

**'No sugar', 'no junk food', 'do more exercise' – moving beyond simple messages to improve the health of Aboriginal women with Hyperglycaemia in Pregnancy in the Northern Territory – A phenomenological study**

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# 'No sugar', 'no junk food', 'do more exercise' – moving beyond simple messages to improve the health of Aboriginal women with Hyperglycaemia in Pregnancy in the Northern Territory – A phenomenological study

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### ABSTRACT

**Background:** Globally, rates of hyperglycaemia in pregnancy are highest among Indigenous women. The highest prevalence has been documented among Aboriginal women in the Northern Territory of Australia. Despite knowledge of this for over two decades, there has been very limited examination of the specific needs and experiences of Aboriginal women regarding this condition.

**Question:** How do Aboriginal women with hyperglycaemia in pregnancy understand and experience this condition, and how can their care be improved?

**Methods:** A phenomenological methodology underpinned semi-structured in-depth interviews with 35 Aboriginal women and seven health professionals across the Northern Territory. Data were inductively analysed.

**Findings:** The findings revealed that in general, participants in this study could recite simple health messaging regarding diabetes (e.g. 'no sugar'), but many lacked in-depth knowledge and this affected the management of their condition. Nevertheless, many identified pregnancy as a powerful motivator for change, signalling scope to improve health messaging. Women consistently expressed the need for diabetes education that was culturally appropriate, a clear desire for maternity care that was family-centred, based on respectful relationships with the same care provider, and respected Aboriginal ways of knowing and being.

**Conclusion:** Existing health messaging around hyperglycaemia in pregnancy has limited reach with Aboriginal women in the Northern Territory. Reducing the burden of hyperglycaemia in pregnancy among these women requires a sustained commitment to redesign of maternity and diabetes care to incorporate the cultural and social context of women's lives.

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#### Statement of significance

#### Problem or issue

Aboriginal women experience high rates of hyperglycaemia in pregnancy. Yet, little is known about their understanding, experiences and management of this condition.

**Abbreviations:** AHP, Aboriginal Health Practitioner; AN, Antenatal; CA, Central Australia; FNQ, Far North Queensland; GDM, Gestational Diabetes Mellitus; HREC, Human Research Ethics Committee; MGP, Midwifery Group Practice; MW, Midwife; T2DM, Type 2 Diabetes Mellitus; TE, Top End.

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### What is already known

Effective health messaging and culturally appropriate care is critical to the effective management of diabetes in other settings.

### What this paper adds

Women know basic messages about hyperglycaemia in pregnancy, but there is a need for new approaches to strengthen understanding and improve management of this condition. Improving education and care to better engage family, elders and the Aboriginal Health Workforce and incorporate Aboriginal knowledge are critical. This study is a first step in supporting a co-design approach to promote the delivery of enhanced care.

## 1. Introduction

Indigenous populations around the world experience disproportionately high rates of diabetes when compared with their non-Indigenous counterparts (1,2). This is evident at all stages in the lifespan, including during pregnancy. Hyperglycaemia in pregnancy, either due to gestational diabetes mellitus (GDM) or pre-existing type 2 diabetes (T2DM), is associated with a range of adverse perinatal outcomes including congenital malformations. The effects are intergenerational: in-utero exposure to maternal hyperglycaemia increases the risk of obesity, T2DM and cardiovascular disease among offspring with evidence that this occurs in Indigenous populations at concerning young ages (3,4).

Australian Aboriginal women have unacceptably high rates of hyperglycaemia in pregnancy. In these women, the prevalence of T2DM in pregnancy is 10 times higher than for non-Aboriginal women, and for GDM, the rate is 1.5 times higher (5). Further, the prevalence of type 2 diabetes in the Northern Territory (NT) for Aboriginal women was recently reported in a systematic review as the highest in the world across all Indigenous women (6). This is particularly alarming as young motherhood is more common among Aboriginal women, and young maternal age is typically associated with a reduced risk of diabetes (5,7). There also appears to be a higher risk of progression from GDM to T2DM after pregnancy, with one study reporting that 22% of Aboriginal women with GDM subsequently developed T2DM within three years' postpartum (8).

In Australia, a higher proportion of Aboriginal people live in a remote setting than non-Aboriginal people. The provision of health care in this setting is challenged by the remote setting, workforce shortages, fragmented care and the use of different health information systems from one health service to the next (9,10). Most communities are serviced by health clinics and outreach services, with antenatal care predominantly provided by primary care with remote specialist support (11).

Compounding these challenges are that Western biomedical models underpin the mainstream understandings and approach to health care (12) and do not adequately consider Aboriginal worldviews and understandings of health (13). As a result, provision of health care is often not culturally relevant, and this contributes to disengagement with health services (14). The Diabetes in Pregnancy Partnership was established in the NT in 2012 to improve the care of women with hyperglycaemia in pregnancy across the health system, recognising that this is a community priority (9). The program has since expanded to Far North Queensland (FNQ) and now considers the intergenerational impacts of diabetes, thus the formation of the Diabetes across the Life-course Partnership ([www.dipp.org.au](http://www.dipp.org.au)). This paper presents findings of the first Partnership study on consumer perspectives.

The study aimed to explore Aboriginal women's experiences of hyperglycaemia in pregnancy, associated health care, and their understandings of the condition and health behaviours, to better understand women's specific needs and inform future systems change.

## 2. Setting

The NT is home to more than 58,000 Aboriginal people – almost 30% of the total population (15). Eighty percent of this population live outside the major centre (Darwin) in rural and remote communities (15). The region comprises of the Top End (TE) in the north and Central Australia (CA) in the south. Thirty-three percent of all births in the NT are to Aboriginal women, of whom, fifteen percent experience GDM in pregnancy, and 4% have pre-existing T2DM (7). Two large services in the NT that aim to provide culturally safe care to Aboriginal women include: the Midwifery Group Practice (MGP) in the TE (16) and Congress Alukura in CA (17). For most women who live remotely, health care is provided by primary health care centres located in their communities, with outreach support offered by these two services and hospital-based services. This study engaged with three urban and three remote sites across the NT.

## 3. Ethics

Ethics approval was obtained prior to commencing this research in all sites (NT Department of Health and Menzies School of Health Human Research Ethics Committee (HREC) Approval numbers: 2017-2819 and 2015-2461; CA HREC Approval number HREC 15-345). It was guided by the NHMRC roadmap for respectfully conducting research with Aboriginal people (18).

## 4. Methods

This interpretivist study was underpinned by a phenomenological methodology (19), enabling women's experiences and understanding of hyperglycaemia in pregnancy to be the focus of enquiry. This approach privileged the voices and viewpoints of Aboriginal women, whose perspectives have historically been repressed (20). This was an appropriate approach given the misalignment of the health system with Aboriginal worldviews and provided an opportunity for health system enhancement in the NT context to be informed by the lived experiences of these women.

This study was designed by investigators of the project (RK, SG, JB, CW, TS, AR, LMB). RK, a non-Aboriginal qualitative researcher with ten years of experience working with Aboriginal communities on health research, led the implementation of this project under the supervision of LMB. Participant recruitment was strengthened by the pre-existing relationships and rapport SG an Indigenous researcher, had with many of the women participating in the study. In collaboration, RK and SG undertook the interviews, recorded notes and debriefed around interpretation of meanings following each interview, and undertook preliminary data analysis. In each site, a community based Aboriginal co-researcher was employed to work with the research team. They assisted with ensuring the study methods were appropriate and respectful to: each community, identifying potential participants, translating information, and cross-checking interpretation of meaning with participants and the researchers as interviews were conducted. These co-researchers were purposively recruited to work in the study through the networks of the research team.

The Darwin-based research team recruited participants to the study across all six sites in the NT between May and August 2017. Participants were known to researchers through work of the

Partnership or were introduced to researchers through the local clinics. Participants were also asked to nominate a health professional they considered important in delivering their hyperglycaemia in pregnancy care, who were then approached by the research team and invited to participate in an interview. As this study aimed to consider the views of Aboriginal women, their perspectives are predominant. Perspectives of health professionals are reported when they provide additional insights.

Participants needed to be a minimum of eighteen years of age, proficient in English (as this was the language the interviews were undertaken in), diagnosed with hyperglycaemia in pregnancy and between 32–35 weeks gestation or up to 12 months' post-partum. Involvement in any care related to hyperglycaemia in pregnancy was the requirement for participation of Health Professionals. Participants were excluded if they were unable to provide informed consent or were known to have had pregnancy complications resulting in poor pregnancy outcomes (i.e. miscarriage or stillbirth). It was not deemed appropriate nor necessary for this study to ask women to recount sensitive experiences of this nature. The study was described to potential participants and a mutually convenient time and space for the interview to be conducted agreed upon. This space was a private room in the health clinic, in the participant's home or another location suggested by the community-based co-researcher or nominated by the participant (such as in a park). All Aboriginal participants were given the opportunity to have the local Aboriginal research assistant to be present for the interviews. Informed consent was obtained prior to undertaking the semi-structured in-depth interviews.

Interviews were audio-recorded and transcribed verbatim by an external company. One woman did not give permission for her interview to be recorded. In this instance, extensive notes were made throughout the interview. Interviews were an average duration of 21.31 minutes (minimum 11.39; maximum 54.50). Each participant received a voucher to the local community store to the value of \$30 to thank them their involvement in the study. Participants were given the option to receive their transcripts to cross-check for accuracy, with the support from the project team if required, however no participant chose this option. Researchers' interpretation of meaning post-interviews (RK and SG) and during analysis (RK, SK, AR) were cross-checked for congruence or further exploration of possible meaning.

## 5. Analysis

Transcripts were de-identified and pseudonyms assigned (as evident in this manuscript). Transcripts and reflective notes were analysed inductively by SG, SK and RK to develop a coding structure. This was followed by a second round of in-depth coding by SK, under the supervision of RK and AR, who used data extracts to create textual descriptions of what participants had experienced. The influence of context and setting were also explored as well as constructs that created structural descriptions of how participants experienced different phenomena. Data were then re-identified to allow contextual information important to data interpretation to be considered, including type of diabetes, parity, and whether the participant was from a remote or urban community.

Saturation was reached on many constructs – particularly those relevant to women across all geographic locations, of all age groups and either diabetes category. Unique cases, or experiences that were not commonly described, provided alternate perspectives and important insights for consideration.

## 6. Findings

Participants interviewed for this study included 35 women with experiences of hyperglycaemia in pregnancy. Of these participants:

two were pregnant at the time of interview; 33 were in the post-partum period and had T2DM or GDM (10 and 25 respectively); ages spanning 21 to 44 years. To complement these perspectives, seven female health professionals were also interviewed. This included two midwives, one Aboriginal Health Practitioner and four Strong Women Workers (local Aboriginal women employed to assist women in maintaining good health in pregnancy). The two midwives interviewed were the only non-Aboriginal participants involved in this study.

Four main constructs emerged from the interviews. These were related to women's understanding and sources of information about diabetes, motivational factors, the need for culturally appropriate messages, education and respecting family structure, and access to culturally appropriate care.

### 6.1. Women's understanding and sources of information about diabetes

It became apparent that most participants understood the key health promotion messages of diabetes education. Key statements included 'no sugar', 'no junk food' and 'do more exercise'. However, overall, there were limited in-depth understanding of hyperglycaemia in pregnancy. To elaborate, many of the questions that were designed to prompt participants to provide more in-depth explanations around the importance of managing hyperglycaemia in pregnancy or probing for participant understandings around diabetes, were met with silence.

To elicit further information around women's understandings of hyperglycaemia in pregnancy, participants were asked what they would tell a young woman if she were diagnosed with hyperglycaemia in pregnancy. Responses highlighted that discourses around hyperglycaemia in pregnancy were limited to diabetes management, including diet modification and taking medication:

You need to rest off sugar [ . . . ] Got to do more exercise [ . . . ]  
Eat the right food [ . . . ] I've been taking some tablets too.  
Trinity, GDM, remote community

References to 'Coke' were predominant in discussions touching on recommended dietary changes and seemed to be used as a synonym for sugary drinks. An example of the impact of this is when Rhianna (GDM, remote community) was asked whether there was anything she changed when she found out she had hyperglycaemia in pregnancy, she stated that "I just stopped [drinking Coke] and started drinking Sprite [lemonade] . . .". This highlighted that in this instance, Coke was understood to be a sugary drink, but Sprite was not.

When women were asked about whether or not they understood the information they had received from the health centre, it became evident that in most cases they did not. One example of this includes:

Interviewer: You know when that mob were saying that you got diabetes in pregnancy, did you understand what they meant or was it a bit confusing for you?

Amelia: A bit confusing

Interviewer: So, when they were talking to you, did you understand or not really?

Amelia: Not really

Interviewer: Is there different ways they could tell you about it?

Amelia: If they had someone like someone who maybe can understand Kriol but work here

GDM, remote community

This participant went on to explain how she "keep asking that [diabetes educator] who comes every once a month to have a chat with [ . . . ] all of us ladies [ . . . ] keep asking what it is, and how do

we get them [...] she says something about kidney or something.”

Another participant described how the diabetes education she received from the clinic was “*too much*”. In addition, Memory, who lived in an urban community and had GDM described how the comorbidities she experiences cause her to “*sometimes [...] zone out, because I’m always at risk of something. I just get tired of hearing it.*”

A midwife [Camila] working in a remote community also described how women in her clinic “*are told*” about the risks of having hyperglycaemia during pregnancy. Yet, she was unsure why women did not take their medication as instructed when informed of the consequences of sub-optimally managed diabetes:

... she’s in the last stages of her pregnancy, and she’s got really big and she hasn’t been taking her medication. So, you know, we are concerned, but she knew all that, you know. I don’t know. I don’t know what the answers are.

Of note, two Aboriginal Health Practitioners described how some of their clients do not adopt suggested behaviours to manage their diabetes. For example, Merindah, an Aboriginal Health Practitioner with 10 years’ experience working in a remote community explained how: “... I talk to [the women] about diabetes. You know, soft drink, don’t look at the soft drink. Soft drink a big lot sugar. But some, they don’t listen. They go shop and buy soft drink.” This was reiterated by Alexis, an Aboriginal Health Practitioner working in an urban setting, who said:

... you see the [women] that have understood the information because they are taking their medicine and that. And then you see others that walk down the stairs and buy a Coke right in front of you.

Challenges around food security were also raised by many health professionals. Specifically, the availability of fresh and affordable foods in remote communities. As further described by Alexis:

... the problem the women have in the community is there isn’t a lot of fresh fruit and vegetables [...]. So it’s easier to buy takeaway [...] cheaper for any of us to do that rather than cook a good meal.

Health professionals were not the only sources of information about hyperglycaemia in pregnancy. Women highlighted that through their lived experiences of diabetes, family often provided insights. Zoe, a mother of five with T2DM from a remote community, had a family history of diabetes. She described how family educated her about hypoglycaemic events and the long-term effects of diabetes. Zoe was well supported by her sister who was “*an Aboriginal nurse*” that “*used to work at the health centre*”. She described how her sister was particularly supportive with promoting healthy eating and would bring her healthy food. Similarly, Indy with T2DM living in an urban community described how she better understood information delivered by health professionals “*only because it’s in the family, my mums got it.*”

Many women identified that having a family member with diabetes increased their own risk of developing diabetes and spoke about the development of diabetes being inevitable. As Evelyn, a woman with GDM from an urban community described, “*I know it’s pretty strong in the family, so I knew I’d either get it sooner or later.*”

## 6.2. Motivational factors

Pregnancy appeared to be a powerful motivator for lifestyle change for many of the women interviewed. Jemma, who had GDM and lived in an urban community, described how “*I had to [change what I ate when I found out about my diabetes] because I didn’t want [...] my baby to have diabetes.*”

Rosella who lived in an urban community and had T2DM for 13 years, knew a lot about her condition. The effects that diabetes can have on the unborn baby was the catalyst for her to change. When asked what made her take better care of herself she stated:

Having a baby. Like having something inside of me. I would hate to have one of my children go through it, like I’d hate for one of them to have diabetes, you know, and I wouldn’t want them to be putting needles in their stomach at a young age or you know, going through it all. So I took [...] my insulin all the time [...] it was hard.

In contrast, the fear of not being able to return to community was Indy’s motivation for managing diabetes:

I don’t want it to get worse, that I have to go on insulin as I’m getting older. That’s the worst thing [...] I’m wanting to live out bush, remote, and I think that’s my biggest worry.

### T2DM, urban community

For other participants the negative symptoms of diabetes encouraged them to make changes. For example, participants described how they felt “*no good*”, “*weak and lazy*”, and “*tired*”.

However, some participants identified a lack of overt symptoms as contributing to sub-optimal management. Jemma was confused by her diagnosis of GDM “*What are the symptoms? That’s the thing [...] it’s really complicated. I didn’t even know I had it [...]*”. Similarly, Rosella also seemed puzzled by her T2DM diagnosis:

I never had the symptoms of going to the toilet, being thirsty, all those signs and symptoms [...] they say you’re sick, or that your cuts take a long time to heal. All mine healed really good.

### T2DM, urban community

For Rosella, having this *silent condition* affected her medication taking. She described how when “*I [...] feel fit and healthy [I questioned] why do I need them?*”

There many other examples given by participants that impacted on motivation, highlighting competing priorities in their lives, including caring responsibilities for children and family, comorbidities and dealing with grief and loss (including the death of a family member).

## 6.3. The need for culturally appropriate messages, education and respecting family structure

Many participants with experiences of hyperglycaemia in pregnancy wanted information and care to be provided in ways that were respectful and accessible. This included improving the ways messages were being delivered. It was suggested that information would better reach women if we:

... start putting it out in the media and putting it out in our language. Telling our people that it’s wrong to eat hot food all the time, like food made in the shop. It’s right to cook your own food, where you can be healthy and just start living off the land, getting bush food and that.

### Jemma, GDM, remote & urban communities

Other suggestions included delivering information using “more pictures than wording”, “photos [...] showing them what they should be eating and what effects it will have on them”, “show them video [...] then have talk.” Furthermore, providing information in multiple languages was also recommended as a strategy for improving knowledge transfer.

Many women mentioned the need for aunties or grandmothers to be involved in sharing diabetes education messages. Trinity believed the best way to teach young women about diabetes is “... one day at the camping for young, for them out bush ... women’s stuff out bush” taught by the “*older ladies*”. Zari (GDM,

remote community) believes that young girls will listen to “. . . old women, old ladies”.

Two of the Aboriginal Health Practitioner's were interested in learning more about hyperglycaemia in pregnancy so that they could be more involved in sharing educational messages. Bindi, an urban Aboriginal Health Practitioner, explained how it would be good to:

. . . us[e] me as an Aboriginal Health Practitioner a bit more effectively [ . . . ] I'd be happy to [ . . . ] learn, up-skill for myself, but also, you know just learn, you know, some more about diabetes in pregnancy and how [ . . . ] they [doctors/diabetic educators] actually go about it, you know what are [ . . . ] they actually teaching, [ . . . ] so that [education] is not just left up to them.

#### 6.4. Access to appropriate, respectful and inclusive maternity care

Relationships with supportive, long-term health professionals were valued by participants and promoted engagement with clinics. Kaylee (GDM, remote community) described how “it takes a lot for like local ladies, like even myself, to warm up . . . to someone.” She also said that “if you get them bad ones come through and are a bit rough with you” the consequence is that it “puts that ( . . . ) gap there even further, and they don't want to go to clinic.” Similarly, despite having many questions about her diabetes, Lina (GDM, remote community) did not approach the midwife in her community as she felt that they were “not [ . . . ] comfortable with me”.

Established relationships also enhance the quality of care provided. For example, Indy found that because of her relationship with midwives at the clinic they “. . . knew I didn't look well”. She needed a subsequent blood transfusion which she believes she may otherwise not have received.

Other examples of where opportunities to improve continuity of care exist is when women are transferred to urban centres for specialist care. Trinity, a mother of four with GDM who lived in a remote community, was transferred to Darwin four times during her pregnancy. This client described inconsistency with seeing the midwife allocated to her when in town and could not remember this health professionals' name.

Another factor contributing to challenges in establishing meaningful relationships and providing continuity of care were highlighted. As Lina described:

You get your really good one that you want to keep in community and is really good with community, and then they get whizzed off to somewhere else. And then you'll get like agency mob come in that [ . . . ] say they're paying off their mortgage somewhere; they're not here for the right reasons to work in community.

(GDM, remote community)

Bindi, an urban Aboriginal Health Practitioner noted the importance of long-term remote staff and implications for continuity of care. When she requires information about a client: I go back to the midwife or the RN on the community and whether their long term staff or, you know community members themselves, well they've worked at the clinic for some time so . . . they know their history of that family and . . . when they do present and they are pregnant . . . you know that that staff member [will make] sure that [diabetes] is on that care plan because they've got that underlying history [ . . . ] the nurses going out following children up for immunisations . . . they'd get a good snapshot of who their . . . clientele is and the families that actually have those chronic diseases.

## 7. Discussion

The findings of this study demonstrate the limitations of current health messaging and education surrounding prevention and management of hyperglycaemia in pregnancy for Aboriginal women in the NT. While simple messages about diabetes and associated health behaviours were generally understood by participants, many did not link this information back to their own specific condition. In addition, there was limited in-depth knowledge among participants, some of which was associated with inappropriate delivery of diabetes education. Health care providers also spoke of difficulties communicating with women and were sometimes at a loss to understand why women did not heed the information they provided about the risks of hyperglycaemia in pregnancy. This highlights the disconnect between Aboriginal and Western worldviews and understandings of health.

The findings from this study are consistent with previous research that has identified poor understanding of common health messages regarding chronic diseases among Indigenous adults (21,22). In one study of Indigenous pregnant women with rheumatic heart disease, limited understanding of the severity of this illness was linked to ineffective communication by health care staff with health messages based on a biomedical model, and culturally inappropriate care (22). Effective communication in this context was considered critical for community members to integrate Western biomedical explanations (related to causes, consequences and management of chronic disease) with their own health knowledges based on Aboriginal world views. Previous research has also found that shared understandings of key health concepts about renal disease are rarely achieved between health professionals and Aboriginal renal patients (23). These findings support the recommendation from this study that for health messages to be effective, they need to be culturally relevant and align with the context and realities of women's lives. It is important that in collaboration with senior women and families in the community, the Aboriginal health workforce lead the development of these messages and strategies for effective dissemination within health services as well as across the wider community.

Our findings also align with previous research that highlights the limitations of mainstream health care approaches for type 2 diabetes care among Indigenous populations in Canada. In particular, care that was based on the Western biomedical model of health was found to have limited acknowledgement of and engagement with Indigenous worldviews (24), including wider holistic understandings of health and wellbeing, and spiritual dimensions (25). This has relevance to Aboriginal communities in Australia, with previous research showing that the predominant Western medical management of diabetes, including treatment protocols informed by bio-medical knowledge, can challenge the personal autonomy at the core of Aboriginal social identity (26). Thus, identifying as having a chronic illness could impact on participation in some ritual and social functions that are central to identity. As a result, diabetes may be publicly ignored or denied. This provides insight into the complexities that may impact on Aboriginal women's engagement with health services, including diabetes education and health messaging around hyperglycaemia in pregnancy. We recommend the delivery of care surrounding hyperglycaemia in pregnancy be redesigned to encompass Western and Indigenous perspectives. It is crucial that Aboriginal health staff and community members are central to the re-design and implementation of these approaches, to ensure relevance to local contexts (14).

The need to involve family in the development and dissemination of health messages and subsequent support of women with hyperglycaemia in pregnancy was a key finding of this study. Participants who had family members with diabetes or who worked in health reported that they were a good source of

information and support, as were Aboriginal Health Practitioners, Strong Women Workers and elders. This aligns with literature documenting that family are important sources of support, particularly in the management of chronic conditions (27). We recommend strategies for families to be more engaged in the management of hyperglycaemia in pregnancy: enhancing families' understandings of the condition and establishing practical supports for women. This is in line with family-centred care models which may be more beneficial in collectivist cultures (28).

The findings from this study also highlight the need to consider broader structural factors that influence the management of hyperglycaemia in pregnancy. Many psychological and health promotion approaches adopted in mainstream health care focus on increasing individual-level knowledge to promote behaviour change. However, knowledge alone does not produce behaviour change (29), and a focus solely on behaviour situates responsibility entirely on the individual, downplaying the social and material circumstances that constrain opportunities for good health. By acknowledging a social realist perspective, the interplay of individual agency with social and structural determinants of health can be better understood in the delivery of care (30,31). In the NT setting, factors such as material poverty (including food security), high levels of distress, caring responsibilities and cultural obligations need to be considered when designing health systems and policy to improve diabetes related support.

Meaningful relationships with health professionals and continuity of care were valued by women in this study as important for the management of hyperglycaemia in pregnancy and their pregnancy care overall. As described by Jennings (32), it is important that these approaches are underpinned by equity, with attention to reducing power differentials by promoting respect. In recent years there have been a number of important initiatives in the NT that have been implemented to improve the continuity of care for Aboriginal women. These include the introduction of the Midwifery Group Practice for some women in remote areas (33), integration of maternity services to improve access to services based on clinical need (34) and work of the NT DIP Partnership to improve co-ordination of care (9). Early evaluation of these approaches have produced promising findings, particularly in relation to improved information systems (including referral pathways), more culturally responsive services and increased client satisfaction (11,16,35).

A comprehensive approach to improving care that builds on existing strengths and current initiatives is required. This should include Continuous Quality Improvement activities that focus on strengthening organisational systems and processes to improve quality of care and the provision of culturally appropriate care (36). Such initiatives have been found to improve screening for hyperglycaemia in pregnancy at primary health care centres attended by Aboriginal and Torres Strait Islander women (37). Despite this, the high staff turnover and lower numbers of Aboriginal Health Practitioners have been a major challenge for primary health care services that will continue to affect opportunities for health service improvements (10). Continuing to strengthen the Aboriginal workforce as well as sustained provision of cultural safety training for the non-Indigenous workforce are critical to improving the delivery of care (10,38,39).

Pregnancy is an opportune time to enhance health knowledge, promote behaviour change and supports, and support healthy outcomes for mother and infant. This is critical for women who have a pregnancy complicated by diabetes, or for those in the pre-pregnancy period. It is important that recommendations from this study extend beyond the pregnancy period, to increase support for women during the post-partum period and through to pre-pregnancy (inter-pregnancy if applicable). This will improve outcomes for any subsequent pregnancy and for the woman's health in the longer term.

Strengths of this study include in-depth interviews with a large number of Aboriginal women across diverse regions of urban, rural and remote northern Australia. Culture and language of Aboriginal people remains very strong in our region and Aboriginal people contributed to the study design, data collection, interpretation and presentation of findings. Limitations include that all participants declined the offer of an interpreter as they felt confident undertaking the interview in English. Despite this they reported that many women require more education in language.

In conclusion, we report the need for improvements in culturally safe and appropriate education and care of Aboriginal women with hyperglycaemia in pregnancy in the NT. Opportunities to enhance women's understanding and experiences were revealed and will inform future work to improve care and outcomes of this condition. It is crucial that Aboriginal women, families, communities and health staff are central to changes to design and delivery of care for Aboriginal women with hyperglycaemia in pregnancy.

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## Ethical statement

Ethics approval was obtained from the Human Research Ethics Committee prior to commencing this research in both the Top End (HREC 2017-2819 and HREC 2015-2461) and Central Australia (HREC 15-345). It was guided by the NHMRC roadmap for respectfully conducting research with Aboriginal people.

## Conflicts of interest

None declared.

## CRediT authorship contribution statement

**R. Kirkham:** Conceptualization, Methodology, Data curation, Data curation, Writing - original draft. **S. King:** Formal analysis, Writing - original draft. **S. Graham:** Data curation, Formal analysis. **J.A. Boyle:** Conceptualization, Writing - review & editing. **C. Whitbread:** Conceptualization, Writing - review & editing. **T. Skinner:** Conceptualization, Writing - review & editing. **A. Rumbold:** Conceptualization, Formal analysis, Writing - review & editing. **L. Maple-Brown:** Conceptualization, Supervision, Writing - review & editing.

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## References

- [1] S.B. Harris, J.W. Tompkins, B. TeHiwi, Call to action: A new path for improving diabetes care for Indigenous peoples, a global review, *Diabetes research and clinical practice* 123 (2017) 120–133.

- [2] L.J. Maple-Brown, D. Hampton, Indigenous cultures in countries with similar colonisation histories share the challenge of intergenerational diabetes, *The Lancet Global Health* 8 (5) (2020) e619–e620.
- [3] Y. Yu, O.A. Arah, Z. Liew, S. Cnattingius, J. Olsen, H.T. Sorensen, et al., Maternal diabetes during pregnancy and early onset of cardiovascular disease in offspring: population based cohort study with 40 years of follow-up, *British Medical Journal*. 367 (2019) 16398.
- [4] E.A. Sellers, H.J. Dean, L.A. Shafer, P.J. Martens, W. Phillips-Beck, M. Heaman, et al., Exposure to Gestational Diabetes Mellitus: Impact on the Development of Early-Onset Type 2 Diabetes in Canadian First Nations and Non-First Nations Offspring, *Diabetes care* 39 (12) (2016) 2240–2246.
- [5] Australian Institute of Health and Welfare, *Diabetes in pregnancy: its impact on Australian women and their babies* Canberra, (2010) .
- [6] B. Voaklander, S. Rowe, O. Sanni, S. Campbell, D. Eurich, M.B. Ospina, Prevalence of diabetes in pregnancy among Indigenous women in Australia, Canada, New Zealand, and the USA: a systematic review and meta-analysis, *The Lancet Global Health*. 8 (5) (2020) e681–e698.
- [7] L. Li, L. O'Neil, *Mothers and Babies 2015*, Department of Health, Northern Territory, 2018.
- [8] C.R. Chamberlain, B. Oldenburg, A.N. Wilson, S.J. Eades, K. O'Dea, J.J. Oats, et al., Type 2 diabetes after gestational diabetes: greater than fourfold risk among Indigenous compared with non-Indigenous Australian women, *Diabetes/metabolism research and reviews* 32 (2) (2016) 217–227.
- [9] L. Edwards, C. Connors, C. Whitbread, A. Brown, J. Oats, L. Maple-Brown, Improving health service delivery for women with diabetes in pregnancy in remote Australia: survey of care in the Northern Territory Diabetes in Pregnancy Partnership, *The Australian & New Zealand journal of obstetrics & gynaecology* 54 (6) (2014) 534–540.
- [10] J. Wakerman, J. Humphreys, D. Russell, S. Guthridge, L. Bourke, T. Dunbar, et al., Remote health workforce turnover and retention: what are the policy and practice priorities? *Human resources for health* 17 (1) (2019) 99.
- [11] R. Kirkham, J.A. Boyle, C. Whitbread, M. Dowden, C. Connors, S. Corpus, et al., Health service changes to address diabetes in pregnancy in a complex setting: perspectives of health professionals, *BMC health services research* 17 (1) (2017) 524.
- [12] S.J. Thompson, S.M. Gifford, Trying to keep a balance: the meaning of health and diabetes in an urban aboriginal community, *Social science & medicine* (1982) 51 (10) (2000) 1457–1472.
- [13] Douglas VK. *The Inuulitsivik Maternities: culturally appropriate midwifery and epistemological accommodation*. 2010;17(2):111-117.
- [14] S. Campbell, N. Roux, C. Preece, E. Rafter, B. Davis, J. Mein, et al., Paths to improving care of Australian Aboriginal and Torres Strait Islander women following gestational diabetes, *Primary health care research & development* 18 (6) (2017) 549–562.
- [15] Australian Bureau of Statistics, *Census Data Summary: Aboriginal and Torres Strait Islander population*, (2016) [11 July 2018]. Available from: <https://www.abs.gov.au/ausstats/abs@nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Aboriginal%20and%20Torres%20Strait%20Islander%20Population%20Data%20Summary~10>.
- [16] C.M. Josif, L. Barclay, S. Kruske, S. Kildea, 'No more strangers': Investigating the experiences of women, midwives and others during the establishment of a new model of maternity care for remote dwelling aboriginal women in northern Australia, *Midwifery* 30 (3) (2014) 317–323.
- [17] Central Australian Aboriginal Congress Aboriginal Corporation, *Alukra Women's Health Service Available from:*, (2020) . <https://www.caac.org.au/client-services/alukura-womens-health-service>.
- [18] National Health and Medical Research Council, *Road Map 2: A strategic framework for improving Aboriginal and Torres Strait Islander health through research*, (2010) .
- [19] B.E. Neubauer, C.T. Witkop, L. Varpio, How phenomenology can help us learn from the experiences of others, *Perspect Med Educ*. 8 (2) (2019) 90–97.
- [20] L.T. Smith, *Decolonizing methodologies: Research and indigenous peoples*, Zed Books Ltd., 2013.
- [21] A. Lowell, E. Maypilama, S. Yikaniwuy, E. Rrapa, R. Williams, S. Dunn, "Hiding the story": indigenous consumer concerns about communication related to chronic disease in one remote region of Australia, *International journal of speech-language pathology* 14 (3) (2012) 200–208.
- [22] S. Belton, S. Kruske, L. Jackson Pulver, J. Sherwood, K. Tune, J. Carapetis, et al., Rheumatic heart disease in pregnancy: How can health services adapt to the needs of Indigenous women? A qualitative study, *Australian and New Zealand Journal of Obstetrics and Gynaecology*. 58 (4) (2018) 425–431.
- [23] A. Cass, A. Lowell, M. Christie, P.L. Snelling, M. Flack, B. Marrganyin, et al., Sharing the true stories: improving communication between Aboriginal patients and healthcare workers, *The Medical journal of Australia*. 176 (10) (2002) 466–470.
- [24] R.S. Pilon, *Promoting a decolonized model of type II diabetes care for Aboriginal peoples living along the North Shore of Lake Huron*, Laurentian University of Sudbury, 2015.
- [25] R. Bell, C. Smith, L. Hale, G. Kira, S. Tumilty, Understanding obesity in the context of an Indigenous population—A qualitative study, *Obesity Research & Clinical Practice*. 11 (5) (2017) 558–566.
- [26] F. Dussart, "It is hard to be sick now": Diabetes and the reconstruction of indigenous sociality, *Anthropologica* 52 (1) (2010) 77–87.
- [27] C. Aspin, N. Brown, T. Jowsey, L. Yen, S. Leeder, Strategic approaches to enhanced health service delivery for Aboriginal and Torres Strait Islander people with chronic illness: a qualitative study, *BMC health services research* 12 (1) (2012) 143.
- [28] H. Deek, S. Hamilton, N. Brown, S.C. Inglis, M. Digiacomio, P.J. Newton, et al., Family-centred approaches to healthcare interventions in chronic diseases in adults: a quantitative systematic review, *Journal of advanced nurs.* 72 (5) (2016) 968–979.
- [29] E. Barry, T. Greenhalgh, N. Fahy, How are health-related behaviours influenced by a diagnosis of pre-diabetes? A meta-narrative review, *BMC medicine* 16 (1) (2018) 121.
- [30] M. Archer, *Taking time to link structure and agency. Realist Social Theory: The Morphogenetic Approach*, Cambridge University Press, Cambridge, 1995, pp. 65–92.
- [31] J. Connelly, Critical realism and health promotion: effective practice needs an effective theory, *Health Education Research*. 16 (2) (2001) 115–120.
- [32] W. Jennings, C. Bond, P.S. Hill, The power of talk and power in talk: A systematic review of Indigenous narratives of culturally safe healthcare communication, *Australian Journal of Primary Health*. 24 (2) (2018) 109–115.
- [33] Banskott Health Consulting Pty Ltd, *Maternity Services Review in the Northern Territory*, (2007) .
- [34] *Top End Health Service. Project Closure Report, Maternity Services Integration*, 2016/17–2017/18. Darwin; 2020.
- [35] Y. Gao, L. Gold, C. Josif, S. Bar-Zeev, M. Steenkamp, L. Barclay, et al., A cost-consequences analysis of a Midwifery Group Practice for Aboriginal mothers and infants in the Top End of the Northern Territory, Australia, *Midwifery* 30 (4) (2014) 447–455.
- [36] M.E. Gibson-Helm, A.R. Rumbold, H.J. Teede, S. Ranasinha, R.S. Bailie, J.A. Boyle, Improving the provision of pregnancy care for Aboriginal and Torres Strait Islander women: a continuous quality improvement initiative, *BMC pregnancy and childbirth* 16 (2016) 118.
- [37] M.E. Gibson-Helm, H.J. Teede, A.R. Rumbold, S. Ranasinha, R.S. Bailie, J.A. Boyle, Continuous quality improvement and metabolic screening during pregnancy at primary health centres attended by Aboriginal and Torres Strait Islander women, *The Medical journal of Australia*. 203 (9) (2015) 369–370.
- [38] B.U. Devsam, F.E. Bogossian, A.S. Peacock, An interpretive review of women's experiences of gestational diabetes mellitus: proposing a framework to enhance midwifery assessment, *Women and birth* 26 (2) (2013) e69–76.
- [39] S. Kildea, Y. Gao, M. Rolfe, C.M. Josif, S.J. Bar-Zeev, M. Steenkamp, et al., Remote links: Redesigning maternity care for Aboriginal women from remote communities in Northern Australia – A comparative cohort study, *Midwifery* 34 (2016) 47–57.