

Listening to First Nations women's voices, hearing requests for continuity of carer, trusted knowledge and family involvement

A qualitative study in urban Darwin

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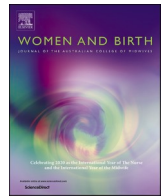
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Listening to First Nations women's voices, hearing requests for continuity of carer, trusted knowledge and family involvement: A qualitative study in urban Darwin

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ABSTRACT

Problem: Australian First Nations women are more likely to commence care later in pregnancy and underutilise maternal health services than non-First Nations women.

Background: Disrespectful maternity care is a major barrier to care-seeking in pregnancy, often resulting in later commencement and underutilisation of care.

Aim: We aimed to identify barriers and enablers to pregnancy-related care-seeking for Australian First Nations women living in the Darwin region through yarning about their experiences of pregnancy care.

Methods: Ten Australian First Nations women shared stories about their pregnancy care journeys. Yarns took place at a time and location determined by the women, with recruitment continuing until saturation was reached.

Findings: Emerging themes included a desire for continuity of carer, particularly with midwives; access to trustworthy information, enabling informed decision-making; and a need to have family involved in all aspects of care. No specific barriers were identified within this cohort

Discussion: Universal access to continuity of carer models would provide women with the relational care they are asking for as well as address other identified needs, such as a desire for information relevant to their pregnancy; and space for partners/family members to be involved. The themes that emerged provide a picture of what a positive, respectful pregnancy care experience could be for First Nations women within the Darwin Region, thus enabling care-seeking in pregnancy.

Conclusion: Although the public sector and Aboriginal Controlled Community Health Organisations currently provide continuity of carer models, robust systems ensuring these models are made available to all women are lacking.

Statement of significance

Problem

Australian First Nations women are more likely to commence care later in pregnancy and underutilise maternal health services than non-First Nations women.

What is already known

Respectful maternity care is widely acknowledged as a fundamental aspect of care for pregnant and postpartum women. Disrespectful maternity care has been identified globally as a barrier to seeking care in pregnancy.

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What this paper adds

This qualitative study involving ten women found themes that paint a picture of what a positive, respectful pregnancy care experience could be for First Nations women within the Darwin Region, thus enabling care-seeking in pregnancy.

Introduction

Respectful maternity care, defined as ‘*an approach to care that emphasises the fundamental rights of women, newborns, and families, and that promotes equitable access to evidence-based care while recognising the unique needs and preferences of both women and newborns*’ [1] is increasingly identified as a fundamental aspect of care provision for pregnant and postpartum women. The World Health Organization (WHO), in their recommendations on ‘Antenatal Care for a Positive Pregnancy Experience’, identify that women value receiving antenatal care from ‘*knowledgeable, supportive and respectful health care practitioners*’ [2]. This is also recognised at a national level in Australia where it is recommended by the Nursing and Midwifery Board of Australia’s (NMBA) Code of Conduct for Midwives, that midwives practise in respectful ways. [3] For example, in the domains of ‘Safe, Effective and Collaborative Care’, and ‘Acting with Professional Integrity’, there are numerous references to respectful care embedded throughout key principles within each domain [3].

Literature from many low- and middle-income countries (LMICs) identified that disrespectful maternity care is a major barrier to seeking care in pregnancy, often resulting in later commencement of care or underutilisation of maternal health service, sometimes with devastating consequences. [4–6] In Australia, Aboriginal and Torres Strait Islander women, hereafter referred to as First Nations women, are less likely than non-First Nations women to commence pregnancy care in the first trimester (65% compared to 77%) [7] and are more likely to have fewer than five antenatal appointments than other women in Australia (12% compared to 4%) [7]. Furthermore, Australian First Nations women are more likely to experience maternal death [8] or severe maternal morbidity (SMM) [9].

While evidence is limited from high-income countries (HIC), models of care well known to be respectful and highly acceptable to women, such as continuity of care models and culturally tailored programs, [10] result in increased antenatal clinic, antenatal class and postnatal visit attendance for certain cohorts of women [11–13]. In addition, outcomes are also seen to improve for the neonates of mothers receiving care within these models. [14,15].

This study aimed to identify barriers and enablers to seeking care in pregnancy for Australian First Nations women living in the Darwin region through yarning with women about their experience of pregnancy care.

About the authors

This study was conducted and written up through the lens of a non-First Nations woman, ERB, who has lived and worked in the Northern Territory (NT) for seven years; four and a half years on Yolngu Country (Nhulunbuy), and two and a half years on Larrakia Country (Darwin), working in both the midwifery space and research alongside a range of First Nations and non-First Nations people. MRT is an Kooma/Euahlayi woman and experienced researcher from Brisbane. ABC is a non-First Nations medical doctor and researcher who continues to and has > 25 years of providing clinical service to First Nations children including in rural and remote regions in the NT, Central Australia and Queensland. GBM is a non-First Nations woman, also with decades of experience working with First Nations children and their families in urban, rural and remote regions of the NT and Central Australia. RLW is non-First

Nations woman and researcher who has lived and worked for many decades in the Northern Territory and has significant personal and working relationships with many Australian First Nations peoples.

*Research approach**Ethics*

This study is aligned with the National Health and Medical Research Council (NHMRC) guidelines on the ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities [16]. 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.

Methods*Methodology*

There is considerable contention over whether Yarning as a method and/or methodology is appropriate to use when the primary researcher is non-First Nations. Atkinson et al. [17] note that focus group discussions and semi-structured interviews are sometimes erroneously described as Yarning by non-First Nations researchers in an attempt to give legitimacy to their work. They go on to say that the researcher must show respect for the relationship between the research participants, the topic and the researcher to demonstrate accountability, and that this relationality can contribute to mitigating settler colonial processes in research [17]. Walker et al., [18] however, identifies Yarning as a credible and valuable method for research in a First Nations health context and that the process of Yarning can help to establish relationality and determine accountability between those people [18].

As a non-First Nations woman, with limited experience with Yarning, I feel a certain level of discomfort in identifying Yarning as my method or methodology. However, I recognise that Yarning, as a decolonising method and methodology, privileges the voices of Australian First Nations women, which more westernised approaches to research have historically failed to do. Therefore, with permission and as modelled by MRT, this study was conducted using the ‘spirit’ of Yarning, as described below. To differentiate between the ‘theory’ behind Yarning and the ‘spirit’ of yarning employed for this study, an upper-case Y is used when discussing the theory, and a lower-case y is used when discussing the spirit of yarning in relation to this study.

Barlo [19] describes Yarning as an emerging methodology grounded in ancient practices. It is a methodology which allows participants to control the direction and content of the Yarn, and to discuss, without fear of redirection or interruption. He goes on to say that participants are allowed to present their knowledge in whatever style they see as appropriate [19]. In addition, there are a number of protocols, that are to be observed by those participating in the Yarning. Observance of these protocols “*keeps the participants safe while they are engaging in the research project*” and “*ensures equality along with shared responsibility*” [19]. These protocols are described below (see Table 1) and were always observed.

Bessarab and Ng’andu [20] further legitimize Yarning as a culturally safe way of engaging with First Nations people in research, describing the research Yarning process as having four components (see Fig. 1).

The research Yarn process starts with what some First Nations Australians call a social Yarn. This is a conversation that takes place prior to the research Yarn and facilitates the building of rapport through the sharing of personal information and making connections. Next comes the research topic Yarn. As the name suggests, it is the time when data is gathered via participants stories, related to the research topic. There is a defined beginning and end to the research Yarn. During the research

Table 1 Yarning protocols [19].

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 Space	What and how the participant chooses to share is freedom. 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.

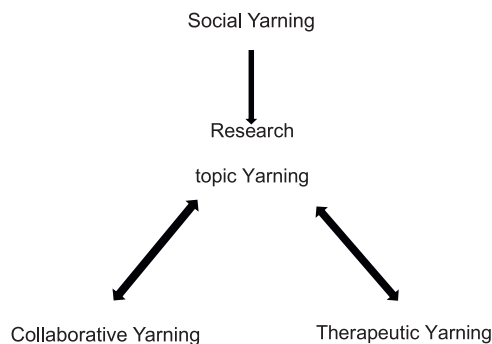


Fig. 1. The research Yarning process [20].

Yarn, however, two other types of Yarn have the potential to arise. These are the collaborative Yarn, where new ideas emerge and are explored; and the therapeutic Yarn, a time when the researcher must move from 'researcher mode' to 'listener' as the participant shares information that is traumatic or emotional. [20] These deviations from the research Yarn are both important and useful, as Bessarab and Ng'andu say 'the rigor in the yarn is to allow the story to flow while looking for threads that relate to the research topic.' [20] Further, Yarning, as described above, reduces the risk of introducing researcher bias or harm to participants by facilitating a participant led Yarn with minimal re-directions or interruptions by the researcher.

Setting\context

This study was conducted in Darwin, the capital of Australia's Northern Territory (NT), with recruitment of women from the wider Darwin region, an area spanning 3100 km² and a population of approximately 140,000. [21] In the NT, 26.3% of people identify as Australian First Nations, [22] with over 14,000 Australian First Nations people residing in the wider Darwin region.

There are two publicly funded hospitals in the wider Darwin region that provide care for women throughout their pregnancy journey, and one private hospital for those who have private health insurance. In addition, there are a wide range of General Practitioners (GP), some who function within GP shared care arrangements with the public hospitals. Aboriginal Community Controlled Health Organisations (ACCHOs) also provide antenatal care for First Nations women or women carrying First Nations babies, primarily within a continuity of carer model.

The public hospitals run a Midwifery Group Practice (MGP), which is designed to provide care to women with high-risk pregnancies, women from remote communities travelling to Darwin for birthing, and women with normal risk pregnancies planning a home birth in the Darwin and Palmerston area. Women with high-risk pregnancies also receive care

from an obstetrician allocated to specific MGP teams. In addition, Midwifery in Small Teams (MIST), as the name suggests, is a small midwifery team offering off-site antenatal care to women with a normal risk pregnancy, and operates within the public sector.

Design

For this research study, Australian First Nations women were recruited using convenience sampling through two clinical trials being undertaken by Menzies School of Health Research at the two public hospitals. The clinical trials were investigating the impact of interventions (pneumococcal vaccination in pregnancy [23] or vitamin D administration) [24] on child respiratory health. Inclusion criteria for this current study included Australian First Nations women within the first 12 months postpartum, who lived in the Darwin region, and spoke English or consented to the use of an interpreter. Exclusion criteria included being under 18 years of age, having experienced a perinatal death, or the baby having a significant, documented congenital abnormality. In the first instance women were approached by a research nurse/midwife known to them from one of the two clinical trials in which they were enrolled (as above), to gain consent for ERB to make contact. ERB made contact via email, short messaging service and/or phone call. Once contact was made, ERB explained the study in greater detail and if the woman agreed to participate, a time and meeting place was arranged to have a yarn. Contact by ERB was attempted a maximum of three times, and if contact was not able to be made, it was recorded as 'declined to participate'. It was determined that using a third party to make initial contact was a culturally safe approach, allowing women to decline without feeling the discomfort that can come with saying no to a request. Women were given the choice of where the yarn took place. Seven yarns were conducted in the individual women's homes, with her infant, and sometimes other members of the family, present or in the background, two yarns occurred over 'Zoom', and one woman elected to have a yarn at the local playground, allowing her children to play at a watchful distance while we shared stories.

Participants were offered the opportunity to share their story using other mediums, such as artwork, if they chose, however, all participants chose to yarn verbally. All participants consented to having their yarn audio recorded. The yarn commenced with the women being asked an open-ended question about their experience of their first antenatal check-up. A list of trigger questions and follow up prompts was available and referred to at various times throughout the yarns (see Table 2). Audio recordings were transcribed verbatim by the first author soon after the yarn and saved in a password protected database accessible only to them. Participants were offered the opportunity to review the transcript and make comments, corrections or add further material. Six women took up the offer to review the transcript, with no comments, corrections or additional material added. Four women declined to review their transcripts.

Table 2

Trigger questions and follow up prompts.

Trigger questions	Follow up prompts
Could you tell me about the first time you went to the clinic/GP when you knew you were having a baby?	Explore themes around respect, cultural sensitivity, language used, quality of care – extend discussion to include subsequent visits, the birth, hospital stay
Did you ever feel afraid or worried during your pregnancy? Could you tell me more about that?	Explore themes around fear of the unknown/unconsented procedures, recognition of complications, consent
In your family, who is the person who helps you make decisions about things to do with pregnancy?	Explore themes around health literacy, family involvement in decision making
Is there anything you think should be done differently by the health services that would make women's experiences better?	

A distress protocol approved by the HREC was in place, which provided researchers with guidance on how to approach the situation if a participant became upset (see Supplementary file, Fig. 1). The target sample size was 10–15 women, or until saturation was reached.

Data collection

Of 11 women approached to participate in this study, ten provided written informed consent and one woman declined, for reasons not specified. The yarns commenced with a social yarn, where ERB shared some information about her family and background, including her years living in South-East Asia working as a midwife, and her time living and working in East Arnhem Land. The women then shared what they felt comfortable to about themselves and their families. Once a rapport was established, the research topic yarn commenced, signified by the signing of the consent form and commencement of audio recording. If information pertinent to the research topic yarn had been discussed in the social yarn, the matter was brought up again, by either party, during the research topic yarn. Research topic yarns lasted between 25 and 60 min. At the conclusion of the yarning, women were presented with a gift voucher for a local supermarket as a token of appreciation for their time.

Data analyses

ERB's experience as a midwife working with First Nations women for many years in East Arnhem Land, and already having a strong appreciation of barriers and enablers to care-seeking in pregnancy, informed a deductive analysis approach. Data was analysed using the thematic analysis method described by Braun and Clarke. [25] Interviews were transcribed verbatim by ERB and read and re-read several times to facilitate familiarisation /immersion with the data. Transcriptions were cross checked with the audio file to ensure accuracy. During transcription and reading, some patterns emerged. These patterns were coded, and data related to each code were extracted from the transcripts and compared. A list of codes was developed by two of the researchers (ERB and RLW). These codes were then sorted into broad sub-themes. All coded data were re-read and their position within sub-themes was reviewed. Data forming sub-themes was reviewed and refined by three researchers (ERB, RLW and MRT) into themes. Three main themes emerged and are explained below, supported by participant quotes. A Coding Process Table was generated (see supplementary file, Table 1). Recruitment ended when the data were characterised by repetition, and no new data were found that could be categorised, indicating saturation. NVivo 12 software was used to organise the data for management and analysis.

Results

Results

Of the ten women who participated in yarns with ERB, seven identified as Aboriginal, one as Torres Strait Islander, and two as both Aboriginal and Torres Strait Islander. Most women ($n = 6$) were aged 31–40 years, with the rest being younger. Two women had birthed their first baby prior to the yarn, the rest had given birth two or more times. Two women received care within a continuity of carer model, a model of pregnancy care where women are seen by the same maternal care provider throughout their pregnancy journey and considered by many to be the 'gold' standard of care. [26] Eight women received hospital-based care, characterised by seeing many different care providers throughout their pregnancy, hereafter referred to as 'fragmented' care. All women reported commencing their pregnancy care in the first trimester and attending all, or nearly all, of their scheduled antenatal appointments. The Socio-Economic Index for Areas (SEIFA) was used as a proxy to denote the socio-economic status of the women [21] (see Table 3 for Participant characteristics). The SEIFA is a system of national

Table 3
Participant characteristics.

Characteristics	Total participants $n = 10$ (%)
<i>Ethnicity</i>	
Aboriginal	7 (70)
Torres Strait Islander	1 (10)
Aboriginal and Torres Strait Islander	2 (20)
<i>Age group (in years)</i>	
18–25	1 (10)
26–30	3 (30)
31–40	6 (60)
<i>Socioeconomic index for areas score</i>	
5	1 (10)
6	0
7	3 (30)
8	2 (20)
9	1 (10)
10	2 (20)
unknown	1 (10)
<i>Employment</i>	
Currently on maternity leave	9 (90)
Currently working	1 (10)
<i>Parity</i>	
1	2 (20)
2	2 (20)
3	2 (20)
4	2 (20)
5	2 (20)
<i>Mode of birth</i>	
Vaginal	7 (70)
Elective caesarean	2 (20)
Emergency caesarean	1 (10)
<i>Model of antenatal care</i>	
Continuity of carer	2 (20)
Fragmented care	8 (80)
<i>Gestation at birth</i>	
Term	10 (100)
Preterm (<37 weeks)	0
<i>Risk factors (self-identified by women)</i>	
Gestational diabetes mellitus	6 (60)
Postpartum haemorrhage	1 (10)
Low lying placenta	1 (10)
In vitro fertilisation (IVF) pregnancy	1 (10)

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

Theme one: continuity

The first theme that emerged was 'continuity'. Without exception, the women expressed a desire for continuity of carer during their pregnancy. In particular, continuity of care from a midwife, was seen as most desirable by women in this study, particularly the relationship formed with their midwife, and accessibility to the midwife (or student midwife), between appointments. This included women receiving pregnancy care from a previously known provider.

"I've been going there [ACCHO] all my life and I used to work there, so you know, I know a lot of the staff on a personal level so there was that level of comfort there."

(Participant 001)

"She [midwife] was great, yeah. It was a lot easier 'cause she already knew me, we already had that relationship. I find it's different, it's harder when you jump from one midwife to the next."

(Participant 006)

Women who received continuity of carer with a doctor, also stated that this was positive.

“I thought it was a lot better because you could build a bit of rapport and a bit of a relationship. Because you just didn’t know who you were getting when you went into the hospital, it changes all the time, so you don’t get that one consistent. And then having the same doctor see you throughout the whole time as well, was very, comforting, I suppose. You could be a bit more open and honest. And yeah, I just felt you could be a bit more yourself instead of every time having to re-introduce yourself, they knew who you were straight away.”

(Participant 009)

Continuity of carer facilitated good relationships with the caregivers, and appointment times were able to be used more efficiently, with women feeling freer to share worries or concerns more openly during the appointment. Women who had continuity of carer either during this pregnancy or previously, appreciated that when they saw the same caregiver with each appointment, there was no need to share the story of their pregnancy repeatedly because the caregiver knew them and their history. The appointment time was able to be used to discuss the issues that were relevant to the woman, and there was no risk of the story changing over time, as one woman commented could happen.

“When you have to repeat yourself, you sort of change, the sort of story changes a little bit.”

(Participant 005)

Having a relationship with the caregiver allowed women to share concerns that sometimes carried with them an element of shame. The comfort derived from these relationships was valued from initial pregnancy care from a known GP and extended throughout the pregnancy with other health care providers.

“Most of the time when I don’t know people it’s quite...it’s not easy to talk about the stuff that you want to talk about. You get shame job sometimes.”

(Participant 005)

“I’m 37, but, you know, they say after a certain age it’s higher risk and stuff like that. And she [known GP] never made me feel awkward or uncomfortable...you know, my shame factor was that it was a little bit, um, embarrassing to go in and say that I’m pregnant with baby number 5, at the time I was 36...and um, I was really comfortable.”

(Participant 010)

A number of women in this study commenced care within a continuity model, but once a risk factor was identified, predominantly gestational diabetes, they were required to transfer their care to the ‘high-risk clinic’. Frustrating aspects of this included having a harder time finding parking and longer waiting times, and no appreciable difference in what occurred during the appointments.

“I didn’t really go back to MIST [Midwifery In Small Teams] anymore ‘cause I was more getting more into the high-risk pregnancy so that really sucked. The only thing that I found frustrating, it was the same things they were doing at MIST. The only thing the doctor was doing was checking my GD booklet but the MIST girls were doing the same thing. There was nothing different, they weren’t doing like a mini ultrasound each time or anything that the girls at

MIST would have differently...But otherwise we’re talking about the same thing measuring the belly, this is the heart rate, talking about, you know my food and exercise. I just I had to wait longer and, you know, get a car park and walk and spend a bit more time, where I would just go straight to my MIST appointment, and it would be on time.”

(Participant 002)

The care provided at the high-risk clinic could be described as fragmented, with women seeing different doctors each visit, experiencing long waiting times for appointments that typically lasted only five to ten minutes and felt rushed, with inflexible appointment dates and times.

“And having to go into an appointment with the doctors then have to go back out and wait for the next one...I was spending hours.”

(Participant 001)

“You felt very much like a number, and the amount of times you would just repeat the same things that were already in the file, like they hadn’t even looked in the file to see whatever was in there. It was very impersonal it felt like, and inconvenient.”

(Participant 003)

When questioned, many of the women who received fragmented care could not recall seeing a midwife beyond the initial booking in visit. Some of the women wondered why they could not be seen regularly by a midwife once they were considered high-risk, as they felt that time spent with a midwife was a valuable thing.

“yeah, definitely, especially if they [midwives] were at the appointments with the other people, just to be able to filter that information I think that’s something that I think nurses and midwives in general, obviously pick up very quickly through their training, to be able to translate from what a doctor might say into a way that is easily understood by a patient and has a bit more humanity to it.”

(Participant 003)

With those who did see midwives regularly reinforcing this.

“And it wasn’t just so clinical. It was human you know.”

(Participant 008)

Continuity with a student midwife was also considered desirable. For those women who had a good experience with a student midwife, it did not seem to matter how experienced they were, but rather, it was their accessibility to the women, and their friendly, kind demeanour that was appreciated. Students were identified as people with whom women could ‘bank’ questions and concerns to raise at appointments and to be a companion during long waiting times in the hospital.

“Just having that support to come into your appointments with, someone to talk to in the waiting room, someone to be there to witness everything that happened in the appointment so you can talk about it later, and any concerns that you might have, or any questions for your next appointment, or all that kind of stuff so I think that was really good.”

(Participant 004)

“Yeah, I also had a student midwife follow me through the pregnancy. I loved her, we are still friends now.”

(Participant 006)

Interestingly, all the women in this study entered labour without a known midwife, even those who had continuity of carer antenatally. This was, for the most part, not identified as a problem, as there was a great deal of respect for midwives generally.

“I knew once I got into the labour stage that I wouldn’t be dealing with those doctors, I’d be dealing with the midwives and I know midwives are a whole different kettle of fish, so I didn’t have to worry so much about the politics and the egos so much once the midwives came into play.”

(Participant 003)

In addition, midwives caring for women intrapartum were frequently identified as having a good understanding of women’s needs, often doing ‘the little things’ to make women feel comfortable, for example, playing calming music or setting up battery operated candles around the birthing room. Understanding a woman’s needs sometimes meant going against ‘protocol’ such as performing a vaginal examination within 4 h of the previous examination without a clinical indication, because that is what the woman requested. This was identified as a respectful, empowering response and appreciated by the women.

“They were always informative, encouraging, they didn’t force you to do anything you didn’t want to they were always giving options or talking through it or just getting you an ice pack when you needed one or...just all the little things.”

(Participant 002)

“Um, they were hands on and really encouraging. They just made the area safe and welcoming. And they explained things well, um, they got my partner involved. It was just a really good weekend even though what came about of it. They were very approachable, and they engaged really well. You know, we felt comfortable talking to them. They were really good with us, and let me do whatever, like you know if I wanted to walk or take a shower, they let me have a shower, or if I wanted to sit on the toilet, they made it all happen.”

(Participant 007)

In addition, a sense of humour and thoughtfulness were identified as characteristics of a ‘good midwife’.

“I had pushed my button and she had come in and she’s like ‘tell me what you want what you really want’ And I was like, oh, she’s cool. But yeah, she was really lovely and had a really good sense of humour and just very happy and friendly.”

(Participant 008)

Theme two: trusted knowledge.

The second theme identified was that of ‘trusted knowledge’, or more specifically, seeking trusted sources of knowledge to enable informed decision making. Women wanted to make choices that were well informed. Continuity with the same midwife and/or doctor contributed to the women’s sense of making informed choices, as discussions were able to be tailored easily to each woman, and irrelevant topics avoided. Several women who experienced fragmented care, expressed a desire

that midwives be present for all appointments, as they would be able to ‘translate’ what the doctor said into understandable language. Midwives were identified as the profession which was most able to provide clear and understandable explanations to woman, and to add ‘humanity’ to a situation.

“The explanation that we got from the doctors was pretty much them explaining the sound of what it [heart murmur] sounds like not what it is. So, when we had to take the baby back to the hospital two, three days later to get a tongue tie cut, the lactation consultant was the person who gave us the best description of what a heart murmur is.”

(Participant 004)

Women also identified that they sought knowledge from those with lived or shared experiences. For example, when asked who in their ‘circle of trust’ they would go to for medical questions, it was very often a mother or another female relative who had previously given birth to a few children or had a similar experience, such as giving birth to twins, or having a particular complication.

“Mum always encouraged me to make sure I was attending. I definitely trusted her; she’s had four kids. “

(Participant 002)

“She’s got 5 kids so, including twins as well, and a number of grandchildren too so she’s very handy to have.”

(Participant 003)

“The number one person I would go to would be my mum. She’s had 6 kids, so she.yeah, I just ask her stuff all the time.”

(Participant 005)

Other sources of knowledge as identified by the women were social media, for example, a diabetes in pregnancy Facebook group, and other forums where women with similar complications shared their experiences.

“There’s lots of mother groups on Facebook and stuff, where we’ve all been [muffled] together. Um, there’s a lot of stuff online which is really good to look at as well.”

(Participant 004)

“I would look up forums and google, like I would put in whatever I was concerned about and then look up the chat rooms and I would just read other people’s experience.”

(Participant 008)

“Well, I went to that course. Obviously, it’s a quick course...but google, I have to say, but also one of my work mates who had her baby 2 years ago, she had pregnancy diabetes as well, so I got a lot of knowledge from her. But apart from that, it was definitely ‘Google’.”

(Participant 010)

A number of women ‘Googled’ their questions or concerns but were unable to articulate how they determined the reliability of the site they were looking at. For those women who had continuity with a student midwife, they were able to message the student to ask a question, or to ‘bank’ the question until their next appointment.

“Yeah so we Facebook messaged and whenever I had a concern or if I had questions that I needed to ask she was always great at reminding me about stuff that I wanted to talk about and also she was like

another voice that I could bounce ideas off... and then it was brought up at the midwife appointments and then we would talk about it all and how I felt about it and what options I had, all that kind of stuff, so it was really good.”

(Participant 004)

Theme three: Family involvement.

The third theme identified was that of ‘family involvement’. Some women expressed a sadness that, mostly due to the COVID-19 pandemic, their partners were not allowed into the hospital to attend antenatal visits and ultrasounds. For those women who did have their partner with them, they drew strength and encouragement from them when they were feeling overwhelmed or had worries. Partners were quoted as saying things like, ‘*we have spoken to the midwife about this,*’ thus reducing stress and anxiety. In addition, partners were identified as being a needed source of comfort and support during labour.

“It wasn’t a bad thing, it was just slightly frustrating at the time because my partner had to leave at a time I really needed to have him there to rub my back and sooth me a little bit so that the pain wasn’t so...bad”

(Participant 010)

Further, partners were reported as being instrumental to some women’s processing of events after the birth. One woman stated that she is ‘delirious in labour’ and relies on her husband to tell her what happened afterwards.

“...my partner tells me...because I’m delirious going through birth, and he tells me afterwards”

(Participant 010)

This idea of being ‘delirious’ or overwhelmed in labour or the immediate postpartum period was echoed by several women, impacting their ability to make informed choices.

“And I know if I had the mental capacity at the time I could have pushed for having other options, but I just didn’t.”

(Participant 003)

Mothers were equally identified as being vital to the woman’s experience of labour. Two women recounted stories from previous pregnancies when they had made informed decisions prior to labour, not wanting an epidural for pain relief in the case of one woman, and not wanting a fetal scalp electrode to be applied to the baby for another. Both women commented that during labour when those options were repeatedly and forcefully offered to them, they were too exhausted and lacked the ‘mental capacity’ to say no, but it was their mother being present, with a clear understanding of their wishes, who was able to act as an advocate, and provide a ‘firm no’ on behalf of the woman.

“They would keep on asking and asking and because I was in that much pain I was just like, oh, whatever, just do it. Mum was like, no, she said no so that’s no!

(Participant 005)

Limitations

There are several limitations to this study. Firstly, nine of the ten participants came from areas with a relatively high SEIFA score, thus not reflective of all First Nations women living in the Darwin region, but rather a relatively homogenous sub-section. Including women from more diverse socio-economic backgrounds or those living in different regions of the NT, specifically remote communities, perhaps larger numbers would have been required to reach saturation. Secondly, the

women in this study received pregnancy care and birthed in a time of high COVID-19 prevalence and transmission in the NT, during which strict policies were in place limiting attendance at the hospital by partners, children, and student midwives. This undoubtedly influenced women’s ability to have, for example, their partner attend an ultrasound, or a small child not yet at school tag along for an antenatal visit, thus requiring babysitting. Further, it restricted the number of birth companions a woman was allowed, including student midwives. These same women, following the same journey in non-COVID times may have had vastly different experiences. Finally, all the women were at the time of yarning enrolled in one of two large randomised controlled clinical trials aiming to improve child lung health. Their willingness to participate in both studies may indicate their high levels of trust in the health system, therefore potentially excluding women without those same levels of trust.

Discussion

These experiences of Australian First Nations women receiving maternal health care living in the Darwin region were studied with the aim of identifying barriers and enablers to care seeking in pregnancy. The three main themes identified were: women’s desire for continuity of carer, in particular with a midwife; access to trustworthy, relevant information to enable informed decision making; and a need to have family involved in all aspects of their care.

This study’s results supports that of previous studies which report that continuity of carer with a midwife has been identified as a model that women find acceptable and desirable [10]. In addition, continuity of carer models facilitate higher attendance rates antenatally [14,15]. Other benefits of continuity of carer models include fewer babies being born preterm or with a low birthweight, and less likelihood of admission to the neonatal intensive care unit. [14,15,27] Furthermore, women receiving care within a continuity model are more likely to be exclusively breastfeeding on discharge from hospital [14]. These are important data as it has been identified that Australian First Nations women are more likely to commence pregnancy care at a later gestation and attend fewer appointments than recommended. [7] In addition, more Australian First Nations babies are born preterm and with a low birthweight than non-First Nations babies [7].

MGP and MIST are both examples of continuity models being offered to women receiving pregnancy care through the public system in the Darwin region. Furthermore, the ACCHO operating within the Darwin region offer a continuity model of care for First Nations women. Data from this study identified each of these services as highly desirable and able to meet a woman’s needs. Our data also identified, however, that while designed to cater to high-risk and normal risk women, and in some cases specifically for Australian First Nations women, many are not able to access these services. If offered to eligible women, the data suggests that the uptake into these services would be high, thus leading to a more positive experience of pregnancy care for women and better outcomes for neonates.

While not specifically a barrier to seeking care to the women in this study, their frustrations associated with fragmented care are well documented in the literature [4–6].

Ensuring that women can provide informed consent is an ethical obligation faced by providers of maternal health services. It requires women to be given adequate, accurate and understandable information, and requires that women have the ability to understand and reason through this information and are free to ask question and to make an intentional and voluntary choice [28]. Data from this study suggests that women do not always get the information they need to make informed decisions from their health care providers.

As the literature also demonstrates, the internet is widely used as a source of health information for making decisions in pregnancy [29]. For some women in our study, exploring the internet reflected their desire to hear from women with lived experience, for example, other

women who'd received a diagnosis of gestational diabetes; while others were content to 'browse' until they found the information they were looking for. Women want timely answers, and the internet offers this in abundance. Disturbingly, a recent qualitative analysis of 153 internet discussion forum threads centred around pregnancy found that nearly half the responses sharing advice were erroneous, incomplete, misleading, or lacked credible evidence [29]. Women should be directed by health care providers to reputable sources of information to ensure that what they are receiving is accurate, reliable, and culturally safe [29].

Alternative sources of information and support identified by women in this study included family members and friends, most often because of their lived or shared experience or perceived expertise based on their background of having some medical knowledge. Other studies have shown the advice-giving role of female friends and family members in pregnancy [30] to be significant. As with internet-based forums, there is a need for women to be discerning when interpreting the information provided by friends and family. Thus, involving a woman's chosen family member in all aspects of her care could be protective.

Continuity of carer with a midwife, while facilitating relationship and maternal satisfaction, also serves to be a reliable source of information. Appointment times can be utilised more efficiently to address women's concerns and answer questions to the woman's satisfaction. It was identified in this study that midwives more often have the skills necessary to provide adequate explanations than some doctors, and the relationship formed between woman and carer enables more frequent and 'out of session' interactions to occur. Further, appointment times are generally longer and, when offered off-site, are logistically easier for women, and for family members to attend as support.

For women in this study receiving fragmented care, student midwives were identified as filling this gap by providing opportunities to ask questions, share worries, and 'bank' queries until their next appointment. Other studies reflect these values of having a student midwife in the role of continuous carer throughout a pregnancy [31]. If women are, for whatever reason, unable to access holistic, woman-centred continuity of carer models with a midwife or doctor throughout their pregnancy, it has been shown that student midwives have the opportunity and perceived experience to step into this gap [31].

A longitudinal study found that 4% of women develop post-traumatic stress disorder (PTSD) after birth [32] with another study finding that low levels of satisfaction with health professionals was predictive of chronic and delayed PTSD [33]. In addition, this same study found that having support during birth was a protective factor against developing PTSD. PTSD and postnatal depression are both associated with poorer maternal and child health outcomes. [34] This serves to highlight the important role of continuity of carer and family involvement in the care of a woman antenatally and intrapartum. Labour companions, who may be family members, provide informational support, often bridging communication gaps between the woman and healthcare professionals and facilitating non-pharmacological methods of pain relief; advocate for women; provide practical support, such as back rubbing or hand-holding; and provide emotional support by being a constant physical presence throughout [35]. This study demonstrated that each of these support mechanisms is important to women, and when present, improved their experience of care.

Conclusions

These findings contribute to the evidence that continuity of carer is crucially important and highly desirable to women antenatally; having the capacity to make informed choices is a priority, and that the knowledge required to make an informed choice is actively sought out by women from several different sources. Additionally, family involvement in all aspects of care, both antenatally and intrapartum, contributes positively to a woman's experience of pregnancy and birthing, and more than that, it is considered a vital component of respectful care. All

the women in this study commenced pregnancy care in the first trimester, and attended all, or nearly all, of their scheduled appointments. This is despite the predominance of the women receiving fragmented care and is potentially a reflection of their high levels of health literacy, rather than the existence of a supportive, consistent, and effective system. It is evident that genuine attempts have been made by the public sector and ACCHOs to provide continuity of carer models, however, robust systems ensuring these models are made available to women are not currently available. Universal access to continuity of carer models, would not only provide women with the relational care they are asking for, but it would also go a long way to addressing their other identified needs: a desire for trustworthy information; and space for partners or other family members to be involved. The themes that emerged from this study paint a picture of what a positive, respectful pregnancy care experience could be for First Nations women within the Darwin Region, thus enabling care-seeking in pregnancy.

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Ethical statement

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. [16] 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.

CRedit authorship contribution statement

This article is the original work of the authors. ERB conceptualised the study (with input from all authors) and yarned with the participants. RLW reviewed the recorded yarns and provided feedback to ERB. ERB and RLW worked together to identify themes, with input from MRT during refinement of identified themes. ERB wrote the first draft with revisions by RLW, MRT, GBM and ABC.

Declaration of Competing Interest

None to declare.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.wombi.2023.05.004](https://doi.org/10.1016/j.wombi.2023.05.004).

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