



First Nations Peoples' perceptions, knowledge and beliefs regarding stillbirth prevention and bereavement practices: A mixed methods systematic review

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ABSTRACT

Background: First Nations Peoples endure disproportionate rates of stillbirth compared with non-First Nations Peoples. Previous interventions have aimed at reducing stillbirth in First Nations Peoples and providing better bereavement care without necessarily understanding the perceptions, knowledge and beliefs that could influence the design of the intervention and implementation.

Aim: The aim of this review was to understand the perceptions, knowledge and beliefs about stillbirth prevention and bereavement of First Nations Peoples from the US, Canada, Aotearoa/New Zealand, and Australia.

Methods: This review was conducted in accordance with the JBI methodology for a convergent integrated mixed method systematic review. This review was overseen by an advisory board of Aboriginal Elders, researchers, and clinicians. A search of eight databases (PubMed, MEDLINE, PsycInfo, CINAHL, Embase, Emcare, Dissertations and Theses and Indigenous Health InfoNet) and grey literature was conducted. All studies were screened, extracted, and appraised for quality by two reviewers and results were categorised, and narratively summarised.

Results: Ten studies were included within this review. Their findings were summarised into four categories: safeguarding baby, traditional practices of birthing and grieving, bereavement photography and post-mortem examination. The results indicate a diversity of perceptions, knowledge and beliefs primarily around smoking cessation and bereavement practices after stillbirth. However, there was a paucity of research available.

Conclusions: Further research is needed to understand the perceptions, knowledge and beliefs about stillbirth among First Nations Peoples. Without research within this area, interventions to prevent stillbirth and support bereaved parents and their communities after stillbirth may face barriers to implementation.

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Statement of significance

Problem or Issue: First Nations women endure disproportionate rates of stillbirth compared with non-First Nations women. Current interventions to mitigate the risk of stillbirth often overlook the cultural nuances that could significantly influence their effectiveness in these communities.

What is already known: Interventions to reduce stillbirth in First Nations Peoples have been developed and implemented without necessarily understanding perceptions, knowledge and beliefs that could influence implementation.

What this paper adds: In addition to shedding light on the scarcity of research exploring the perceptions, knowledge and beliefs of First Nations Peoples regarding stillbirth, this review highlights a diversity of outlooks, especially with regard to smoking during pregnancy and bereavement practices after stillbirth. These findings and recommendations may inform the development of culturally appropriate prevention and bereavement interventions.

Introduction

The loss of a baby before birth is a devastating event for parents and the wider community [1] and First Nations Peoples experience disproportionate rates in high-income countries [2,3]. First Nations Peoples typically experience persistent racism, discrimination, dispossession, marginalisation, and intergenerational trauma, stemming from a history of colonisation [4] that still profoundly impact both stillbirth risk factors and the care First Nations women receive during their antenatal period.

To co-design effective interventions it is critical to understand the perceptions, knowledge and beliefs that are present within the community about stillbirth as these are required to provide an initial baseline to understanding what needs should be addressed to reduce stillbirth and appropriately support bereaved parents [5].

Perceptions, knowledge and beliefs associated with stillbirth and people impacted by stillbirth have been explored in non-First Nations Peoples [6–8]. Consistently, individuals who have not experienced a stillbirth, and even health care providers, are found to have limited knowledge of stillbirth, including how often it occurs. Participants in Australian studies had incorrect beliefs about stillbirth including e.g., that it is normal for babies' movements to slow down while preparing for labour because they 'run out of room' [5]. Health care providers may also have limited knowledge and perceptions of stillbirth, with one global study indicating that stillbirth was due to the sins or fault of the mother (29%), and that after a stillbirth the mother is impure and taboo (13%) [9]. Stillbirth and stillbirth stigma frequently result in long-term negative psychological, physical, social, and financial implications for bereaved parents and families around the world [7,10]. Furthermore, some studies have examined the risk factors for stillbirth, such as sleep position [11] and smoking [12]. However, there is a scarcity of research that has explored knowledge about the association of stillbirth risk factors with First Nations Peoples.

Perceptions, knowledge and beliefs can be answered through both qualitative and quantitative methods, and there is a desire by our group to be able to identify implications for policy and practice. No previous systematic review has been found which addresses this topic. Therefore, a mixed methods systematic review (MMSR) on First Nations Peoples' perceptions, knowledge and beliefs regarding the prevention and bereavement of stillbirth was undertaken.

Important note on terminology

In discussion with our advisory board, the term 'First Nations' was selected as the most appropriate and inclusive term to describe the

Peoples included within this review—although we recognise that there is contention with this term in Australia and there may be preferences for other terms in this context [13]. We define First Nations Peoples as those who descended from those who inhabited a region prior to colonisation by a foreign power and acknowledge that they have diverse and rich histories, culture, rituals, traditions, and experiences. We have used the specific cultural group names when describing distinct First Nations Peoples, such as Aboriginal and Torres Strait Islander, Māori, Inuit, Métis, Native American and Alaska Native.

Review question(s)

The review question was 'What are First Nations Peoples' perceptions, knowledge and beliefs about stillbirth?' This was divided into two broad themes:

- 1) The risk factors for stillbirth and its prevention
- 2) Stillbirth, the stillborn baby and bereaved parents.

Methods

This systematic review was conducted in accordance with the JBI methodology for MMSR [13] and reported according to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) standards [14]. A protocol describing the methods of this review was published in *JBI Evidence Synthesis* [15]. This systematic review is registered with PROSPERO (CRD42023379627).

Inclusion criteria

The inclusion criteria were developed utilising the PICO (Population, Phenomena of Interest and Context) question framework as described by the JBI methodology for MMSR.

Participants

This review considered studies that included First Nation Peoples of any age. These included bereaved and non-bereaved members of the community; and First Nations Peoples who were health care providers, such as obstetricians, midwives, registered nurses and allied health care providers.

First Nations Peoples included, but not limited to, Aboriginal and Torres Strait Islander, Māori, Inuit, Métis, and Native American and Alaska Native Peoples.

Phenomena of interest

This review included studies that investigated the perceptions, knowledge and beliefs about the prevention or bereavement of stillbirth.

Due to the variety of stillbirth definitions amongst countries [16], the review authors accepted the study definition of stillbirth provided by the authors of in-scope studies and did not seek to redefine it. Within this review, both antepartum stillbirth (death of baby whilst in-utero) and intrapartum stillbirth (death of baby during labour) were included.

Context

This review only considered studies that investigated First Nations Peoples from the US, Canada, Aotearoa/New Zealand and Australia because of comparatively similar health care systems.

Types of studies

This review considered primary quantitative, qualitative, and mixed methods studies of any methodological design. Studies were not restricted on date of publication, however, only studies written in

English were included. Research papers or reports that were conducted by government or non-government organisations were also eligible for inclusion.

Engagement with community

This review is part of a larger research project aimed at reducing stillbirth among Aboriginal and Torres Strait Islander peoples and is supported by an advisory board of Aboriginal Noongar Elders living on Whadjuk Noongar Boodja in Western Australia, researchers (including Aboriginal researchers and bereaved parents), and clinicians (midwives and obstetricians). The advisory board were involved in this review by prioritising this topic and deeming it important for the community; providing feedback (either orally or written) throughout each stage of the review and input into the interpretation of the narrative summaries and identifying relevant evidence sources—in particular grey literature sources.

Search strategy

The comprehensive search aimed to locate both published and unpublished papers and was developed with the help of an expert health librarian (CP) and with extensive consultation with individuals identified by the advisory board. Additional terms were gathered from publications on Indigenous health research [17] and published online search filters [18]. The search strategy, including all identified keywords and index terms, was adapted for each included information source and was peer-reviewed using the Peer Review of Electronic Search Strategies (PRESS) guideline statement [19].

The following databases were searched on December 7th, 2022: PubMed (NCBI), MEDLINE (Ovid), PsycInfo (EBSCO), CINAHL (EBSCO), Embase (Ovid), Emcare (Ovid), Dissertations and Theses (ProQuest), and Indigenous Health InfoNet. Trove and Indigenous Informit were also searched. Advisory board members were asked to identify key members of the community, government and/or non-government organisations, or known researchers within this area and contact them to identify any known government reports that may be present within communities but not available through databases. There were government reports known to members within the review's advisory board, and permissions were sought to include these reports, but none were received.

All identified citations were imported into the Deduplicator tool (Bond University, Queensland, Australia) to remove duplicates and then uploaded into Covidence (Veritas Health Innovation, Melbourne, Australia) for title and abstract, then full-text screening [20].

All included studies were imported into SpiderCite (Bond University, Queensland, Australia) to facilitate backwards and forwards citation searching [21]. All identified articles from SpiderCite were then imported into Covidence (Veritas Health Innovation, Melbourne, Australia) and screened for eligibility by two reviewers (DP and SH).

Study selection

Piloting for title and abstract screening and full-text screening occurred with ten articles at each stage. Title and abstract screening (DP, SH, CV and ZM), and full text screening were conducted in duplicate (DP and SH). Disagreements that arose between the reviewers at either stage of the study selection process were resolved through discussion or with a third reviewer (ZM).

Assessment of methodological quality

Eligible studies selected for retrieval were assessed by two independent reviewers (SH and DP) for methodological validity. All included qualitative studies were critically appraised using the JBI Critical Appraisal Checklist for Qualitative Research [22], whilst quantitative studies used the JBI Checklist for Analytical Cross-Sectional Studies [23].

Data collection

Quantitative and qualitative data were extracted from studies included in the review by one reviewer (DP) and then checked by a second reviewer (SH). The data extracted included: study characteristics, study methods, and verbatim findings. Full extractions of the included articles can be reviewed in the supplementary file.

Data synthesis and integration

Due to a lack of richness in the data of included studies as well as variation within the areas of focus, we were unable to complete a full integrated analysis and produce synthesised (or pooled) findings. DP reviewed the extracted findings from each study and grouped them together according to similarity. SH then reviewed these findings and then confirmed the results. These results were then reviewed and confirmed by the broader author team. As there was a lack of richness within the data, only a description (narrative summary) of the findings from these studies is presented.

Results

A total of 2845 records were identified from the databases. After removing duplicates and title and abstract screening, 76 articles were sought for full-text retrieval and 75 full texts were screened by two reviewers (DP and SH). In conjunction with grey literature searching (including an identified list of relevant agencies or experts) and forward and backway citations retrieval utilising SpiderCite, a total of ten studies were finally included in this review. Full descriptive details of the extensiveness of the search can be found in the [supplementary materials](#). The full search and screening results are presented in a PRISMA Flow Diagram [24](Fig. 1).

Methodological quality of the included studies

Results of the individual studies' critical appraisal can be reviewed within the [supplementary materials](#). All included studies, regardless of the results of their methodological quality, were extracted and synthesised where possible.

There were mostly no concerns regarding the methodological quality of the included studies. However, there were some concerns of methodological quality related to qualitative studies where the authors did not clearly report or consider the philosophical perspective they used, their cultural or theoretical standpoint, and the influence of the researcher on the research.

Characteristics of included studies

There were two studies by the same authors- Blood and Cacciatore [25,26]. Even though these studies were from the same population of individuals, they focused on separate issues within bereavement photography—one which discusses best practice, and the other exploring the narrative, meaning, culture, and context in parental grief and bereavement photography. The decision was made to treat these as two separate studies. Full characteristics information of the included studies (USA (n=2), Canada (n=2), NZ (n=2) and Australia (n=4)) are shown in [Table 1](#). First Nations Peoples included Native American, American Indian, Oji-Cree, Cree, Ojibway, Saulteaux, Māori, Aboriginal and Torres Strait Islander and Indigenous women, with participants including bereaved mothers, pregnant Indigenous women, Elders with knowledge of birthing practices, and midwives. Four studies explored the knowledge and beliefs about stillbirth prevention, whilst six studies focused on the beliefs, perceptions, and knowledge of bereavement.

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

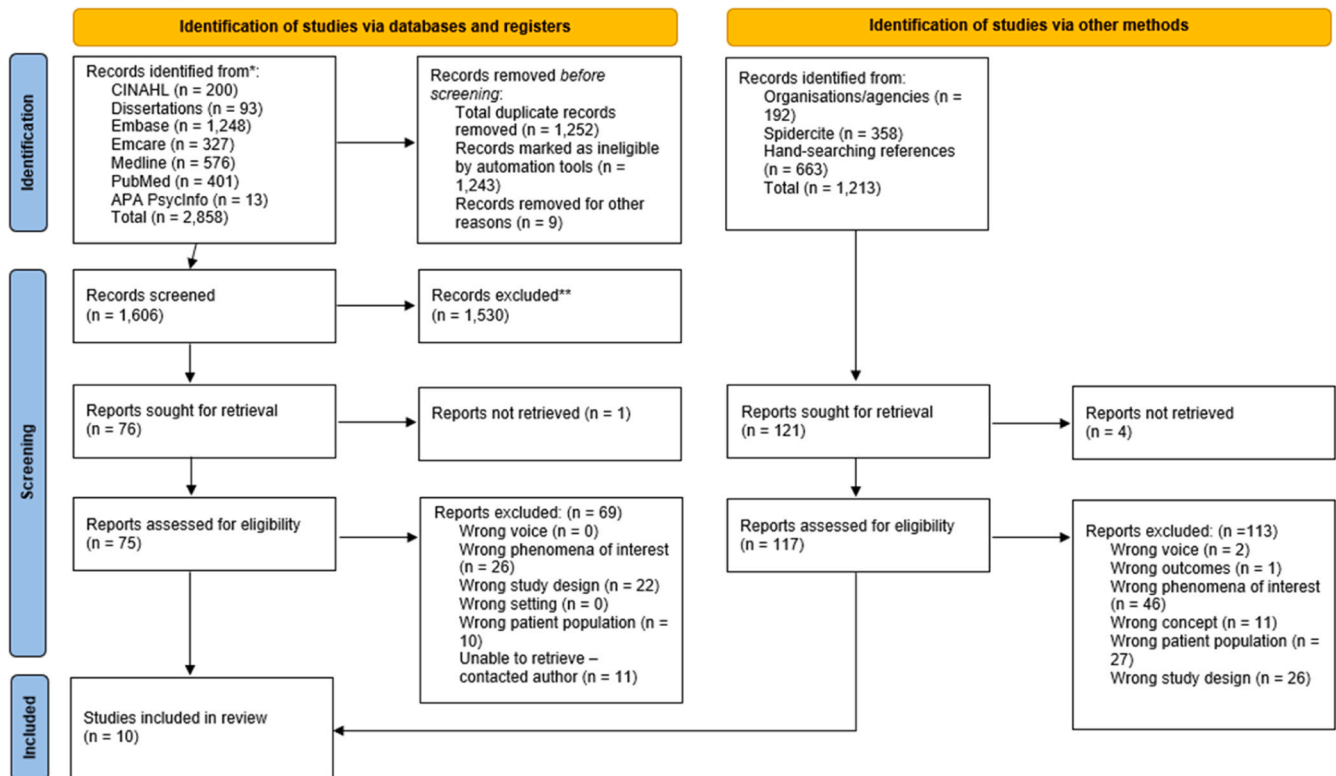


Fig. 1. : PRISMA flow diagram.

Findings of included studies

The studies specifically focused on the following categories: safeguarding baby (n=4); bereavement photography (n=2), autopsy of the stillborn baby (n=2), and traditional practices of birthing and grieving (n=2). A sample of the extracted findings from each study, and the category that they have been allocated to can be seen in [Table 2](#) and [Table 3](#). The full individual study findings that relate to each category can be seen in the [supplementary materials](#). It should be noted that across some studies the words ‘miscarriage’ or ‘losing baby’ rather than the term ‘stillbirth’ were used. However, within the author team it was agreed that this may have been the intention of the authors, and they were included.

What are First Nations Peoples’ perceptions, knowledge and beliefs about the risk factors for stillbirth and its prevention?

Four studies contributed data to question one, with eight findings (3 qualitative; 5 quantitative) and one category identified- safeguarding baby.

Safeguarding baby. One study explored antenatal beliefs to safeguard against losing baby from loss [27]. Sokoloski [27] explored Canadian First Nations Women’s beliefs about pregnancy and prenatal care. They described that strenuous activity could result in miscarriage or preterm birth (pg. 95–96), and that the consumption of alcohol could cause miscarriage. Smoking was also considered harmful.

The further three included studies explored Aboriginal peoples’ perspectives, attitudes, and knowledge regarding antenatal smoking. Passey et al. [28] identified that smokers were less likely than non-smokers to agree that smoking could cause miscarriage (losing the baby) (adjusted odds ratio (aOR)=0.4 (0.26, 0.71)). Gilligan et al. [29] found no difference (p=.87) in knowledge between smokers and non-smokers regarding the risk that smoking posed to spontaneous

abortion or miscarriage (losing the baby). Rahman et al. [30] identified a theme that motivations for quitting were to protect the health of their unborn child. However, one woman stated that she was informed to not quit by her health care provider as this could cause stress and ‘loss of baby’ (pg. 11)[30]. During the woman’s second pregnancy when she did quit, she reported: ‘*Second pregnancy I quit altogether and lost my twins at 18 weeks, 3rd and 4th I quit in the last few months of pregnancy.*’ (pg. 11) [30].

Passey et al. [28] also identified several differences in attitudes between those women who smoked and did not smoke. For example, 24 smokers (n=23 continued and n=1 quit smoking; 20%) and 16 non-smokers (11%) (aOR= 1.7 (0.80, 3.81)) agreed that light smoking does not cause harm to unborn babies. In addition to this statement eight smokers (all continuing smokers; 6.8%) and two non-smokers (1.4%) agreed that cannabis was ‘OK when you’re pregnant because it’s natural’ (aOR=4.8 (0.97, 23.96)) (pg. 612). Furthermore, 26 smokers (17%) and 14 non-smokers (10%) (aOR=3.1 (0.37, 26.89)) agreed with the statement that ‘It’s OK to drink alcohol when you’re pregnant as long as you don’t drink a lot’ (pg. 612).

Further attitudes that were explored within the Passey et al. [28] study included agreement with the statement that within the individual’s respective community it is ‘OK to smoke when you are pregnant’ (pg. 612), where 32 smokers (29 continuing vs 3 smokers who quit; 25%) and 20 non-smokers (14%) agreed. Smokers (n=25; 21%) who continued throughout their pregnancy were also more likely to agree with the statement that ‘quitting smoking is just too hard it is not worth the effort’ (pg.612) compared to six non-smokers (4.3%) (aOR=5.5 (1.60, 18.82)).

What are First Nations Peoples’ perceptions, knowledge and beliefs about stillbirth, the stillborn baby and bereaved parents?

Six studies contributed data to question two, with 13 findings (10 qualitative; 3 quantitative) and three categories identified in response to question two: 1) Traditional practices of birthing and grieving; 2)

Table 1
Full characteristics of included studies.

Author and year	Title	Aim of study	Country	Participants	Context	Type of study	Data Collection	Bereavement (Q1) and/or Prevention (Q2)	Phenomenon of Interest	Category
Blood and Cacciatore, 2014	Best practice in bereavement photography after perinatal death: qualitative analysis with 104 parents	This study contributes 104 parents' experiences and opinions toward the understanding of best practice in perinatal bereavement photography	United States of America	104 bereaved parents; 3 bereaved parents (2.97%) identified as Native American/American Indian	Online within United States of America	Qualitative	Survey	Bereavement	Beliefs	Bereavement Photography
Blood and Cacciatore, 2014	Parental Grief and Memento Mori Photography: Narrative, Meaning, Culture, and Context	This study is an examination of the meaning, utility, and social context of post-mortem photography in a sample of 181 bereaved parents	United States of America	181 bereaved parents; 2.6% identified as Native American	Online within United States of America	Mixed Methods. Modified grounded theory approach	Survey	Bereavement	Beliefs	Bereavement Photography
Cronin et al., 2018	Late stillbirth post-mortem examination in New Zealand: Maternal decision-making	To identify factors influencing maternal decision-making about post-mortem examination after late stillbirth	Aotearoa/New Zealand	169 women with singleton pregnancies; 27 (16.0) identified as Māori consented to autopsy; 22 (25.9%) did not consent in autopsy	Aotearoa/New Zealand Multicentre Stillbirth Study; seven health regions	Mixed Methods	Structured face-to-face interviews as soon after the stillbirth as possible (within 6 weeks of birth); maternity and post-mortem records	Bereavement	Perceptions	Post-mortem examination and autopsy
Gilligan et al. 2009	Knowledge and attitudes regarding smoking during pregnancy among Aboriginal and Torres Strait Islander women	To identify factors associated with antenatal smoking and explore characteristics of smoking behaviour among pregnant Aboriginal and Torres Strait Islander women	Australia	145 pregnant Aboriginal and Torres Strait Islander women	A health service in Far North Queensland between November 2005 and December 2006	Cross-sectional	Interviews, Questionnaire	Prevention	Knowledge; Beliefs	Safeguarding baby
Kenney, 2009	Me aro ki te ha o hineahuone. Women, miscarriage stories, and midwifery: Towards a contextually relevant research methodology	1. To develop a contextually relevant research methodology that is based on a Māori worldview and incorporates the theoretical concepts and philosophical principles of Midwifery and 2. To apply the methodology to collect and analyse women's and midwives' narratives about their first trimester miscarriage in Aotearoa, New Zealand	Aotearoa/New Zealand	20 women participated in the research project. 9 identified as midwives. 12 participants were non-Māori. 8 participants identified as Māori	Aotearoa, New Zealand. Māori and Midwifery communities (Māori, health service providers, kaumatua, and communities)	Qualitative	Dialogical interviews	Bereavement	Perceptions; beliefs	Traditional practices of birthing and grieving
Kilcullen et al. 2020	Decisions to consent for autopsy after stillbirth: Aboriginal and Torres Strait Islander women's experiences	The current study explored the reasons why Aboriginal and Torres Strait Islander women did or did not give permission to autopsy after stillbirth.	Australia	5 Aboriginal and/or Torres Strait Islander women; 3 who accepted autopsy; 1 who declined autopsy; 1 not offered an autopsy, however, accepted alternative investigations	Townsville Hospital	Qualitative Phenomenological framework	Semi-structured interviews	Bereavement	Beliefs; Perceptions	Post-mortem examination and autopsy

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Table 1 (continued)

Author and year	Title	Aim of study	Country	Participants	Context	Type of study	Data Collection	Bereavement (Q1) and/or Prevention (Q2)	Phenomenon of Interest	Category
O'Driscoll et al. 2011	Traditional First Nations Birthing Practices: Interviews with Elders in North-western Ontario	A qualitative research study to understand some of the traditional practices in maternity care	Canada	12 Elders who had knowledge and experience of historical birthing practices in their home communities	Remote communities in North-western Ontario, two of which are accessible only by fixed wing aircraft. The communities have Peoples of 600–1200, and all are over 400 km from a tertiary care centre	Qualitative	Semi-structured interviews in English and Oji-Cree	Bereavement	Knowledge	Traditional practices of birthing and grieving
Passey et al. 2012	Factors associated with antenatal smoking among Aboriginal and Torres Strait Islander women in two jurisdictions	This paper describes Indigenous women's self-reported antenatal smoking behaviour and compares knowledge and attitudes of those who: (i) smoke and don't smoke during pregnancy; and (ii) quit or continued to smoke since the beginning of pregnancy	Australia	264 pregnant Indigenous women	Northern Territory (NT) and one from New South Wales (NSW)	Mixed methods Cross-sectional	Survey	Prevention	Knowledge; Beliefs	Safeguarding baby
Rahman et al. 2021	Factors Associated with Smoke-Free Pregnancy among Aboriginal and Torres Strait Women and Their Experience of Quitting Smoking in Pregnancy: A Mixed Method Cross-Sectional Study	1. To quantitatively examine the factors associated with smoke-free pregnancies among Aboriginal women in Australia. 2. To qualitatively describe women's self-reported experiences of quitting during pregnancy	Australia	103 Aboriginal and Torres Strait Islander women who quit smoking in their pregnancy.	Online within Australia	Mixed methods	Survey	Prevention	Knowledge	Safeguarding baby
Sokoloski 1995	Canadian First Nation women's beliefs about pregnancy and prenatal care	A qualitative study to explore the health beliefs of Canadian First Nations women regarding pregnancy and prenatal care	Canada	7 English speaking key informants representing three First Nations tribes located in Canada: Cree (n=3), Saulteaux (n=2), and Ojibway (n=2)	Canadian urban centre	Qualitative	Interviews	Prevention	Beliefs	Safeguarding baby

Table 2

Question 1- Examples of extracted findings and category allocation.

Question one: What are the perceptions, knowledge and beliefs held by First Nations Peoples about prevention, including risk factors of stillbirth?		
Included Studies	Findings (F)	Categories
Sokoloski 1995 Passey 2012 Gilligan 2009 Rahman 2021	<p><i>Qualitative findings</i></p> <p>F1: First Nations women believe that during pregnancy strenuous activity, consumption of chemical substances such as alcohol and drugs, and smoking can endanger the health of a mother or baby. Informants unanimously stated that strenuous maternal activity is thought to result in miscarriages or preterm births. Consumption of alcohol during pregnancy is believed to cause miscarriage. Smoking is also considered harmful, although no explanation of the harmful effects had been given by those who taught the women. (Sokoloski 1995)</p> <p><i>Quantitative findings</i></p> <p>F1: Smoking tobacco during pregnancy increases the risk of: Miscarriage (losing the baby)- Smokers: 63, 53% agree; Non-smokers: 104, 74% agreed. (Passey 2012)</p> <p>F2: Light smoking does not cause harm to unborn babies -Smokers: 23, 20% agree; Non-smokers: 16, 11% agreed. (Passey 2012)</p>	Category one: Safeguarding baby

Bereavement photography, and 3) Post-mortem examination of the stillborn baby.

Traditional practices of birthing and grieving. There were two studies that explored the traditional practices of birthing and grieving [31,32]. Both studies were from the perspective of Elders with experience in assisting in birth or prenatal care, or qualified Māori midwives [31,32].

Both O'Driscoll et al. [32] and Kenney [31] described the impact of stillbirth on midwives within their respective Oji-Cree and Māori communities. Within O'Driscoll et al. [32], one participant stated that stillbirth was attended by traditional midwives. However, the experience of attending a stillbirth was very stressful with one participant stating that they: 'Couldn't deliver a baby after that' (pg. 27)[32]. Whilst Kenney [31] discussed the experience of a Māori midwife who was made aware of pregnancy loss by her grandmother and was told that:

'Miscarriages, stillbirths and things DO happen', when I was taking up this role as a midwife. 'That there's no guarantee of a perfect pregnancy' And that's the sort of thing that she would say which has helped me through some difficult times, in some birthing experiences that I've had as a midwife. Just helped me to understand. yeh and to be grateful for some things' (pg. 125)[31].

It was also noted that traditional practices of grieving for a stillborn baby have changed between generations of Māori. Current practices could involve full tangihanga (funeral rites) which would delay burial by three days, however, in previous generations it was commonplace for a burial to take place on the same day the baby was born.

'the baby would be buried before the sun came up, very quickly!...I don't know why, but I mean, in those times there were always plenty of live tamariki to be concerned about, to be thinking of and looking after and yes as sad as it was te mate tonu, the old people were always there and would generally..., Take care of them, make recommendations' (pg. 125) [31].

Kenney [31] also discussed the traditional practice of naming the child which is seen as an important practice within Māori culture. However, Kenney [31] discussed the perception of a Māori registered nurse and midwife who was told by her grandmother that attention needed to be paid to the naming of the child within her generation. Those that were named after ancestors (tupuna) may evoke jealousy from unsettled spirits and could result in pregnancy loss including stillbirth (pg. 115) [31].

Bereavement photography. Two studies found mixed beliefs regarding bereavement photography, with some describing the practice as a violation, and others endorsing the practice [25,26]. Two out of the four Native American Peoples endorsed the practice of bereavement photography, while others felt it to be a violation. One participant noted that the pictures have been a way to: 'memorialize my son. They are a way to share him. To be with him and honor him since I cannot do so.' (pg. 230

[26]. One participant who lost their baby within the neonatal period discussed that they were not made aware of the possibility that this was an option and would have positively reacted to being asked (pg. 230) [26].

Although there were examples where the photos were valued, other Native American peoples within this study viewed the practice: "as culturally insensitive" and "against our traditional beliefs and I personally feel that it is morbid. We are Dine (Navajo)" (pg. 230)[26]. One Native American mother also experienced pictures being taken of their baby without their consent and subsequently was advised by their Native American advisors: "I should not have photos or keep any item that touched my daughter after her death" and "I have always felt conflicted about keeping them" (pg. 6) [26].

Post-mortem examination and autopsy of stillborn baby. There were two studies that explored autopsy consent after stillbirth. Studies were conducted in Australia [33] and Aotearoa/New Zealand [34].

Both studies included women who did and did not consent to a post-mortem investigation and/or autopsy. Three women within the Kilcullen et al. [33] study did consent to an autopsy, with one woman declining, and another woman who gave birth outside of the hospital not being offered but had accepted alternative investigations. Within the Cronin et al. [34] study, nine Māori bereaved mothers consented to a post-mortem examination and autopsy and 18 declined further investigation or autopsy.

Both studies indicated that there was a reluctance for Aboriginal and Māori people to agree to post-mortem examination and autopsy of their stillborn babies. Cronin et al. [34] found that Māori bereaved mothers were more likely to decline post-mortem examination compared with Europeans or any other ethnic group, with the most common reason for declining being that they did not want the baby to be cut. This reason was also reflected within the Kilcullen et al. [33] study where one of the identified sub-themes included the distress regarding the autopsy procedure, with a participant stating: "I opted not to do it, I think...I didn't want them cutting up my baby." (pg. 352) Another reason as to why Aboriginal and/or Torres Strait Islander bereaved women declined autopsy was that they were not given enough time, nor asked in a culturally sensitive manner [33].

The Cronin et al. (2018) [34] study did not provide any reasons as to why Māori women consented to post-mortem examination and/or autopsy. Kilcullen et al. [33] provided five reasons as to why Aboriginal women consented to post-mortem investigation and/or autopsy—these included finding out why their baby died, confirming diagnoses, to understand future risk, to help others and to address any doubt that their own bodies somehow caused the stillbirth.

Discussion

This review sought to understand the perceptions, knowledge, and beliefs, that are present within First Nations Peoples in the US, Canada,

Table 3

Question 2 (Examples of extracted findings and category allocation).

Question Two: What are the perceptions, knowledge and beliefs held by First Nations Peoples regarding bereavement practices?		
Included Studies	Findings (F)	Categories
O'Driscoll 2011 Kenney 2009	<i>Qualitative findings</i> F1: "I couldn't deliver a baby after that." (O'Driscoll 2011) <i>Quantitative findings</i> No quantitative findings were identified.	Category one: Traditional practices of birthing and grieving
Blood and Cacciatore 2017a Blood and Cacciatore 2017b	<i>Qualitative findings</i> F1: "I understood it was meant in a good way...but I viewed it as culturally insensitive." She added, "I was told by the people (Native American advisers) who helped me with my daughter's burial that I should not have photos or keep any item that touched my daughter after her death," and "I have always felt conflicted about keeping them". (Blood and Cacciatore 2017a) <i>Quantitative findings</i> F1: Native American parents expressed mixed opinions, with two of four endorsing memento mori photography. (Blood and Cacciatore 2017b)	Category two: Bereavement photography
Cronin 2018 Kilcullen 2020	<i>Qualitative findings</i> F1: 'wasn't until a few days later. We had processed what had happened...we agreed to [autopsy] just because at the time of it all happening, we didn't know what had happened. Going for – sending her for an autopsy would just – it was a step towards trying to find out what happened.' (Kilcullen 2020) <i>Quantitative findings</i> F1: The most common reason for declining was that women 'did not want baby to be cut' and this was reported by women of all ethnicities (Māori, 50.0%; Pacific, 76.0%; Indian, 100%; Asian, 100%; European and Other, 57.9%). However, no women in our study who chose a postmortem said that they regretted this decision. Women of Māori (adjusted odds ratio 4.99 95% confidence interval 1.70–14.64) ethnicity were more likely to decline post mortem examination compared to European or Other ethnic groups. (Cronin 2018)	Category three: Post-mortem examination and autopsy of stillborn baby

Aotearoa/New Zealand and Australia about stillbirth risk and bereavement practices. Although ten studies met the inclusion criteria, there were no studies that solely discussed the knowledge, and beliefs of stillbirth within First Nations Peoples, and the included studies provided scarce information relevant to the phenomenon of interest for this review.

First Nations Peoples' perceptions, knowledge, and beliefs regarding the prevention of stillbirth identified within the literature were restricted to beliefs which safeguard against losing baby, such as avoiding strenuous exercise and smoking tobacco and drinking alcohol during pregnancy. The evidence primarily focused on safeguarding baby through smoking cessation during pregnancy within Aboriginal and Torres Strait Islander peoples, however there were mixed beliefs amongst these populations regarding the effects of smoking. Tobacco smoking is a significant concern and research has consistently shown that smoking prevalence is disproportionately higher among First Nations Peoples compared with their non-First Nations counterparts, leading to an increased risk of exposure to tobacco-related harms during pregnancy [35,36]. Maternal smoking has been linked to adverse fetal health outcomes such as miscarriage, stillbirth, and low birth weight and other complications [35–37]. Some studies explored Aboriginal women's knowledge about the risks of smoking during pregnancy, such as having a smaller baby, as well as the barriers and facilitators to smoking [35, 38, 39]. These studies suggest that smoking rates among First Nations pregnant women are often influenced by interconnected social determinants of health, such as socioeconomic disadvantage, stress including intergenerational trauma, limited access to culturally appropriate healthcare, and cultural factors. Findings such as 'smoking can harm the baby' and 'I quit smoking for the health of my baby' were recurrent, however, there was no discussion as to what 'harm' or 'health' meant for baby and stillbirth. Similar findings were also demonstrated in the Sokoloski (1995) [27] study set in Canada.

Although smoking cessation is important, there is a need to build evidence on understandings of other known stillbirth risk factors among First Nations Peoples. In Canada, there is advocacy to develop a National Action Plan, with plans to implement strategies for reducing risk factors. [40] The Canadian National Action plan will be based on Australia's approach to reducing stillbirth, such as the implementation of the Safer Baby Bundle package within Australian maternity care [41] which was based on a similar bundle that has been successful in reducing stillbirth rates in the UK and Scotland [42]. The elements other than smoking

include fetal growth restriction, change in fetal movements, side sleeping and timing of birth. Despite being identified as key elements within the Safer Baby Bundle, there was no evidence found within the literature that indicates any research into the knowledge and awareness of these in relation to stillbirth within First Nations Peoples. Accordingly, this may hinder the efficacy of the implementation of this bundle and other current interventions for First Nations Peoples.

The perceptions, knowledge and beliefs, regarding the bereavement of stillbirth were focused on the traditional beliefs associated with the grief and burial of a stillborn baby and the profound impact of stillbirth within First Nations Peoples. The identified studies were from the US, New Zealand, Australia and Canada, and focused on traditional practices, bereavement photography, and post-mortem examination. There were diverse views regarding the perceptions and attitudes within First Nations participants of post-mortem examination and bereavement photography. It is important to acknowledge that like any community, there is a diversity of values and beliefs within each First Nations groups. This highlights the need for shared decision-making between health care providers and the bereaved parents, for First Nations Peoples decisions may also need to be made with Elders. The framework for the practice of respectful and supportive perinatal bereavement care does state that care in Australia and New Zealand should consider the cultural context of the bereaved parents [43]. Shared decision-making includes not only the needs and wants of the bereaved parents within their cultural context, but also the health care provider being able to share the best available evidence. As this review identified, evidence is sparse within bereavement photography and post-mortem examination and the experience of First Nations Peoples and there is an urgent need for further research in this area.

Engagement with community

There was discussion within the advisory board regarding the results of this systematic review, noting that there was a paucity of evidence. The advisory board recommended the following actions should be taken to improve research within this area. These recommendations mostly stem from the perspective of Aboriginal women from the Noongar region of Western Australia and may not reflect the views of other First Nations Peoples.

Action one: The advisory board felt that further research should focus on strengthening prevention messages and that knowledge about stillbirth be handed down and discussed without triggering further trauma. Prevention messages should be a part of culturally appropriate care from the first pre-natal appointment within the community. Culturally appropriate care will also make pregnant Aboriginal women feel safe and heard during their pre-natal appointments. Furthermore, when prevention messages are being developed for Aboriginal peoples, they should align with developing maternity service delivery models which emphasise the importance of ‘birthing on Country’ and include Aboriginal leadership and control which is collaborative and respectful of culture [44].

Action two: The advisory board discussed that there are significant structural challenges preventing work in this area from being conducted. They indicated that there is an urgent need to facilitate the capability of Aboriginal researchers to do work in this area and to publish their findings. This may be achieved by engaging First Nations Peoples throughout the research process, and scholarships/grants to include more First Nations Peoples in academia.

Action three: As our group was attempting to collate evidence for this review, we were unable to access known government documents relating to the perceptions, knowledge, attitudes, beliefs and myths (relating to stillbirth) that refer to First Nations Peoples. It is crucial that these documents are made available to the research and broader community, as not knowing their content may be causing harm.

Limitations of included studies and the systematic review

The paucity of the studies and their specificity to stillbirth was a major limitation within this study. Furthermore, although the overall quality of the included studies was good within the included qualitative studies, the influence of the researcher on the research and vice-versa was consistently not addressed and no study reported if authors were from First Nations Peoples. Some studies did have First Nations researchers supporting the collection of data, however, their role in the interpretation of the findings was not clear. This may indicate that, for some of these studies, non-First Nations researchers are interpreting the voice of a community that has already been disenfranchised. Future research should be mindful that First Nations People must be meaningfully engaged in all parts of the research process (from the earliest stages, preferably using participatory processes of co-design, co-decision making and research governance) [45], and that reporting should adequately reflect their roles within the project. This limitation could also extend to this review—our advisory board included Australian Aboriginal Elders and did not have a diversity of voices from other First Nations Peoples and, therefore, the interpretation of the findings and the actions developed by our research team cannot necessarily be generalised.

Most of the included literature is from the voice of pregnant women and Elders within the community. There were no studies that included the perspectives from the wider community within First Nations Peoples, which may warrant further exploration. For many First Nations groups, men are not included within the discussion of reproductive health in their community, so it was not surprising that we were unable to find studies featuring the perspectives of men. The included studies only represented a small sample of First Nations population groups, and we acknowledge that there are different cultural practices surrounding pregnancy and stillbirth between First Nations Peoples. The results of this systematic review should only be considered reflective of the included First Nations Peoples and the study participants and therefore may not be generalisable to all groups.

A limitation of this review is that it did not include languages other than English, and therefore, the search did not include non-English language library databases. Consequently, studies in French which is a dual first language of Canada, and First Nations languages may have been missed if these were not published in French and English.

Implications for research

It is important to acknowledge that there are a myriad of different cultures and perspectives throughout First Nations Peoples. The absence of dedicated research on this topic may reflect a broader research disparity and an inadequate representation of First Nations voices in the scientific discourse on stillbirth and culturally appropriate bereavement care. The scarcity of studies directly addressing the perceptions, knowledge, attitudes, beliefs, and myths surrounding stillbirth within First Nations Peoples is a notable gap in the literature. This highlights the need for more culturally appropriate and sensitive, and community-centred, research efforts that aim to gain a comprehensive understanding of the perceptions of stillbirth among First Nations communities.

There is a need for primary research in this area (across all First Nations Peoples) which specifically addresses stillbirth rather than overall pregnancy related factors. Furthermore, primary research which includes the wider community within First Nations Peoples, including men and bereaved fathers may provide further understanding that could be beneficial. Secondly, as this review only explored the perceptions, knowledge and beliefs of stillbirth, a further systematic review exploring the importance of common risk factors for stillbirth specifically in First Nations Peoples (including, for example, smoking, fetal growth restriction, change in fetal movements, side sleeping and timing of birth) and associated strategies for reducing stillbirth would be beneficial. Furthermore, this suggested review could also explore the understanding of these risk factors with First Nations Peoples and their health care providers. This would further our understanding of the gaps in knowledge, and the perceptions, attitudes, beliefs, and myths that could potentially hinder the uptake of implementation packages aimed at reducing stillbirth in non-First Nations Peoples.

Implications for practice

As no study focused solely on stillbirth, the included data were neither rich nor homogenous enough to create synthesised findings and, as such, it is difficult to identify implications for practice based on this evidence. Furthermore, this review emphasises the need for First Nations Peoples to be meaningfully engaged in all parts of the research and policy making process (from the earliest stages, preferably using participatory processes of co-design, co-decision making and research governance).

Conclusion

This systematic review explored perceptions, knowledge, and beliefs regarding the prevention of stillbirth and bereavement following stillbirth among First Nations Peoples. Ten studies were included, none of these studies exclusively focused on the topic of stillbirth, instead being centred on beliefs to safeguard baby, traditional practices, antenatal smoking, bereavement photography and post-mortem examination.

The lack of research highlights a gap in the evidence and the need for further investigations to gain a comprehensive understanding of the cultural perspectives surrounding stillbirth in First Nations communities. In addition, it highlights the importance of including First Nations researchers in stillbirth research and amplifying the voices of First Nations Peoples in research to ensure their perspectives and experiences are adequately represented. By doing so, we can foster a more collaborative and culturally safe approach, which has the potential to pave the way for improved stillbirth prevention and bereavement care that aligns with the needs and values of these communities.

Author contributions

DP, HB, and SH conceptualised and designed the review topic, collected data, performed the analysis, and wrote the original draft of the manuscript. ZM, CV, CS, CP, RM, JG, CL, CM, MB, MP, TR, JW, BF,

SW, and CJS reviewed the review project, provided guidance, and edited the manuscript. CP developed the search strategy.

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Ethical statement

Ethical approval is not required as this is a review of studies.

Conflict of interest

None declared.

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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.2024.101604.

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