetes, for collaborative research, and for communication among patients, Aboriginal Health Workers, community members, researchers and other clinicians. Interventions based on recommendations from this study will be the focus of further collaborative research.

Additional keywords: Aboriginal Health Worker, community control, culturally appropriate, management, qualitative research, three-way learning.

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Introduction

The Kimberley region has the highest proportion of Aboriginal residents in Australia (Department of Health Western Australia 2013), with many living in remote Aboriginal communities where attachment to land, traditional culture, family and community is strong. Over 30% of Kimberley Aboriginal adults have type 2 diabetes mellitus (T2DM) (Department of Health Western Australia 2014). The management of T2DM is a long-term health priority for Kimberley Aboriginal Community Controlled Health Services (ACCHS).

While ACCHS can provide sustained high-quality care (Stoneman et al. 2014), T2DM remains a significant contributor to morbidity and mortality. It accounts for 7.9% of Aboriginal and Torres Strait Islander deaths, compared with 2.6% of non-Indigenous deaths, and is a significant contributor to the 9.5- (female) to 10.6- (male) year life expectancy gap (Australian Institute of Health and Welfare 2015). Aboriginal and Torres Strait Islander people are diagnosed at a younger age, have lower diabetes-related quality of life, higher mortality at a younger age, higher glycated haemoglobin A (HbA1c) levels, lower rates of insulin use and lower rates of self-monitoring compared with non-Indigenous Australians (McDermott et al. 2004; Davis et al. 2007).

Several factors influence how Aboriginal people understand and manage their diabetes, including effects of colonisation and dislocation from Country, lack of trust in non-Indigenous health staff with limited understanding of Aboriginal culture, and fragmented care in remote clinics (Webster et al. 2017). This is exacerbated by low socioeconomic conditions, including overcrowding, poor access to nutritional produce and
What is known about the topic?
- There is high prevalence of diabetes-associated morbidity and mortality in remote Aboriginal communities. Community and Aboriginal Health Worker involvement in research, planning interventions and health provision can maximise cultural appropriateness and improve outcomes.

What does this paper add?
- Perspectives from Aboriginal participants, Aboriginal Health Workers, researchers and clinicians form a framework for recommendations to guide intervention to improve diabetes management in multiple aspects, as well as to inform further collaborative research.

undervaluing of traditional bush medicine practices (Hudson 2010; Sinclair et al. 2016).

Diabetes management in remote Kimberley communities is provided by clinics staffed by local Remote Area Nurses (RANs) and Aboriginal Health Workers (AHWs), with minimum twice-weekly visits by Kimberley-based GPs and regular visiting schedules for Kimberley-based physicians, diabetes educators, dietitians, podiatrists and optometrists. Pharmacotherapy is based on a standard drug list (WA Country Health Service Government of Western Australia 2018) of medications widely available in the region. A combination of oral hypoglycaemic agents (OHAs) (predominantly gliclazide, metformin, sitagliptin), and injected insulin and exenatide are used.

In this population, satisfaction with treatment and understanding of challenges in management are not likely to be reflected in blood glucose measurements or through checklist approaches familiar to health professionals (Burridge et al. 2016). This biomedical approach to medicine is often in juxtaposition to the family-centred approaches valued by Aboriginal communities. For interventions to be most culturally appropriate, they need to be community driven, involve Aboriginal leaders and focus on two-way capacity building between healthcare providers and Aboriginal community members (Durey et al. 2016; Webster et al. 2017).

This study aims to explore lived experiences of Aboriginal people with T2DM in remote communities, linked with feedback from AHWs, clinicians and researchers, to identify key issues and recommendations for improving diabetes management and further collaborative research.

Methods
This report was created and operates within a community-based participatory research approach (Israel et al. 2001), which has brought community and academic worlds, as well as Indigenous and Western methodologies, together.

Developing local research capacity and knowledge about diabetes
The research team consisted of Kimberley-based clinicians who either lived in (AHWs), visited each week (GPs), or provided outreach services (physicians) to the two communities, and Kimberley-based researchers (including an Aboriginal researcher). A team workshop was held to develop the research protocol and teach skills in diabetes management and qualitative research. The senior researcher led discussion on conducting research, the doctors and diabetes educators provided education on diabetes, and Aboriginal team members provided cultural education and ensured that the research protocol was culturally safe and relevant.

A phenomenological approach (Giorgi 2012), using yarning in semi-structured interviews (Bessarab and Ngandu 2010), was used to elicit a participant-led narrative, exploring experiences of having diabetes, including how it affected their life. The yarning methodology is framed on the development of rapport between the participant and interviewer that allows for respectful and robust exploration of the research topic. The Aboriginal team members guided the development of culturally appropriate interview questions (Appendix 1).

Participants and interview procedure
Aboriginal patients aged over 15 years with T2DM managed in two remote clinics operated by an ACCHS, Kimberley Aboriginal Medical Services Ltd (KAMS), were eligible to participate in the study. Maximum variation sampling (Palinkas et al. 2015) by treatment modality was used to ensure that participants were representative of the range available (e.g. insulin, exenatide, OHAs). Aboriginal clinic staff invited eligible community members to take part in the study. Participants were de-identified and given a unique study identifier (ID 1 – ID 13).

AHWs from the two communities conducted interviews from 15 May to 20 July 2017. Interviews were conducted in English, with further explanation or response given in local language if required, which was translated by AHWs. Another research team member attended interviews to transcribe and assist in audio recording. The scribe checked details with the interviewer and interviewee at the conclusion of the interview to ensure transcription accuracy. Interviews were conducted in clinic rooms, community spaces or participants‘ homes, depending on participant preference.

Qualitative analysis
Data from interviews were transcribed into Microsoft Word documents (Microsoft Corporation, Redmond, WA, USA). The transcripts were reviewed as a whole and then combined into a textual database in Microsoft Word 2007. The focus of thematic analysis was to describe the phenomenon of diabetes diagnosis, management and education, with segments of text coded appropriately. The first author conducted the initial coding of the transcripts, which were further refined by another author (J. V. Marley). The data analysis workshop involved most members of the team, with Aboriginal team members guiding interpretation of the data. As meanings became known, we reflected on the whole database. During the preparation of the report to the participating service, a Microsoft PowerPoint presentation was used to go over the detail contained within the report with all of the AHWs involved in the project. Changes were made based on their recommendations to ensure accuracy, relevance and cultural appropriateness.
Reflections on the research process

Feedback from AHWs was obtained regarding the effect of the project on their knowledge and skill in diabetes management and qualitative research. Non-Aboriginal team members provided reflection on what they had learned regarding communication and improving care for Aboriginal patients. Feedback was obtained by written surveys and informal discussion.

Audit of clinical data of patients with T2DM in two remote communities

The audit included Aboriginal and Torres Strait Islander patients seen at the two clinics who had met eligibility criteria; confirmed T2DM based on HbA1c ≥48 mmol mol⁻¹ (6.5%), age >15 years and being regular patients of either participating clinic. Patients were considered ‘regular’ if they had three or more visits to that clinic recorded in a 24-month period before 21 July 2017 (Australian Institute of Health and Welfare 2011).

Data were extracted on 21 July 2017 from the MMEx web-based electronic health record (ISA Technology, Perth, WA, Australia) and transferred into Microsoft Excel 2007. Demographic details, diabetes medications and date of diabetes diagnosis were extracted. Analysis of the audit data was descriptive. Recommended targets were based on the Royal Australian College of General Practitioners guidelines (The Royal Australian College of General Practitioners 2016).

Ethical and community approval

The project was supported by the ACCHS for the communities involved (KAMS), council members and elders from each community, and the Kimberley Aboriginal Health Planning Forum Research Subcommittee (Reference 2017–003). Ethical approval was obtained from the Western Australian Aboriginal Health Ethics Committee (Reference 760). All interviewed participants were provided with verbal and written study information, and provided written informed consent. Individual consent was not required for the data audit. A report including the recommendations from the community has been presented to KAMS.

Results

The overall clinical characteristics of audited patients with T2DM are shown in Table 1. Over one-quarter of patients within the communities had been diagnosed with T2DM, and most of them did not meet the glycaemic control target (HbA1c ≤7%). The 13 interviewed participants had a duration of diabetes from nine to 33 years. Table 2 shows participants’ pharmacotherapy at the time of study.

Feelings about the diagnosis of diabetes

Many participants did not realise the significance of their diagnosis of diabetes or did not feel they were given enough information at diagnosis. This particularly affected participants who were diagnosed on screening with minimal symptoms: ‘I didn’t think it’d go that far. I thought it would get fixed’ [ID 2]. One participant did not recall being told of their diagnosis: ‘It (the medication) was just given to me, and then they tell me later on down the line that I had been diagnosed with diabetes.’ [ID 6]. When symptoms became apparent or when participants had family with diabetes, they were more likely to understand the severity of the diagnosis. Participants expressed fear and shock at diagnosis: ‘felt a bit of a shock. ‘Cos I have always been active…that sort of knocked the wind out of my sock’ [ID 9].

Education

Most participants felt they did not have enough education about diabetes or diabetes medications. Some felt there was not enough education from people who understood their unique situation and needs, and could provide consistent support: ‘We need someone who will sit with us on a weekly basis to talk to us. Not just fly in and fly out’ [ID 9]. Some participants felt they were not adequately told about potential side-effects of their medications and that this resulted in reduced adherence: ‘They didn’t explain to me before, they never explain, just say take it. …even with side-effects’ [ID 6]. Participants felt that pictorial resources were most useful for education: ‘It didn’t really hit me ’till I started watching them pictures’ [ID 8].

Self-management and lifestyle modifications

Only one of the participants using insulin stated that they monitored their blood sugar levels (BSL) at home. Participants cited losing their glucose monitor and not wanting needles at home where children were present, as impediments to self-

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<thead>
<tr>
<th>Table 1. Characteristics of audited patients with diabetes in the two participating communities</th>
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<td>HbA1c, glycated haemoglobin A</td>
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<tr>
<td>Community</td>
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</tr>
<tr>
<td>A</td>
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<td>No. of patients aged ≥15 years (n)</td>
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<td>No. of patients with diabetes (n (%))</td>
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<tr>
<td>Glycaemic control</td>
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<td>No. with HbA1c ≤7%</td>
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<td>No. with HbA1c &gt;10%</td>
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<td>No. on insulin</td>
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<td>No. on exenatide</td>
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<th>Table 2. Diabetes pharmacotherapy of participants at the time of the present study</th>
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<td>OHA, oral hypoglycaemic agent</td>
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<td>Pharmacotherapy</td>
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<td>Agents</td>
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<td>Metformin</td>
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<td>Sitagliptin</td>
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<td>Exenatide</td>
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monitoring. Few were comfortable managing hypoglycaemia without seeking assistance.

Most participants had made significant changes to their lifestyle: some had increased their exercise, reduced their alcohol intake or attempted weight loss by dietary change. Some participants referred to traditional practices, the knowledge of elders and connecting to Country to improve their diabetes management, especially catching and eating fish; ‘I’m also learning off the old people how they do it’ [ID 8]. Some participants were concerned about providing healthy diet choices to their family, while another found it challenging having to eat different food to other members in the household [ID 4]. One participant focussed on protecting their feet: ‘I don’t walk around bare feet, never’ [ID 8].

None of the participants had noted any significant loss of weight. Many felt frustration at receiving dietary advice that was not relevant to their community, where food options were limited to hunting or fishing, or the one community shop. ‘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’ [ID 9]. AHWs from the communities provided local knowledge that people used to burn off fat with walking long distances, but now they are more often driving to go hunting.

Effect of diabetes on daily life: symptoms and complications

Some participants felt that diabetes did not affect their lives at the time of diagnosis, but that it progressed to do so. Others felt diabetes had a significant effect on quality of life: ‘I don’t even enjoy going out picnic with my grandson like I used to or go out walking anymore’ [ID 2]. Activities such as cleaning, walking, fishing and spending time with grandchildren are valued in these communities, with participants referring to an inability to participate in these activities causing reduced quality of life. Another participant reported that they had to cease employment due to diabetes. Some were determined to carry on with their normal daily life despite their diabetes: ‘I gotta do those things... I can’t just be sitting down’ [ID 10].

Common symptoms attributed to diabetes included feeling tired or run down, pain, weakness, dizziness and urinary problems. Most participants reported complications from their diabetes; visual change, foot wounds, pain, heart problems and poor wound healing or ulcers.

Taking diabetes medication

Most participants felt that their medications were helpful and improved symptoms. Some reported missing their medication doses sometimes, citing reasons including personal problems, forgetting, being on too many medications and side-effects. Some had supportive measures to take their medications including setting routines, using a dose administration aid or family support. One participant felt that when their medication was increased, it represented worsening of their diabetes and a failure of control. Another felt frustrated by changes in medications: ‘There have been a lot of changes in my medications from month to month... it’s just tiring me out’ [ID 13]. Adverse effects of insulin included pain, weight gain and hypoglycaemia; ‘you gotta be careful with all this insulin because you might have a high dosage in the morning and you might leave the community without any provision... you gotta come back bloody quick into town’ [ID 9]. None of the participants on exenatide noticed weight loss. One stopped taking exenatide due to side-effects, feeling it ‘is too strong’ [ID 1] and caused dizziness. Another was initially frightened because of the bigger needle size compared with insulin.

Support from clinic, family and community

When asked about major avenues of support, most participants reported having support from their family or partners: ‘That’s the main people... they look after us’ [ID 2]. Others found it difficult to obtain support from family: ‘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!’ [ID 8].

Almost all participants found their local clinic to be very supportive, particularly citing nursing, doctors and podiatrists. They found the clinic useful for dietary advice; performing exercises; having blood tests; obtaining medications; checking sugars; and when feeling unwell. However, one participant suggested men in particular were frightened to go to the clinic and would only go when they were very sick. Another felt that they were not able to get any support from the clinic and felt very frustrated. ‘I been trying to talk to the doctors and but they don’t tell me nothing. We get doctors coming in telling [us] off. They don’t help anybody. Plenty of things in town but we got nothing. No support’ [ID 9]. None of the participants felt that the community in general provided support for their diabetes: ‘There no support, there’s nothing... no programs here for well-being’ [ID 9].

Outcomes and recommendations

During the interviews, five participants were given direct follow-up care. This included seeing a doctor to discuss adverse effects from medications; being given advice on insulin administration by an AHW; being given further education regarding their medications by an AHW and doctor; and consulting a nurse regarding a related issue.

Capacity building and reflection for AHWs

All AHWs who attended the initial education and planning workshop stated they felt their knowledge of diabetes, qualitative research and conducting research interviews had increased, and subsequently co-authored this paper.

The AHWs who conducted the qualitative interviews reported enjoying being involved in a process that allowed participants to share their stories about living with diabetes; ‘got a lot of weight off their chest too’ [Researcher 8 (R 8)]. They all felt more confident in interacting with patients and clinicians as a result of the project.

Interviewing someone with someone sitting there with you. Before I was too shamed to do this. But I built confidence... with a white person sitting there we go stone cold, a bit scared at first. But once I started, I pretended they weren’t there and just let the patient tell his story [R 6].

They felt their understanding of the effect of diabetes in their community had increased and they would be better equipped to
educate patients about diabetes; ‘Gets you more understanding. You learn a lot from asking them questions’[R 2]; ‘I was not supportive of it like I could have been. Diabetes isn’t a quick fix. It’s an ongoing daily struggle’ [R 8].

All reported wanting to become more involved in patient education and research.

Capacity building and reflection for non-Aboriginal team members

Other team members learnt unique communication skills by observing interviews between Aboriginal participants and AHWs. One clinician was ‘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’ [R 9]. Another clinician felt the project helped them recognise ‘how our patients have a preformed idea about diabetes’ and that ‘people who have had diabetes for a long time don’t necessarily have a clear understanding of the disease’ [R 6].

Involvement of AHWs proved crucial for the development of questions that participants would understand and feel comfortable answering, as well as interpreting the interviews. ‘The interview questions were drafted before we engaged the AHWs. When we tried these questions in a mock interview, we ended up going down a rabbit Warren. We had to acknowledge that, 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’ [R 4].

Recommendations for improvement

Responses from participants, AHWs and other clinicians included several recommendations to improve the experience and management of Aboriginal people with T2DM living in the remote Kimberley communities (Table 3). These recommendations target clinicians, researchers, AHWs, ACCHS and communities.

Discussion

A multi-faceted team approach was used to explore the experiences of remote Aboriginal people with T2DM. We developed a model to improve culturally appropriate communication for patients, AHWs, researchers and clinicians. Participants were able to discuss the effect of diabetes on their lives and their recommendations for improved services. AHWs and non-Aboriginal doctors reflected on their own practise and communication methods, and researchers adapted the study to reflect community needs with input from Aboriginal team members. Involving clinicians in the interviews resulted in participants being given direct follow-up care if required.

In the two communities, 27% of patients aged over 15 years had been diagnosed with diabetes, similar to other Aboriginal and Torres Strait Islander populations, but over three-fold the rate of adults aged ≥25 years (7.4%) in the general Australian population (Tanamas et al. 2013; Department of Health Western Australia 2014). Most patients (83%) with T2DM in the two communities had poor glycaemic control (HbA1c ≥7%) compared with the general Australian population (44%) (Tanamas et al. 2013), supporting the need to understand barriers to management and seek improvement.

Similar to other reported experiences of non-Indigenous people with T2DM living in disadvantaged areas, and Indigenous peoples in Australia, Canada and Latin America (Barton et al. 2005; Bird et al. 2008; Carolan et al. 2015; Frank and Durden 2017), participants described emotional, physical and social challenges related to their experience with diabetes. Diagnosis of T2DM caused fear and shock for many participants, with perceived threat to their identity. They struggled to see a connection between their diabetes diagnosis while feeling well, and the complications that could occur without adequate management (Burridge et al. 2016). They reported difficulty in self-management and noted the link between loss of traditional methods of hunting and cooking and diabetes, which was also reported by Aboriginal patients in rural New South Wales (Webster et al. 2017). While they emphasised the importance of family support (Carolan et al. 2015), it was concerning that none of the participants felt they had community support for their diabetes.

Participants described a lack of contextually relevant education at diagnosis, and with medication changes, which is likely to inhibit uptake of management and lifestyle change (Carolan et al. 2015; Burridge et al. 2016). AHWs and other clinicians involved were shocked by the number of participants who felt they did not understand their condition, and who did not feel comfortable seeking further education. This highlights difficulties in communication between non-Aboriginal doctors and Aboriginal patients. Non-Aboriginal doctors were privileged to witness the unique communication skills between Aboriginal participants and AHWs, which built rapport and opened pathways for education with participants (Stoneman et al. 2014; Durey et al. 2016). Improving health literacy and culturally appropriate training for community members, families and clinical staff is likely to be of benefit in these family-centred communities (Carolan et al. 2015).

Recommendations from this study include involving AHWs in consultations in which diabetes is diagnosed or medication changes are made, enabling culturally appropriate information sharing. AHWs could assist in providing relevant education resources, particularly pictorial resources, as recommended by participants and found to be useful in other studies (Sinclair et al. 2016). Management strategies based on a greater understanding of the patient’s perspective could be explored collaboratively between patients, AHWs, other clinicians and community members.

Access to appropriate food choices is an important but complex problem in resource-poor environments (Hudson 2010; Sinclair et al. 2016; Leonard et al. 2017). Patients are frustrated that they are provided with education about appropriate food choices, but are unable to put this into practice due to lack of supply. Many felt that lifestyle modifications that reflected traditional practice, such as hunting, catching and eating fish, and learning from their elders (Aspin et al. 2012), were more practical and acceptable. There was some enthusiasm for group cooking programs, which have been undertaken in other populations (Nilson et al. 2015). While some participants felt that community support groups, ideally gender-specific, would be beneficial, others felt that they would have too much ‘shame’ to be involved (Queensland Government Cultural Capability Team 2015).

Recommendations will be further discussed with the ACCHS involved, as well as AHWs and community members. Individual
**Table 3. Framework of recommendations to improve the experience for Aboriginal people with type 2 diabetes living in remote Kimberley communities**

<table>
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<tr>
<th>Theme</th>
<th>Recommendation</th>
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| Improved clinic-based education | • Increased number of AHWs available for patient education and assistance with chronic disease management, with appropriate skills and knowledge and ongoing professional development.  
• Presence of AHWs in clinic consultations, especially when diagnoses are made or medications changed. Provision of culturally specific education with unique understanding of the community and continuity of care.  
• Ongoing education and reinforcement over time with promotion of demonstrated understanding.  
• Focus on the role of each individual medication, potential side-effects and means of identification for those with poor vision.  
• The development and use of culturally specific pictorial education aids to explain medications, symptoms and complications of diabetes. |
| Improved clinic support | • Improved access to point-of-care HbA1c testing.  
• Long-term clinicians with detailed knowledge of community, available for continuous support.  
• Use of social yarning to build rapport before discussing clinical issues.  
• Gender-appropriate clinicians where possible.  
• Meeting with patients in their homes / outside of the confines of the clinic to increase comfort and open communication.  
• Promotion of regular sessions with clinicians and AHWs to provide ongoing support and guidance.  
• Individualised management plans that include how to manage personal lifestyle factors and management of medications. |
| Clinic-based intervention to improve use of diabetes medication | • If using a glucagon-like peptide-1 receptor agonist (e.g. exenatide) consider weekly injected preparation, given by clinic staff if patients prefer.  
• Encourage open discussion of barriers to taking medications with AHWs, without judgement or blame. |
| Clinic and community interventions to improve lifestyle modifications and self-management | • Provision of a safe place in the community for patients to check their own BSL.  
• Cooperation between council, community and local store to ensure affordable fresh and diabetes-appropriate food choices are available.  
• Dietary advice that is specific to what is available at the community shop or what can be hunted or gathered.  
• Clinician- / AHW-led tours of community store to explain good food choices.  
• Diabetes-appropriate cooking classes using only foods accessible in communities.  
• Promotion of walking, hunting and fishing and education about traditional healthy living by elders or AHWs. |
| Improved family and community support | • Education, especially at diagnosis, to be provided to patients’ families if desired.  
• Community support groups, ideally gender-specific. May address diabetes education, shared experiences, diabetes-friendly group meals. Involvement and leadership by AHWs and Aboriginal elders.  
• Community education sessions to increase awareness, including discussions and visual media. |
| Further collaborative research | • In further qualitative research, ensure gender-appropriate AHWs as interviewers, in participant’s own home or non-clinic setting.  
• Social yarning to build rapport before questions.  
• Short, simple questions allowing participants to tell their stories.  
• AHW involvement in development of study protocol, communication with participants and analysis of data. |

Table 3. Framework of recommendations to improve the experience for Aboriginal people with type 2 diabetes living in remote Kimberley communities

AHW, Aboriginal Health Worker; BSL, blood sugar level; HbA1c, glycated haemoglobin A

recommendations thought most appropriate and achievable will be further investigated, with the aim of a collaborative approach to any intervention.

This study provides an example of collaboration and three-way capacity building between AHWs, non-Aboriginal clinicians and researchers. Research and health promotion is likely to be successful if it is responsive to the particular circumstances, values and need of Indigenous peoples, and empowers communities to be involved (Sinclair et al. 2016). Time, feasibility and financial constraints limited the study to two communities in which experiences may differ to other remote communities in the Kimberley. Although significant attempts were made to optimise comfort and rapport in semi-structured interviews, some participants provided minimal responses to some questions, limiting the qualitative data collected. While AHWs approached potential participants in a culturally appropriate manner, it remains likely that the group of interviewed participants reflect those most likely to engage with the medical clinic and health interventions, and thus have greater control of their diabetes than other community members.

**Conclusion**

This study provides a framework for culturally relevant recommendations to improve diabetes experience and
management, culturally relevant research and communication among participants, AHWS, community members, researchers and other clinicians. Recommendations for ACCHS, clinicians, researchers and community members have been developed through collaboration and community input. Interventions based on these recommendations using a collaborative approach will be the focus of further research to improve the experience of Aboriginal people living in remote communities with diabetes, because ‘it don’t come and go, it stays’.

Conflicts of interest

Sally Singleton and Naomi Houston were GPs at the community clinics involved. Lydia Scott and Sarah Straw were members of the general medical physician team attending community clinics as part of an outreach service. Louie Yanawana, Vaughan Matsumoto, Denetta Cox and Erica Cox were Aboriginal Health Workers or Aboriginal Health Practitioners living and working in the communities involved.

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Appendix 1. Semi-structured interview guide for Aboriginal Health Workers

I want to talk to you about your diabetes, your history of diabetes, how it has affected your life and how you manage your diabetes. Are you happy to talk about these things? (Items in italics can be used as further prompts if required).

Your Diabetes
Can you tell me a bit about the time when you were diagnosed with diabetes and how you felt? How does diabetes affect your life? Your social life, your family, relationships, lifestyle, fishing, travel, physical activity, diet. What did it change about your life? What has happened to your diabetes and your life since then? Has the diabetes made you feel sick? Have you had other problems because of your diabetes (with your eyes, kidneys, feet, heart)? What is the hardest thing for you about having diabetes?

Do you have support (Clinic, Doctors, Nurses, Diabetes Educators, Health Workers, Family, Friends)?

Your Medications
Can you tell me about the medications you’ve been on and how you feel about them? The medications you started on or the ones you’ve been on in the past. Changes to your medications. The medications you’re on now. Whether you think they’ve been good for your diabetes, side-effects, whether they’ve been hard to take, whether it’s hard to remember to take them, how often you take them and how often you forget or can’t take them, anything that worries you about them. What is it like taking the medications? Can you tell me a bit about how you feel about insulin? What do you think about it? (If not already discussed, even if not on insulin).

Has anyone discussed other medications that you could be on for your diabetes? What medications and what did they say about them? What do you think about them? Do you think you’ll try them? What education were you given when you started on your medications? Do you feel like you were told enough about them? Have you heard of Byetta, Bydureon or exenatide? What do you think about it?

Looking after your diabetes
Do you feel comfortable looking after your diabetes? Do you feel like you know what things are good and bad for your diabetes? What sort of things do you do to look after your diabetes (check sugars, exercise, watch diet, go to clinic, take medications)? Do you feel like you know enough about it? What would you like to know more about? Anything else?

Is there anything else you would like me to know about you, your diabetes, your medications or the support you have?

They’re all the questions I have for you. Is there anything I can do to help you now (make an appointment for a diabetes care plan, diabetes education, dietitian, review by doctor, podiatrist, blood test, or check your medications)?

Is there anything you would like me to tell your doctor / clinic?