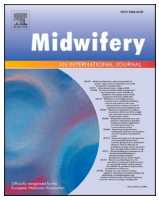
Midwifery 141 (2025) 104277

Contents lists available at ScienceDirect

Midwifery

journal homepage: www.elsevier.com/locate/midw



'Walking the journey' with pregnant and birthing women from remote Australian First Nations communities: A qualitative study in the Top End of the Northern Territory

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ARTICLE INFO

Keywords:
Remote and very remote communities
First Nations
maternity care
cultural determinants of health
cultural safety
systemic disadvantage

ABSTRACT

Problem/Background: Australian First Nations people experience disproportionate burdens of poor outcomes compared to non-First Nations people. Further, women living in remote communities face more barriers to care-seeking in pregnancy. Despite work being done in some remote communities, there is limited data exploring women's experiences of pregnancy care, thus a limited understanding of specific barriers and enablers to care-seeking for these women.

Aim: This study aimed to identify barriers and enablers to care-seeking during pregnancy for Australian First Nations women living in several remote communities in the Northern Territory, by listening to their stories.

Methods: Yarning, highly regarded and rigorous qualitative approach developed by and for First Nations peoples, was undertaken in several settings with women living in remote First Nations communities. Using purposive sampling, nine women participated.

Findings: Two themes emerged: (1) the importance of family and community for women's emotional wellbeing; (2). ways healthcare providers and services build trust with pregnant women.

Discussion: Women identified various family and community members as significant sources of support in community and while hospitalised, including having companions while away from home. Further, reduced access to community life impacted emotional wellbeing.

Continuity-of-care throughout pregnancy was essential for building trust, as was responsive, clear communication. Intentional connection building by care providers enabled development of trust.

Conclusion: Providing culturally safe care will likely facilitate enablers and reduce barriers to care-seeking in pregnancy in remote communities. It requires ongoing and sustained efforts to ensure true partnership and collaboration between First Nations peoples and health services.

Introduction

Australian First Nations women and babies, particularly those living in very remote communities, continue to experience a disproportionate burden of poor perinatal outcomes when compared to their non-First Nations counterparts (AIHW, 2023; NTG, 2020; ABS, 2021). Inadequate access to safe housing, limited opportunities for education and employment (AIHW, 2022a), and irregular contact with specialist medical services, contribute significantly to this gap in health outcomes between Australian First Nations and non-First Nations peoples (AIHW, 2022b).

As recommended by the World Health Organization (WHO) (WHO, 2017) and supported by a recent systematic review and metanalysis (Bowden et al., 2023a), providing maternity services over and above what is currently considered 'routine care', primarily in the form of continuity models of care, increases utilisation of maternal health

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https://doi.org/10.1016/j.midw.2024.104277
Received 21 February 2024; Received in revised form 17 October 2024; Accepted 20 December 2024
Available online 25 December 2024

services, improves outcomes for neonates and improves women's experience of pregnancy care. Further, culture specific continuity models like this have been shown to decrease levels of smoking, increase feelings of trust and safety, and result in high levels of satisfaction with care for First Nations women in some urban settings (Hartz et al., 2019; McCalman et al., 2023). In one very remote community in the Top End of the Northern Territory training of a First Nations doula workforce, referred to as Djäkamirr, has commenced, and work is ongoing in that same community to establish a '*national very remote exemplar demonstration Birthing on Country maternity service*' (Ireland et al., 2022). There is, however, insufficient data from other very remote communities in the Top End of the Northern Territory exploring women's experiences in the maternal health care system, resulting in a limited understanding of specific barriers and enablers to seeking care in pregnancy for these women.

The purpose of this study was to identify barriers and enablers to care-seeking in pregnancy for Australian First Nations women living across the Top End of the Northern Territory in very remote communities by listening to their experiences of pregnancy care.

Issue/Problem	Women living in remote First Nations communities commence pregnancy care later, have fewer appointments, and experience poorer outcomes than women living in cities.
What is already known	First Nations residents of remote communities commonly face systemic disadvantage and poorer health stemming from disproportionate exposure to adverse social and cultural determinants of health, as ongoing effects of colonisation.
What this paper adds	This qualitative study involving nine Australian First Nations women from remote communities in the Northern Territory (Australia) highlights the importance of family and community in women's wellbeing, and ways health care providers and services build trust, thus enabling care-seeking in pregnancy.

Research approach

Methods

Methodology

In this study, we used a similar methodology to our previous paper (Bowden et al., 2023b), whereby a decolonising approach was employed to prioritise the voices of Australian First Nations people, seeking to honour First Nations ways of being and doing, with Yarning as the chosen method of engagement. Decolonizing approaches acknowledge that First Nations ways of knowing have historically and willfully been reshaped and restructured using Western frameworks and worldviews and seek to privilege First Nations voices (Kennedy et al, 2022). While respecting and acknowledging the origins of Yarning, the authors approach its use in this context with sensitivity and a commitment to ethical research. Described in greater detail elsewhere, its use by non-First Nations researchers is not without contention (Bowden et al., 2023b). However, Yarning in this context was used with the permission of, and modelled by, a co-author and experienced First Nations researcher.

Yarning has emerged as a highly regarded and rigorous approach for qualitative research with Australian First Nations peoples (Bessarab and Ng'andu, 2010). Bessarab and Ng'andu (2010) describe Yarning during a semi-structured interview as "*an informal and relaxed discussion through which both the researcher and participant journey together visiting places and topics of interest relevant to the research study*." Further, they go on to say that "*Yarning is conducive to an Indigenous way of doing things; its strength is in the cultural security that it creates for Indigenous people participating in research*." Thus, Yarning allows participants to control the direction and pace of the dialogue, while facilitating mutual exchange of knowledge between all those present.

Yarning was undertaken in two main settings (Darwin and East Arnhem Land) with women who ordinarily live in very remote First Nations communities from the Top End of the Northern Territory. Yarnings commenced with introductions, including family and heritage connections, and an explanation of the purpose of the study. A simple open-ended question asking women to share their pregnancy journey story was the catalyst for ongoing discussion. A list of trigger questions and follow up prompts was available throughout the yarn (see Supplementary file Table 1), and a distress protocol approved by the HREC was in place if required (see Supplementary file, Fig. 1).

To maximise the safety of participants, author and experienced First Nations qualitative researcher was present for the first four yarns who provided reflections and learnings to the first author after each one. However, the First Nations researcher was unavailable for the other yarns due to limited funds available for this study. In addition, a First Nations Strong Woman Worker from the local community in East Arnhem Land was also present for those four yarns. Strong Women Workers are First Nations women employed at the local primary health care centres to support First Nations women during pregnancy by providing education, assistance, and encouragement in a variety of ways, including with the incorporation of traditional ceremonies for women and babies.

The recommended Yarning protocols as described by Barlo et al (2020) were adhered to, thus promoting participant safety, equality, and shared responsibility for each woman (see Table 1).

Settings/context

The Northern Territory of Australia is home to over 230,000 people: 26.3% identifying as Australian First Nations (ABS, 2021). Of these, 76.1% live outside of the broader Darwin region, in areas defined as 'remote' or 'very remote' (ABS, 2021). Antenatal care for normal risk pregnancies is usually provided by the local primary health care centre, however, care for high-risk pregnancies is significantly restricted in many remote and very remote communities and publicly funded birthing services are only provided at four hospitals across the Northern Territory (NTG, 2023a). There is, therefore, an expectation by health services that women relocate to one of these areas for birthing, often from 37 weeks gestation, or earlier if a high-risk pregnancy or birth is anticipated (NTG, 2023a). Costs associated with relocation, including travel and accommodation for the woman, and an escort (with restricted criteria), are covered by the federally funded Patient Assistance Travel Scheme (PATS) (NTG, 2023b).

Design

Using purposive sampling, Australian First Nations women normally living in a very remote community; nearing the end of their pregnancy; or who had given birth in the previous 12 months; and spoke English or consented to the use of an interpreter were recruited. Women were excluded if they were under 18 years of age; experienced a perinatal

Table 1
Yarning protocols.

Gift	As the participant shares knowledge, they are giving a gift, and the researcher receives this gift by accepting and valuing the knowledge shared.
Control/agency	The participant determines the length and direction of the yarn. The yarn is not constrained to talking but can be in the form of talking or drawing. The most appropriate method is determined by the participant.
Freedom	What and how the participant chooses to share is freedom.
Space	Where the yarning takes place should be thoughtfully considered, comfortable, and culturally safe.
Inclusiveness	Everyone is welcome in the yarning space. The researcher must be actively listening and engaged to receive the gift of knowledge.
Gender specificity	Pregnancy, birthing, and the postnatal period are women's business, and as such, only female researchers will be involved in the yarning sessions. The participants are free to choose whoever they wish to accompany them.

Fig. 1. Map of the Top End of the Northern Territory (https://www.australiantraveller.com/nt/arnhem-land/revealing-arnhem-land/).

death during the current or most recent pregnancy; or if their baby had a significant, documented congenital abnormality. Recruitment was facilitated via the regional hospital and a Families as First Teachers (FaFT) group (NTG, 2024), in East Arnhem Land and the Tertiary Hospitals Midwifery Group Practice (remote team) in Darwin. Women were approached by health professionals or program managers at each of these sites to assess their interest and availability. This was determined to be a culturally safe approach due to previously established relationships and thus allowing the women to decline participation without discomfort. One small yarning circle and five individual yarns took place in East Arnhem Land with a First Nations Strong Woman Worker present for the yarning circle and three of the individual yarns in East Arnhem Land, where she provided cultural guidance and acted as interpreter. This was invaluable as she either knew the women already or was able to quickly establish rapport and trust by discussing relationships or acquaintances they had in common and using a shared language. The co-author and experienced Aboriginal qualitative researcher participated on those occasions also.

In another yarn, the participant's mother was present acting as a support person, and for another yarn, a woman declined the involvement of anyone else. A further two individual yarns took place in Darwin, with women either waiting to give birth, or return home following the birth of their baby.

Where specific consent for audio-recording was provided (n=4), these recordings were transcribed verbatim soon after the yarn and saved in a password protected database accessible only to them and stored at the research institution. Where consent for audio recording was declined (n=5), copious notes were taken by two people, transcribed immediately and notes compared. It was not possible to send a written transcript to all participants as many did not have access to email or a computer. Therefore, at the end of each yarn, a verbal summary was made and agreed upon by all those participating.

Data collection

Nine women from six Top End communities of the Northern Territory participated in the study, seven from East Arnhem Land, one from The Tiwi Islands, and one from West Arnhem Land. None of the women approached declined to participate. The yarns, following the protocols described above, took place over a 12-month period from July 2022 to July 2023, with each yarn lasting 20 – 90 minutes. At the conclusion of the yarn, women were presented with a gift voucher for their local supermarket as a token of appreciation for sharing some of their story. Data collection continued until saturation was reached across participants.

Data analysis

Interview transcripts were read multiple times by the primary author to familiarise and immerse themselves with the data. A thematic analysis approach was used and patterns, as they emerged during transcription and reading, were coded. A list of codes was developed and sorted into sub-themes. All coded data were re-read and their position within the sub-themes was reviewed and discussed with an experienced qualitative researcher and co-author. Data forming sub-themes were refined into themes, as described below, and supported by participant quotes. A Coding Process Table was generated (see supplementary file, Table 2). Recruitment ended when the data were characterised by repetition across participants, indicating saturation. NVivo software (NVivo, 2017) was used to organise the data for management and analysis.

Results

Nine women participated in yarns, see Table 2 – Participant Characteristics. Five women were in the final weeks of their pregnancy and were staying in either a regional town or major city for what is colloquially known as 'sit-down', a term used to describe women who have

Table 2
Participant characteristics.

Characteristic	No. of participants
Ethnicity	
Aboriginal	8
Torres Strait Islander	1
Age group	
18 – 25 years	4
26 – 30 years	5
Language used at home	
First Nations language	7
English	2
*SEIFA score**	
1	8
8	1
Parity	
Primpara	5
Multipara	4
Antenate	5
Postnate	4

* The SEIFA is a system of national rankings of suburbs socio-economic status (SES), derived from over 30 variables collected in the National Census. A higher SEIFA score indicates higher SES for the area. Conversely, a lower SEIFA score indicates a lower SES. (2018)

relocated to an area where birthing facilities are available. The remaining four women had given birth between two days and six months prior. All women came from communities denoted as 'very remote' by The Australian Statistical Geography Standard Remoteness Structure (ABS, 2021).

All women received at least part of their antenatal care in their home community. One woman had to relocate to town relatively early in her pregnancy due to risk factors that were deemed unable to be managed safely in a very remote community without regular obstetric coverage. All but two of the remaining women were able to stay in their home community until 36–37 weeks' gestation, before being required to relocate for 'sit-down'. The other two women lived in a community 10 minutes' drive from a regional hospital providing birthing services and were, therefore, able to stay at home until they either were admitted antenatally for a complication (n=1) or went to hospital for labour/birthing care. Of the seven participants required to relocate for birthing, five were eligible for an escort either because it was their first baby (n=3), or their youngest child was under two years of age and therefore allowed to accompany the woman with an escort. One woman was supported through a local non-government organisation who paid for an escort, while three had to 'sit-down' alone.

Theme one: the role family and community play in wellbeing

The first major theme to emerge was the crucial role family and community play in the emotional wellbeing of First Nations women living in remote communities. Emotional wellbeing can be defined as "*a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community. It is an integral component of health and well-being that underpins our individual and collective abilities to make decisions, build relationships and shape the world we live in*" (WHO, 2022). The women in this study identified several factors that contributed to their wellbeing, both while in community and when away from home awaiting the birth of their baby. Some of these factors were further identified as enablers to seeking care. Others, while not specifically barriers to seeking care, did contribute to women's sense of disconnection when away from home. For example, many of the women interviewed talked about the importance of Strong Women Workers being embedded in their community health centre. Aspects of their role identified as valuable by women included using a common language to provide culturally safe explanations and going '*down the track*' with the women. In effect, Strong Women Workers were key people providing support for women as they journeyed through pregnancy.

> *"It was really good to have someone go down the track, along the journey with you" (Participant 3 about Strong Woman Worker)*

The role of Strong Women Workers was not exclusive to the community setting. One woman who relocated far from family for her birth expressed gratitude that a Strong Woman Worker at the hospital stopped by for a visit postnatally. Having '*kin*' to talk to and '*fuss*' over the baby made her feel special and less lonely.

In addition to Strong Women Workers, other female community members, including mothers, aunties, and grandmothers, were identified as a significant source of support and as the people who passed pregnancy and birthing knowledge to the next generation. Women who re-locate early for pregnancy care are at risk of missing out on aspects of this, thus highlighting the importance of remaining connected to community for as long as possible. In addition to this passing on of knowledge, being in community enables women to participate more fully in other important aspects of community life such as sorry business (mourning and grieving practices used to pay respects to deceased loved ones or community members). Missing out on these while 'sitting down' is a great sadness for many women.

> *"Feeling homesick…sorry business happening now" (Participant 4 during 'sit down')*

Other family members, including partners, also appeared to play a major role in maternal wellbeing. For a minority of women, family were reported as causing stress and being a bad influence, principally in terms of diet. However, for most women, it was incredibly important to have family around them, particularly in the context of 'sit down'. Women who had to 'sit down' alone reported feeling '*homesick*', '*lonely*', '*bored*', '*scared*', '*uncomfortable*', often for many weeks. Missing their partner and other children made the time '*long and lonely*'. Conversely, women who did have family with them while 'sitting down' stated that their partners were able to help with managing their diet and medications and provided companionship during prolonged times of waiting.

> *"Yeah, I was uncomfortable, I wasn't thinking straight, plus I got distracted taking my medication. I needed to get him to come and be with me. Well, he is now, but it was stressful at that time" (Participant 7 on being alone during 'sit down'. Partner eventually supported by a non-government organization to come as escort)*

Further highlighting the important role escorts play, some women shared that when difficult or urgent conversations were required, often while in hospital, thinking and conversing in English became more difficult despite having high levels of proficiency in English. The presence or absence of a family member or Strong Woman Worker to provide support at these times could have a significant impact on the outcome of those conversations.

Theme two: Building trust

The second major theme to emerge was the ways in which care providers and services can build trust with pregnant and birthing First Nations women in remote communities.

Continuity with the same care provider throughout the pregnancy was identified as vital. It was seen as preferable to have the same midwife caring for them, not only throughout the pregnancy, but also from one pregnancy to the next. It meant that women did not have to constantly retell their story, and there was a pre-established trusting relationship. Having a new or a different midwife, either at different times throughout the pregnancy or from one pregnancy to the next, and therefore requiring an investment of time to build trust, was described as 'hard'.

> *"Yeah, that's the hard bit because they* [midwives] *are always changing" (Participant 9 on midwifery care in community)*

Midwives were identified by the participants as ones entrusted with knowledge about pregnancy, and some of the women stated that they would wait to ask the midwife rather than speak to a family member or other person in the community about their concerns. Midwives being present at all times in community was more desirable, with women describing '*holding onto*' their questions or concerns if a 'fly-in-fly-out' model of pregnancy care (midwives and/or doctors visit intermittently) was the only option available.

Regular or consistent care by the same medical doctor was also identified as a key factor, however, few of the communities had a doctor on site who could provide care for higher risk pregnancies. Most obstetric trained doctors were 'fly-in-fly-out', and this meant that some women had to relocate relatively early in their pregnancy to be near a facility that could provide regular care. The disadvantages of this included time separated from family and community and thus separated from their familial and cultural support networks.

Communication that was responsive, clear, and actively mitigated against power differentials between health care provider and consumer, was another key building block for trust. Where clear communication was lacking or focused more on complications, women reported feeling fearful. In contrast, unhurried and calm communication from well prepared clinicians allayed fears and women reported feeling comfortable. Overall, midwives and doctors were characterised as patient, supportive and able to provide a range of options for the women to consider.

> *"Yeah, she's not in a rush. That's what made* [me] *feel really good" (Participant 4, about midwife caring for her)*

For some women, doctors and midwives were characterised as '*being there*' and '*available to listen*', and as a result those women reported feeling safe despite complications occurring because health care providers invested time with the women, listening to their concerns. Interestingly, despite the challenges of relocating for birthing and the disruption to families, the women in this current study, when surrounded by health care professionals who they had developed trust with, preferred to birth in hospital as it made them feel '*safe*'. Smaller, regional hospitals were perceived by women to be more '*personal*' and '*calmer*' than the larger tertiary facility, and thus the preferred option for many of the women.

> *"I had a really good experience. Like, I know a lot of things went wrong, but like, I feel like, yeah, they made me feel safe" (Participant 8 about her complicated birth)*

Where women felt their needs were well understood and responded to, trust was more readily developed. For example, inclusion in the Midwifery Group Practice (MGP) was identified as valuable for the women who were accepted into this model of care. The women felt they were able to develop good relationships with the MGP midwives, who were seen to have a strong understanding of the women's needs and were able to support them in a variety of ways, including referral to 'wrap around' services such as social, financial, and other holistic supports.

> *"They talk to you, and they ask you if you have any worries. They actually sit down and talk to you, make sure that you're not alone and don't have to worry" (Participant 7 about MGP midwives)*

Further, some of the auxiliary services, such as transport to and from appointments, were also identified as enabling access to care. Crucially, support to relocate for pregnancy or birthing care, including flights and accommodation, were considered vital, as the cost would be prohibitively high for women if paying out of their own pocket. Women eligible for an escort were effusive in their praise of the Patient Assisted Travel Scheme (PATS), whereas for those not eligible it meant having to 'sit down' alone or without family support due to the extreme financial burden taking a self-funded escort would have imposed on them.

Finally, intentional connection building by care providers was appreciated by the women and enabled the development of trust. For example, several women in this study expressed appreciation of clinicians who had tried to connect through actions like learning some key words and phrases in 'language'. While accepting they were far from fluent or knowledgeable, this type of gesture had a positive impact on these women. An extension of this was when staff and women did activities together while 'sitting down', particularly those without an escort. It helped to pass the time and imbued the women with a sense of value as relationships developed.

> *"Also,* [midwife] *is a nice lady. We go over every Thursday and meet the women* [staying at hostel for 'sit down'] *…and we take them out for a session, for a walk, visit some Aunties" (Strong Woman Worker participating in 1st yarning circle)*

Further still, several women in this study commented that once back in community with their baby, midwives from the community were sometimes welcomed and encouraged to participate in the smoking ceremony for the baby, conducted to promote the health and wellbeing of newborns and mothers. The honour of being included in these types of significant cultural event is a sign of a trusting, culturally safe relationship.

Discussion

We undertook a qualitative study with nine Australian First Nations women living in very remote communities of the Top End of the Northern Territory to understand barriers and enablers to seeking care by listening to their experiences of care in pregnancy. We found two major themes emerged, adding to the body of knowledge about the type of holistic care that is acceptable to women: the crucial role family and community play in the wellbeing of pregnant and birthing women; and the ways care providers and services can build trust.

The importance of emotional wellbeing for pregnant and birthing women globally cannot be overstated. A recent systematic review of 37 studies from 19 countries, spanning 20 years, concluded that safety and emotional wellbeing were equally valued by most healthy childbearing women, and that maternity services should be designed '*to fulfil or exceed women's personal and social-cultural beliefs and expectation*' (Downe et al., 2018). Echoing this sentiment, there is a growing demand amongst First Nations researchers to focus on cultural determinants of health, in addition to social determinants, to improve the health outcomes for First Nations peoples (Verbunt et al., 2021). While there is a wealth of evidence that social determinants, such as education, employment and housing have a massive impact on health outcomes (Backholer et al., 2021), being too narrow in this approach creates a missed opportunity to recognise and make the most of the structural and cultural contexts that permit other opportunities to improve health outcomes. Verbunt et al (2021) say that '*Cultural determinants of health centre an Indigenous definition of health, concentrating on life-giving values from which individuals, families and communities can draw strength, resilience and empowerment*'. While providing a single definition of First Nations health as being representative of Australian First Nations peoples collectively is not possible, many First Nations peoples take a holistic approach to the definition of health which includes '*physical, social, emotional, spiritual, and ecological wellbeing for the individual and community, and extending beyond a biomedical definition of health*' (Verbunt et al., 2021). For the women in this study, their social, emotional and spiritual wellbeing was enhanced by Strong Women Workers and other female relatives and community members walking alongside them during their pregnancy journey. It is important to note at this juncture, however, that having the Strong Woman Worker in the discussion may have influenced these women's descriptions of the benefits of Strong Women Workers, thus may be a limitation of this study. More likely however, the absence of a Strong Woman Worker able to navigate the space between First Nations and non-First Nations cultures, potentially impacted the quality of the data acquired, just as their absence during pregnancy care impacts the quality of care given. The influential role of those women included

supporting the physical needs of the pregnant and birthing woman, such as facilitating attendance at antenatal appointments through providing transport and interpreting and de-mystifying conversations in the clinic. These are both activities identified as important and therefore prioritised by many health services. More significantly, however, was the social, emotional, and spiritual support offered by the strong female members of the community, including the Strong Women Workers. This manifested itself in the passing along of traditional pregnancy and birthing knowledge from one generation to the next, and more intangibly by the women being present in and participating in significant cultural events in community. Research has found that healing or restorative practices (art, song, and ceremony) can enhance resilience when experiencing racism and generational trauma (Verbunt et al., 2021). Both of these are often cited within the context of First Nations peoples' experiences of colonisation and their impact on health and trust in health services (Gee et al., 2023; Topp et al., 2022). These activities should be further prioritised by health services in community, with the local Elders and family taking the lead, as a way to improve outcomes for women and babies; and by providing the required tools to help build cultural self-awareness, process information and build the culturally safe practice of non-First Nations workers. When not in community, the emotional wellbeing of the women in this study was enhanced by the presence of a companion while 'sitting down', and during labour, birth, and the postnatal period. There is a plethora of evidence indicating that all women, regardless of how many times they have birthed, benefit from having a companion of choice during labour and birth. The one-on-one support that such a companion provides has an actual physiological impact on the neurobiological processes experienced by women in labour, reducing stress and pain (Olza et al., 2020). Further, a Cochrane review investigating the impact of continuous support for women during childbirth (Bohren et al., 2017) in both low-middle and high-income settings, reported that women with continuous support in labour were more likely to have a spontaneous vaginal birth, less likely to report negative feelings about their experience, or to use regional analgesia. In addition, their labours tended to be shorter. Knowing the positive impact that a companion can have on a woman in labour, it seems counterintuitive to restrict escorts for women in 'sit-down', or labour and birth, to cohorts, such as primiparas when it is clearly inferred by this data that all women draw strength, resilience and feel empowered by their presence.

Linked to this first theme of the important role that family and community play in the wellbeing of pregnant and birthing women, is the second theme of ways health care providers and services can build trust, previously eroded by a long history of discriminatory policies (Topp et al., 2022; Yashadhana et al., 2020).

The building of trust can only be done within a framework of cultural safety. Cultural safety is:

> *"is the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible and responsive health care free of racism."* (Dune et al., 2021)

As Williams maintains:

> *"The underpinning tenet of cultural safety is that each person should receive care that considers their unique identities and experiences. In summary, cultural safety provides a means to examine how people are treated in society and how they are affected by the systemic and structural issues and social determinants of health."* (Williams, 2019, p76)

As identified by women in this study, and evident in data from other research from the Top End of the Northern Territory (Josif et al., 2014), continuity of carer, a model of care where the same midwife or small group of midwives provides care to women across the continuum of their pregnancy, is highly desirable for women, with trust being a key feature. The benefits of continuity of carer in pregnancy have been well documented (Bowden et al., 2023a), and includes increased attendance at antenatal appointments, fewer babies being born prematurely or with a low birth weight, fewer babies requiring admission to Special Care Nursery or Neonatal Intensive Care Unit, and more likely to be exclusively breastfeeding on discharge from hospital (Bowden et al., 2023a). Knowing this, all efforts should be made to ensure continuity of carer during pregnancy for these women who shoulder a disproportionate burden of disadvantage. Just as a researcher more fully immersed in the community may have been able to dig deeper in this study as a consequence of pre-established rapport and trust, another limitation of this study, so continuity of carer throughout the pregnancy and from one pregnancy to the next, facilitates trust and sharing of knowledge. Despite all we know however, it is often not the case that women are able to access this model of care Women who relocate for birthing from remote communities into urban settings, however, are often accepted into the MGP program, which offers continuity of care for the time they are in town. The women in this study who were accepted into MGP were highly complementary of the scheme, sentiments which are reflected in a review following the introduction of the MGP more than 10 years ago (Josif et al., 2014).

Another strategy widely implemented to ensure the provision of culturally safe care in many Government and Aboriginal Community Controlled Health Services in the Top End of the Northern Territory of Australia, is the integration of First Nations Health Workers, including Strong Women Workers. These positions can only be filled by Australian First Nations people, with the implicit responsibility that they use their cultural capital to '*enact cultural brokerage and promote cultural safety at the facility level*' (Topp et al., 2022).

Despite the relatively small sample size, the findings from this study echo previous research with Australian First Nations women living in urban Darwin (Bowden et al., 2023b), that universal access to continuity of carer models, would not only provide women with the relational care they are asking for, but would likely address their other identified needs: a desire for trustworthy information; and space for partners or other family members to be involved.

The fact that continuity models of care are not available in all communities, the paucity of Strong Women Worker numbers, that women often have to travel long distances to see an obstetrician or have a routine pregnancy scan, are required to relocate for birthing, and are not always able to have a companion of choice with them because of policy, are symptoms of systemic racism. Systemic racism has been defined as '*the totality of ways in which societies foster racial discrimination, through reinforcing systems of housing, education, employment, earnings, benefits, credit, media,* ***health care****, and criminal justice,* ***and its influences on health****'* (Agarwal et al., 2023) ***(emphasis*** *added)*. Other examples of systemic racism include an insufficient cohort of interpreters, both in community and hospital, reinforcing the patient-provider power imbalance; slow transition of primary health centres from government to First Nations community controlled, denying communities self-determination (McCalman et al., 2021); and insufficient funding relative to burden of illness in First Nations communities (AIHW, 2022b).

Conclusions

Addressing both social and cultural determinants of health in (negotiated) culturally safe ways will likely facilitate enablers and reduce barriers to care-seeking in pregnancy for First Nations women living in very remote communities in the Top End of the Northern Territory, Australia. It will require ongoing and sustained efforts to ensure true partnership and collaboration between First Nations peoples and the health services. Encouragingly, women in this study predominantly reported having a positive experience, both of their care in pregnancy, and during labour and birth. This may be in large part due to the resilience of the women, and the kind and respectful way many of the women reported being treated by individuals within the heath system.

Ethics approval and consent to participate

This study is aligned to the National Health and Medical Research Council (NHMRC) guidelines on the ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities. Ethics approval was received from the Menzies School of Health Research and Northern Territory Government Health Research Ethics Committee (HREC) for this study (HREC 2021–4205). The study was also discussed with, and approved by, the Menzies School of Health Research, Australian First Nations Reference Group for Child Health. Informed written consent was obtained from all participants.

Consent for publication

Informed written consent was obtained from all participants.

Data availability

The data and materials used in this study are not publicly available due to the sensitive nature of the qualitative data collected, and the need to protect the confidentiality and privacy of all participants, in accordance with ethical guidelines.

CRediT authorship contribution statement

Emily R Bowden: Writing – original draft, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Maree R Toombs:** Writing – review & editing, Supervision, Conceptualization. **Anne B Chang:** Writing – review & editing, Supervision, Conceptualization. **Gabrielle B McCallum:** Writing – review & editing, Supervision, Conceptualization. **Robyn L Williams:** Writing – review & editing, Supervision, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

The authors would like to acknowledge the women who graciously participated in this study, sharing their stories with honesty and vulnerability; and their families, who were an integral part of their pregnancy journeys.

Funding

The contents of the published material are solely the responsibility of the authors and do not reflect the views of the National Health and Medical Research Council (NHMRC). ERB was supported by an Australian Government Research Training Program Scholarship, administered by Charles Darwin University. ABC is funded by a NHMRC L3 Investigator Grant (GNT2025379). NHMRC practitioner fellowship (grant 1058213).

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.midw.2024.104277.

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