

Aboriginal young people's experiences of type 2 diabetes diagnosis, management and support: A qualitative study in the Kimberley region of Western Australia

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Abstract

Issues Addressed: In Australia, Aboriginal and Torres Strait Islander young people in remote settings are most-affected by young onset type 2 diabetes (T2D). It is necessary to understand young people's experiences, including factors impacting on self-management, to improve models of care.

Methods: A phenomenological methodology underpinned this qualitative study in Western Australia's Kimberley region. Two Aboriginal Community Controlled Health Services supported recruitment of seven Aboriginal young people aged 12–24 with T2D, who participated in interviews. A carer and health professional of one young person in each site were also interviewed and relevant medical record data reviewed to assist with triangulation of data. De-identified transcripts were inductively coded and a coding structure developed with oversight by a Kimberley Aboriginal researcher.

Results: Young people reported varied experiences and emotions relating to a T2D diagnosis. Most recounted this was upsetting and some reported current negative impact on emotional wellbeing. Challenges with understanding and managing diabetes were highlighted, particularly regarding healthy eating, physical activity and medication. Family are a prominent source of self-management support, with the intergenerational impact of diabetes being evident for each participant. Positive relationships with health professionals, entailing continuity of care, were valued.

Abbreviations: ACCHS, Aboriginal Community Controlled Health Service; T2D, type 2 diabetes.

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Conclusions: There are significant emotional and medical challenges for young people with T2D and their families. Recommendations from this work will contribute to the development of local resources and initiatives to improve diabetes-related support.

So What? Alongside broader efforts to support good health at the societal level, enhanced health education and family-oriented support structures including Aboriginal clinical staff for young people with T2D are needed.

KEYWORDS

Australian Aboriginal people; culturally competent care; diabetes mellitus, type 2; family; indigenous peoples; rural health; young people

1 | INTRODUCTION

Historically, type 2 diabetes (T2D) has been considered a chronic disease of adulthood, but over recent decades there has been a significant increase in the incidence of young onset T2D, accompanying the increase in paediatric obesity.^{1,2} Young onset T2D is now recognised as a more aggressive form of T2D.^{2,3} It has poorer response to treatment and faster progression of complications, and concomitant negative impact on quality of life and life expectancy compared to type 1 diabetes and adult onset T2D.^{1,4} Management during this life stage has additional complexities compared to adult T2D, as it is often difficult to engage young people in their health care.⁵⁻⁷

Given the increase in burden of disease during the peak years of a person's development, an earlier onset of T2D not only has an impact on health for the individual, but also a significant family and community impact on social and economic engagement, as well as health system costs.^{2,8,9} Younger onset T2D also has implications for future generations; contributors to this intergenerational diabetes risk include genetic, environmental and epigenetic (due to exposure to diabetes in utero) factors.¹⁰

T2D has a strong association with lower socioeconomic status in developed nations, and an increased prevalence in minority groups, particularly Indigenous populations with historical and contemporary experiences of colonisation.^{1,3,4,9,11} In Australia, rates of T2D among Aboriginal and Torres Strait Islander young people are increasing more rapidly than in non-Indigenous young people,^{1,8,12} and this is even more pronounced in remote settings.^{8,13} An audit of diabetes diagnosed up to age 25 among Aboriginal and Torres Strait Islander people in the Kimberley region of Western Australia, along with the Northern Territory and Far North Queensland, has confirmed a high known prevalence of approximately 7/1000 population, which is likely to be an underestimate.¹⁴ To appropriately support diabetes management and improve clinical and social and emotional wellbeing outcomes for Aboriginal young people, it is crucial that health systems address this challenge.

In the Kimberley, the 'Type 2 Diabetes in Children' clinical protocol was updated in 2020 to promote increased screening and the prioritisation of locally-based clinical support for children with diabetes that is inclusive of families and involves Aboriginal staff.^{15,16} The

updated Kimberley clinical protocol incorporated the new guidelines published by the Australasian Paediatric Endocrine Group in 2020 regarding the screening, assessment and management of T2D in children and adolescents, including specific recommendations regarding care of children and adolescents from Indigenous backgrounds in Australasia.¹ These guidelines note that further research is very likely to have an important impact on the adoption and implementation of recommendations, including identifying adolescents' priorities and "empowering adolescents to manage their risk."¹ The updated Kimberley clinical protocol rationale notes the challenges of young people T2D management and the potential of research to contribute to enhanced support and care, including the current study.¹⁵

This Kimberley-based study forms part of a broader collaboration – the *Diabetes Across the Lifecourse: Northern Australia Partnership* – with aims including improved health outcomes for Aboriginal and Torres Strait Islander children and young people with T2D across northern Australia.¹⁷ The aim of this study was to understand the lived experiences of Aboriginal young people with diabetes in the Kimberley, including factors impacting on self-management, to improve models of care. In a subsequent follow-up study these findings will be used to co-design enhanced models of care for Aboriginal children and young people with diabetes living in the Kimberley, including appropriate interventions and educational resources.

2 | METHODS

2.1 | Study design

This qualitative study was underpinned by an interpretive phenomenological methodology.¹⁸ It utilised decolonising methods including oversight by a local Aboriginal researcher assisting in the important Aboriginal perspectives in data interpretation; thorough explanations of research processes to all participants and health service staff who contributed to the study; a culturally and socially respectful approach to interviews, with an Aboriginal interviewer supporting a non-Indigenous interviewer and participants where possible; and prioritisation of the voices of Aboriginal people.¹⁹ While centred on the experiences of Aboriginal young people, this study also incorporated a case

study approach whereby a carer and a health professional of one young person in each of two sites were also interviewed. Triangulation of data for case study participants used relevant information from electronic medical records.

2.2 | Setting

The remote Kimberley region in north-west Western Australia (WA) spans more than 400 000 square kilometres and is located more than 2000 km from the state capital, Perth. In total, the Kimberley has six towns along with many remote Aboriginal communities. Its estimated population is 34 000, and approximately 42% of residents are Aboriginal people.²⁰ The main health care providers are Aboriginal Community Controlled Health Services (ACCHS) and the WA Country Health Service; the latter is a government service providing primary, community and hospital care. These health systems provide care across vast distances which limits access to clinicians and resources.⁸

Continuity of care can be further compromised by the transient nature of a locum-based workforce⁸ and the need to co-ordinate care between multiple health care providers¹³ in a population that is mobile and widely dispersed.²¹

This study was undertaken in collaboration with two independent ACCHSs, which provide culturally-safe, comprehensive primary health care under the governance of local Aboriginal Boards of Directors. Two sites were included in this study with consideration of time and resource constraints. Both sites were towns; one was located in the West Kimberley and one in the East Kimberley.

2.3 | Participants

Criterion sampling was used for the primary participants (young people), from within the patient populations at Broome Regional Aboriginal Medical Service and Ord Valley Aboriginal Health Service. With consideration of the phenomenological nature of the study, the total intended sample size was 10.²² However, there was a relatively small number of eligible potential participants within the timeframe of this study, and the project team understood that young people and their carers had the right to choose to not participate in the research. Therefore, a range of 6–10 was considered suitable.²³

Searches in the ACCHS's web-based electronic medical record system (MMEx, ISA Technologies) by clinical staff identified patients aged 10–25 years who had a venous or point-of-care A1c $\geq 6.5\%$ in the past 10 years. Potential participants were excluded if they had a diagnosis of type 1 diabetes or did not have diabetes (e.g. had a false A1c result recorded), or had an intellectual disability that precluded ability to consent or engage in the interview process. Local ACCHS staff then attempted to ascertain which of the eligible potential participants were currently residing in the local area and make contact to invite them to participate in the study.

A number of potential participants could not be contacted. The seven young people interviewed were aged between 12 and 24 (three

of whom were younger than 16 years); all but one of the participants had been diagnosed with T2D before the age of 16 (Figure 1).

Three participants had been diagnosed 3–6 months prior to the interview, while for the others it had been a number of years since diagnosis. Both carers interviewed as part of the two case studies were Aboriginal women and the biological mothers of the young people with T2D. Both health professionals were non-Indigenous male general practitioners (GPs).

2.4 | Data collection

Semi-structured interviews were conducted in September–December 2020 by author BH, a non-Indigenous male paediatric registrar with 9 years of experience as a medical doctor. BH had been based in the West Kimberley for 18 months and also provided clinical services to the East Kimberley during that time. ES, KS and RK provided guidance in qualitative interviewing prior to commencement. An informal conversational style was used, and BH emphasised that he was speaking to participants in a research capacity and not in his medical role, through which he was already known to some participants.

Interviews were conducted in Standard Australian English and lasted 30–60 min. Interviews were conducted in various locations depending on participant preference and availability, including the participant's home or health service. Aboriginal health service staff members were present at four of the interviews with young people, and at two other interviews the participant's mother was present (not as part of the case studies).

For each of the two case studies, an interview was conducted with the carer directly following the young person's interview, without the young person present. An Aboriginal health service staff member was present at one of these interviews. One of the health professional interviews was undertaken at their home while the other was conducted by telephone due to the interviewee's limited availability. All interviews were digitally audio recorded and professionally transcribed. Participants received a \$40 store gift card or cinema voucher as thanks for their participation.

This study was part of a broader study across Northern Australia and interview guides were developed for the initial work undertaken in the Northern Territory.²⁴ These were adapted for the Kimberley through paid consultation with local young people coordinated by author ES, a Bardi Jawi Traditional Owner and female researcher living in Broome with personal and family connections across the Kimberley.

Topics in the three interview guides included:

1. The young person's story about finding out they had diabetes, what they knew and were told about diabetes, how they felt about having diabetes, who they talk to about having diabetes, what supports they have, and how could they be better supported.
2. The carer's experiences in providing care, challenges, communication with health staff, perspectives on the young person's diabetes management and care, supports for the young person and carer.

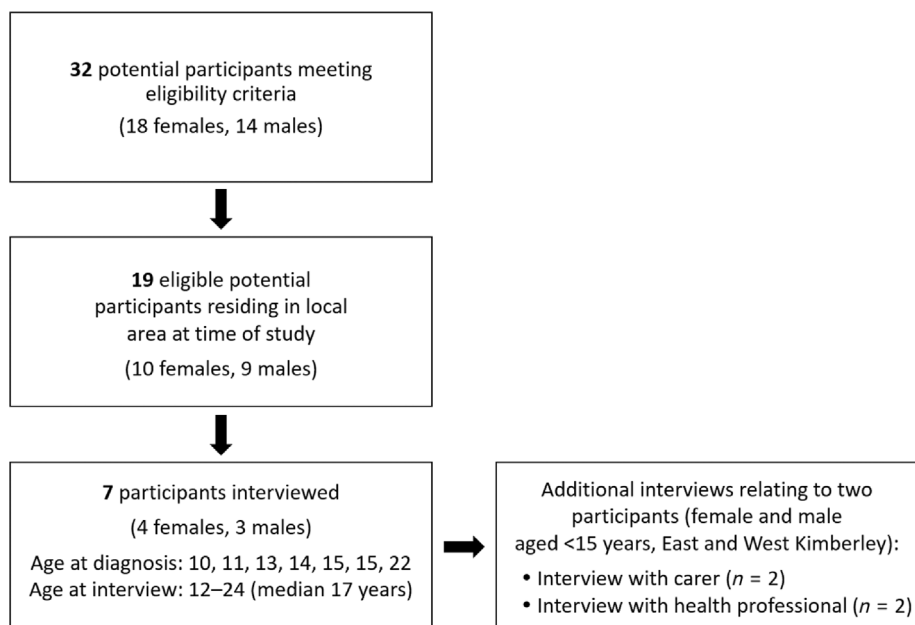


FIGURE 1 Recruitment and characteristics of interviewees.

3. The health professional's role in providing care for the young person, support and resources that assist them in this role, what other support would be useful, perspectives on the young person's diabetes journey, information provided to the young person, challenges in delivering care, suggestions for improving care for young people.

Limited quantitative data were also collected for the two case study participants from electronic medical records, including A1c levels, current medications and co-morbidities.

2.5 | Data analysis

BH and ES analysed the data with author KS, a female non-Indigenous Broome researcher who had been living in the Kimberley for several years and was experienced in qualitative data analysis. De-identified transcripts were inductively coded over four 3-h sessions, with the aid of Quirkos software version 2.4.1.²⁵ Coded data from carers and health professionals participating in the case studies were kept distinct from data collected directly from young people, reflecting the study's primary focus on young peoples' experiences. Where a carer was present at the young person's interview (not participating in a case study carer interview), the analysis team ensured that any coding reflected the young person's expressed perspectives. Coding disagreements were resolved by consensus-based discussion with guidance from ES as a Kimberley Aboriginal person.

Following these initial sessions, the analysis team reviewed all codes and associated data in an additional workshop. Commonalities across codes were identified and the codes were refined. From these, the team defined key themes and checked these against the original data. Quotes were collaboratively chosen to illustrate these main constructs. RK, a female non-Indigenous Darwin based researcher,

provided academic advice on data analysis, including data synthesis and interpretation, and interpretation of findings in the context of the broader project across all regions of Northern Australia. Quantitative data from the case study participants were descriptively summarised and considered in conjunction with their qualitative data.

3 | RESULTS

Key themes in the experiences recounted by young people, complemented by information from carers and GPs, were: varied experiences and emotions relating to a diagnosis of diabetes; challenges with understanding and managing diabetes; prominent family support and the intergenerational impact of diabetes; and the value of positive clinical care relationships.

3.1 | Varied experiences and emotions relating to diabetes diagnosis

Most diagnoses were from opportunistic screening in the study sites, nearby towns and interstate. One participant spoke of noticing physical changes that led to being diagnosed with diabetes:

I just realised I feel weak, tired and feel heavy, couldn't read properly... I [was] just getting fat.

- Participant 1

Participants reported little or no knowledge about diabetes prior to their diagnosis. Two young people reported that they were unsure of their feelings at the time of diagnosis, while others stated they had felt "sad," "bad," "bit yucky," found it "shocking" or did not want to listen.

When I found out, I was 14 turning 15. But I didn't know what diabetes really was, it was the first time I heard 'diabetes'. And, yeah, I didn't really understand it so I didn't really listen ... Like they just, they said, oh, you have diabetes. And then they sort of took me to the clinic... I didn't really understand what the clinic [interstate] was going on about... I wasn't really, yeah, paying attention. Because then your brain isn't, you know, kind of teenagers, some of them are like smart arses.

- Participant 2

Similarly, some young people reported that they currently felt "worried," "nervous" or "scared" about having diabetes, while others stated they did not have any negative emotions associated with having diabetes. One teenage participant, who had been diagnosed with diabetes several years prior, recounted that her understanding of diabetes had increased and this has been accompanied by stronger emotions about having diabetes, along with having experienced greater impacts from having diabetes over time.

I: And what about now, now that you're older and you understand a bit more about it, how do you feel about having diabetes?

P: Scared ... Because I'm at a young age, like I know that old people have diabetes but not like me.

- Participant 7

3.2 | Challenges with understanding and managing diabetes

Other participants also indicated improved knowledge and understanding of diabetes compared to at the time of diagnosis. Understandings focused on blood sugar levels and health behaviours for diabetes management, particularly avoiding sugary drink consumption, eating healthy foods, and physical activity.

I: Can you tell me what you understand about diabetes?

P: It's eating healthy food and drink healthy drinks.

- Participant 5 Some young people expressed an understanding of potential diabetes complications. One young adult recommended that education to support diabetes management should include fear tactics about complications, "just to frighten a little." The GP of a different young person, from the case study, discussed a tailored approach to complications-related education, stating that what may be motivating for some patients may make others disengage. Overall, knowledge gaps regarding diabetes and management were evident; none of the participants indicated a clear understanding of how high blood sugar levels and diabetes complications occur. Young interviewees consistently said they would like to know more about diabetes but were not sure what.

Some participants reported making changes in healthy lifestyle behaviours, including "stop drinking a lot of sugar," consuming healthier foods in smaller amounts, and walking for exercise. These changes were generally described as difficult. Young people mentioned multiple barriers to physical activity, including the hot climate, high body weight, and lethargy. A described barrier to healthy eating was being around sugary foods that were consumed by others. One young person spoke about greater difficulty in town compared to "out bush" where she ate "lots of bush tucker" and was more active. Another participant described her healthier lifestyle before she "dropped out" of school and discussed the difficulty of consistently meeting mainstream dietary guidelines which she did not consider to be culturally or practically suitable.

Some young people spoke about having a useful "routine" for physical activity, monitoring blood sugar and taking medication, with the support of a family member. Case study medical data showed that one young person who had made healthy lifestyle changes had achieved reductions in A1c to <6.5% in the 5 months post-diagnosis without medication.

Medical data for the other young case study participant highlighted the detrimental impact of not taking prescribed diabetes medication on A1c levels (A1c >10% at around the time of the interview). This participant had ongoing difficulties with glycaemic levels and spoke about "how hard it is" to "deal with diabetes." Other participants spoke about challenges with diabetes medication. Some spoke of deliberately missing metformin tablets because "It makes me feel funny inside my stomach" or refusing to take tablets because "It tastes disgusting." Another young person mentioned he would like to take more tablets because "I want [my blood sugar] to go down and I want to be healthy for my mum." For this participant, tablets were preferable to insulin injections that had been recommended by health professionals, as he had an aversion to needles. Another participant spoke about having multiple daily injections of insulin in addition to tablets, with a significant impact on social interaction due to feeling "kind of nervous" about administering insulin outside the home and disposing of used needles appropriately. This participant noted the lengthy and ongoing process to establish consistent medication-taking in addition to healthy lifestyle changes, over several years from teen age to adulthood:

When I first found about it [having diabetes], I didn't really know what it was so I was like, 'oh, it's okay'... But then, a couple of years later, it still, it settled in, so. That's when I just started saying, take my tablets more... So when you get diabetes, you've got to level everything. And that's another hard thing to do.

- Participant 2

Comorbidities posed additional challenges for some participants. In particular, three of the seven young people mentioned having acute rheumatic fever (ARF) or rheumatic heart disease (RHD); one participant who was reluctant to accept her recent T2D diagnosis stated that she had to "deal with three things [chronic medical conditions]

now.” A GP noted that another of these young people had reasonable adherence to penicillin injections for RHD prevention but was less often reviewed regarding diabetes. The GP stated that a solution equivalent to monthly penicillin injections was expected by some patients or family members for diabetes, whereas diabetes management is much more complex.

3.3 | Prominent family support and intergenerational impact of diabetes

Family history and the intergenerational impact of diabetes was evident for all young people. This included mothers, fathers and grandparents, on both sides of the family in some cases, along with a younger sibling. Blindness, amputations and dialysis were mentioned as diabetes complications that had occurred within some young peoples' families. Both carers interviewed had lived experiences with diabetes, one with gestational diabetes at the time of her interview and the other with T2D. In the health professional interview for the latter case study, the GP stated that having diabetes had added to the carer's distress at their child's diagnosis. One of the young adults shared that most of her close family members had a history of T2D, a generational continuous linkage including herself as a mother, and both she and her own mother had experienced diabetes in pregnancy.

When I was pregnant with [child's name] they put me on insulin, because it was keeping my sugar down more than the tablets were... My mum found out she had diabetes when, I think when she was pregnant with me.

- Participant 2

Young people spoke about receiving support from family members. This was most commonly their mother, and others mentioned were father, sister, cousin, uncle and partner. Support included “encouraging me to take medication,” “exercise” and “do the finger pricks”; talking about “what to do and what not to do,” particularly regarding food; preparing healthy food; transport to the health service; discussing concerns; and fostering a positive outlook. In addition, one carer spoke about explaining information to their child; for example, the longer-term consequences of not taking prescribed diabetes medication. This support could also be a source of tension.

One young teenager described self-management encouragement from parents as “humberging” (pestering). In contrast, another young person spoke about the unique support provided by her mother who also has diabetes, as “mum knows actually what she's talking about.” For others, support was limited due to family members not living in the local area, or the young person moving between different carers due to social circumstances.

In addition to their own medical concerns and concerns about their child with diabetes, carers spoke about challenges to supporting

the management of their child's diabetes, including caring for other children, lack of independent transport and reliance on costly taxis, food insecurity and difficulty catering to dietary requirements. One carer stated she had limited support, while the other had some family support. Both carers expressed that their carer role was something they accepted as part of being a mother.

3.4 | The value of positive clinical care relationships and other supports

While family members were often mentioned as support, most young people said they did not talk with their friends about diabetes. Two young men said their friends helped them regarding diabetes, including by encouraging exercise. When asked, all participants said it would be helpful to have an older peer with diabetes to talk to. The carer and GP of one young case study participant identified staff at a school engagement program as strong supports for the young person. The same young person said he would “be shamed” (embarrassed) if there was a guest speaker at school to talk about diabetes.

Positive relationships with clinic staff were clearly valued by participants. Young people spoke of receiving support from “good” health professionals, including GPs, nurses and dietitians. Participants highlighted the importance of continuity of care.

I: Do you see the same person all the time or just different?

P: I had one before but he took off from there ... I haven't been there for a while... About three weeks, four. About a month.

I: About a month. Okay. And so what was it like for you, [Name], when you had a doctor who you were seeing regularly and then they took off, what did that feel like?

P: Pretty shit.

- Participant 6

I don't like seeing, like, people I don't know. I like seeing people that I know very well.

- Participant 3

Support from health professionals included encouragement to take medication and provision of information. One participant stated that while health professionals were helpful, this also entailed “humberging.” Young people, carers and GPs all expressed a need for more patient information resources, with an emphasis on visual information. When young people were asked whether social media may be a useful way for health services to communicate diabetes-related information, most said it would be. However, three young people said they would prefer to keep that aspect of their life separate from their preferred social media platform. Talking through information with health professionals was also considered very important by young people and carers.

The GPs interviewed similarly emphasised the critical importance of relationships and communication for good care. Associated with this, they highlighted the need for additional human resources

focused on children and adolescents with diabetes. In particular, they identified that the dedicated time of an Aboriginal health worker/practitioner or nurse within primary care services would enable thorough follow-up and engagement with young people and their families, who often had complicated life situations; ensure effective coordination with other staff, services, and secondary and tertiary levels of care; and assist with the transition from child health care to adult care.

4 | DISCUSSION

The stories shared in this study contribute to understanding experiences of young people with T2D in the Kimberley region of Australia. They also highlight the potential for enhanced support, including by building on existing strengths within families and health services. Although T2D is a major health issue for Aboriginal people in the Kimberley, a diagnosis of T2D in young people was typically recounted as unexpected and shocking.

Gaps in knowledge regarding diabetes management were highlighted along with the serious implications of a T2D diagnosis at a young age. The intergenerational impact of T2D was evident and reinforces the importance of a family-oriented approach to the substantial challenges that young people experience with diabetes management. Continuity of care with a known health professional is valued by young people with T2D, and complements the important role of family members. There are opportunities to facilitate more supportive peer networks, under the direction of young people themselves, as an additional source of encouragement and assistance with the physical and emotional impacts of T2D.

It is clear that for the young people interviewed in this study, having T2D is challenging, including in regard to their transitional life stages as well as broader life circumstances. This is also consistent with the insights provided by the carers and GPs. Difficulties were not experienced by the young people alone, encompassing families more broadly. Fear and uncertainty, not being ready to focus on T2D, other serious medical conditions, and adverse socioeconomic circumstances were present within this participant group. This was in addition to the more general need to find balance with regard to food consumption, exercise and medication. In line with findings from our study, it has been documented that poor food security, limited access to traditional Aboriginal food produce coupled with the higher cost of fresh food produce, and limited community resources in many remote areas also add to the challenges in managing the lifestyle modifications necessary to achieve good glycaemic levels.⁸

The experiences shared in this study have commonalities with those recounted by young people in urban and remote areas of the Northern Territory,²⁴ along with those across four regions of Western Australia.²⁶ Overall, findings from each study, spanning large geographic distances, emphasise the need for improved health education regarding diabetes and comprehensive support for young people and their families. They also highlighted the stigma often associated with a diagnosis of T2D among young people. In other areas of the

Kimberley, adults with diabetes have also recounted a lack of appropriate diabetes education and difficulties with medication, including being unprepared for potential side-effects.²⁷

Our findings are consistent with a recent qualitative study in the United States with adults aged 21–44 who had been diagnosed with T2D within the previous 2 years who described receiving practical and emotional family support, including from older relatives with T2D, which is similar to the current study's findings.²⁸ In addition, current and possible future children were also a source of motivation for self-management for some participants in the US study, and whole-of-family lifestyle changes were described.²⁸ This has relevance to the current study where there was clear intergenerational impact of T2D. It highlights the importance of routine screening for T2D in pregnant women and their offspring,²⁹ along with a focus on preconception care and supporting reproductive autonomy in this age group.^{30–32}

To support self-management, a much broader campaign of localised T2D-focused health education for young people and their families is required. In the Kimberley and elsewhere, there are currently limited educational resources for young people with T2D.³² Kimberley-specific culturally appropriate resources are needed to complement discussions with health professionals or other advisors, with a focus on visual resources.²⁷ Social media platforms are a significant aspect of many young people interactions and provide a potential means of health communication and support. However, in the current study some young people expressed reluctance to have medical issues intrude upon this aspect of their life. Other potential interactive education formats for young people include apps and gamification, which were not raised in this study, a possible topic of further research.³²

In addition to focusing on potential management strategies for young people with T2D facilitated by health services, it is also important to focus on healthy lifestyle education for all young people. It is well documented that preventive strategies are the most effective approach to decreasing the burden of diabetes care which is best achieved through multiple pathways.⁹ Young people in the Northern Territory study²⁴ spoke of both normalisation and shame regarding diabetes; while this was not a prominent feature of the Kimberley study, it should be noted that one of the participants said a guest speaker at his school presenting on diabetes would be embarrassing.

Further consideration is required about whether diabetes-related education could be better integrated into general health education within schools and community settings, including to help destigmatise T2D in young people and raise the relatively low awareness of young people -onset T2D.³³

This study provides further examples of successes in remote primary health care with the centring of relationships, which was also evident in a previous young people -focused study with another Kimberley ACCHS.³⁴ As noted repeatedly in the Kimberley and other remote contexts, more resourcing is needed to support continuity of care, which was clearly valued by the young interviewees and is highlighted in the 2022 consensus statement regarding management of T2D in young adults.³² As described previously in a remote antenatal care context, staffing shortages require long-term investment

including a systems-level focus on building the local Aboriginal health workforce.³⁵

As recommended by the health professionals interviewed in this study, resourcing an Aboriginal health worker/practitioner or nurse for paediatric-focused diabetes care within primary care services is critical to providing appropriate care to this population. Such a role would also involve guiding the transition of patients from paediatric to adult T2D care, which is a vulnerable period,³² and would likely make an important contribution to fostering social and emotional wellbeing among young people and their carers more generally.

The crucial contribution of Aboriginal health workers and practitioners within multidisciplinary teams is acknowledged in the Kimberley T2D clinical protocols for children and adults,^{15,36} as well as the 2022 consensus statement.³² However, what is lacking in the regional child protocol, and could be made consistent with the adult protocol,³⁶ is to involve an Aboriginal health worker or practitioner during diagnosis and change of medication, along with contributing to continuity of care in the transition from childhood to adult. This recommendation is consistent with identified priorities nationally.^{27,37} Aboriginal staff are also vital in supporting culturally safe care by the non-Indigenous health workforce, which includes yarning, listening to understand, and consideration of protective and risk factors for mental health and wellbeing.³⁸

Navigating care is complex and could be improved by the creation of a dedicated position within clinics.¹³ This could include collaboration with regional government paediatric services, local ACCHS, regional not-for-profit allied health services and Perth-based tertiary endocrine specialists. The most recent iteration of the Kimberley T2D in Children clinical protocol¹⁵ attempts to address the need for regionally based co-ordination by establishing the Kimberley paediatric team as the conduit through which medical decisions are managed, while also recognising the importance of 'case management' within local clinics. Some families reside in different areas of the Kimberley during the year, such as very remote communities to town base, or may travel interstate, which can make it difficult to arrange follow up for diabetes care. This is even more difficult for children who may be moving between care arrangements as was reported by one of the participants.

As part of enhancing co-ordination of care, it may be useful to establish a register of young people with T2D, such as currently exists via RHD control programs and registers for ARF/RHD. There has been a large investment in the screening, diagnosis and management of ARF, in health education with a focus on the serious risk of long-term cardiac damage and the need for undertaking preventive strategies to avoid serious complications (i.e. RHD).³⁹

Online and local resources for families and health services have also been developed. When exploring potential management strategies for young people onset T2D, it may be useful to consider models of care for ARF, which has a high prevalence⁴⁰ and affected three of the seven participants in this study.

This study had limitations including a relatively small sample size, and exploration of any differences in the experiences of participants with respect to age, gender, location or time since diagnosis was not

possible. However, there were consistent themes in these interviews and sufficient information was gathered to enhance understandings of this specific population and how their health care needs could be better met. The study findings were unable to capture the experiences of young people with intellectual disability and T2D diagnosis.

There were many other Kimberley towns and communities unable to be included in the study, and ongoing consultation across the region is required as new initiatives are developed. The young participants who were able to be contacted and agreed to participate in this study may represent patients who are more engaged in their health care, and there may be other important considerations among different patient groups. Aboriginal health service staff made valuable contributions to the study but were not always available at interviews due to staffing constraints. The interviewer was a white middle-aged male doctor, which may have affected participants' willingness to volunteer information about their personal experiences.

The interviews being conducted in Standard Australian English and not in an Aboriginal language (including Kriol) may also have affected the comfort and ease with which participants shared their stories. Strengths of the study included involvement of the two ACCHS and leadership by a local Aboriginal researcher throughout the project.

5 | CONCLUSION

Aboriginal young people with T2D in the Kimberley region of Australia experience emotional, physical and medical challenges, and the support provided by family members and trusted health professionals is valued. Alongside broader efforts to support good health at the societal level, there are considerations to aid T2D self-management. This includes resourcing ongoing dedicated staff within primary care services who could strengthen coordination of care and transition to adult care, support social and cultural and emotional wellbeing along with physical wellbeing, and complement and assist the role of carers.

There is also a need to improve health education for young people and families by developing relevant regional resources that are culturally appropriate, valuing their input and inclusion of Aboriginal languages; and facilitate peer support. Recommendations from this formative work are informing the co-design activities of a larger study across the Kimberley and northern Australia, acknowledging that action is needed to prevent the increase in burden of disease from young onset T2D and its intergenerational impacts.

AUTHOR CONTRIBUTIONS

RK, LMB, VO and DA conceptualised the study. RK, LMB, DA and BH designed the study. BH conducted the interviews. ES, KS and BH analysed the data. BH and KS wrote the original draft and all authors contributed to revisions led by KS. RK provided academic leadership in interpretation of data in the context of the broader study. ES provided cultural oversight and was a major contributor to the final manuscript.

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CONFLICT OF INTEREST STATEMENT

Ben Harkin was a paediatric registrar who was part of the team who provided regional paediatric community clinics at the Aboriginal Community Controlled Health Services involved in this study.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

This study was supported by the Kimberley Aboriginal Health Planning Forum Research Subcommittee and approved by the Western Australian Aboriginal Health Ethics Committee (HREC981). All participants provided written informed consent, along with written consent from a parent or guardian for participants younger than 16.

PATIENT CONSENT FOR PUBLICATION

Written informed consent included for the findings to be published.

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