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**Citation:** Madeley, A-M., Earle, S. & O'Dell, L. (2023). Challenging norms: Making non-normative choices in childbearing. Results of a meta ethnographic review of the literature. *Midwifery*, 116, 103532. doi: 10.1016/j.midw.2022.103532

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**Link to published version:** <https://doi.org/10.1016/j.midw.2022.103532>

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## Challenging norms: Making non-normative choices in childbearing. Results of a meta ethnographic review of the literature

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### ARTICLE INFO

#### Article history:

Received 28 February 2022

Revised 8 October 2022

Accepted 28 October 2022

#### Keywords:

Meta-ethnography

Qualitative

Home childbirth

Birth choice

Non-normative

Declining care

### ABSTRACT

**Objective:** Women have the right to make choices during pregnancy and birth that sit outside clinical guidelines, medical recommendations, or normative expectations. Declining recommended place or mode of birth, routine intervention or screening can be considered 'non-normative' within western cultural and social expectations around pregnancy and childbirth. The aim of this review is to establish what is known about the experiences, views, and perceptions of women who make non-normative choices during pregnancy and childbirth to uncover new understandings, conceptualisations, and theories within existing literature.

**Methods:** Using the meta-ethnographic method, and following its seven canonical stages, a systematic search of databases was performed, informed by eMERGe guidelines.

**Findings:** Thirty-three studies met the inclusion criteria. Reciprocal translation resulted in three third order constructs - 'influences and motivators', 'barriers and conflict' and 'knowledge as empowerment'. Refutational translation resulted in one third order construct - 'the middle ground', which informed the line of argument synthesis and theoretical insights.

**Key Conclusions and implications for practice:** The findings of this review suggest that whilst existing literature from a range of high-income countries with similar healthcare systems to the UK have begun to explore non-normative decision-making for discrete episodes of care and choices, knowledge based, theoretical and population gaps exist in relation to understanding the experiences of, and wider social processes involved in, making non-normative choices across the UK maternity care continuum.

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### Introduction

Informed choice in decision-making is a dominant feature in facilitating woman-centred care (Leap, 2009; Snowden et al., 2011; Sandall et al., 2016). Pregnancy and birth related choices are linked to complex individual, institutional, cultural, and social contexts, within which norms around pregnancy and childbearing develop. Evidence surrounding the decision-making processes in pregnancy provides important insights into how and why women make particular decisions (Coxon et al., 2017, 2014; Hinton et al., 2018; Yuill et al., 2020). However, such data often fail to account for choices that fall outside medical recommendation, and guidelines and routine pathways. The ability to exert agency and control in making informed choices is critical to woman-centred care

and psychological and physical well-being (Henriksen et al., 2017; Yuill et al., 2020).

The World Health Organisation standards for improving quality of maternal and newborn care in health facilities makes explicit the requirement for dignified, respectful and supportive patient-led decision-making, including acknowledgement of self-determination and bodily autonomy (WHO, 2016). Globally, key stakeholders continue to campaign for informed choice in pregnancy and childbirth as a fundamental human right (White Ribbon Alliance, 2011). For many countries including the UK, this notion has been explicitly embedded within national policy (DoH, 1993, 2007; NHS England, 2016). Established legal, ethical, and clinical frameworks protect the rights of women deemed to have capacity under the Mental Health Act (HMSO, 2008) to make choices about their care regardless of the potential maternal or foetal outcome. Human Rights legislation, specifically, article 8 of the European Convention on Human Rights (ECHR) (Council of Europe, 1950), incorporated in the UK by The Human Rights Act 1998 (HMSO, 1998), af-

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firms these rights through respect for private and family life. Articles 2 and 3 of the ECHR also provide protections in respect of bodily autonomy and integrity, dignity, respectful care, equality, and informed consent. Over the past three decades, landmark rulings in Europe and the UK have continued to influence understandings of how women's autonomy is central to safe and respectful care (UKSC, 2015). However, whilst legal rulings in the UK make clear expectations about the centrality of women's decision-making, there is evidence of a culture of "expected compliance" (Nicholls et al., 2019, p. 136) which can bring women into conflict with practitioners (Beech, 2014; Hollander et al., 2016). The expectation of compliance is evident in accounts of withdrawing care, coercive behaviours and bullying, including threatened legal action and social services referral (Feeley and Thomson, 2016a; Care Quality Commission, 2019). For some women who seek to make a choice that falls outside of normative expectations, the aspiration of choice contrasts with the reality. For the purposes of this review, we define non-normative choice as an autonomous decision made by women deemed to have capacity to do so, made at any point along the childbearing continuum, which reflects one or more of the following elements:

- 1 Desiring care outside of established guidelines or medical recommendations which would not routinely be offered as a choice e.g., home birth where clinical recommendation is to birth in hospital.
- 2 Withholding consent to any routinely offered intervention which is offered as a choice e.g., declining cardiotocograph monitoring, routine screening, or induction of labour.
- 3 Moving outside cultural, social, or familial expectations and non-medical 'norms' e.g., placentophagy, acceptability of receiving blood products.

## Review aims and question

The review asks, "What are the views, perceptions, and experiences of women who make non-normative choices along the childbearing continuum?". The aim of the review was to establish what is known about the experiences, views, attitudes, and perceptions of women who make non-normative care choices during pregnancy, labour, and the puerperium to identify knowledge, theoretical and population gaps to inform future empirical research and practice.

## Methods

### Research design

A systematic review of existing literature was undertaken utilising Noblit and Hare's (1988) meta-ethnographic method (Fig. 2).. This method adopts seven canonical phases to search for, extract and explore new conceptual understandings and insights (Noblit and Hare, 1988; Walsh and Downe, 2005). These canonical phases are detailed below.

### Phase 1: search strategy

Phase 1 involves the development of search, screening, and reporting mechanisms. These were guided by the eMERGe guidelines for meta-ethnography (France et al., 2019). Search terms were developed to identify papers specific to the phenomena combining functional and Boolean phrasing, MESH headings and free text. The searches were conducted by author 1 between December 2019 and February 2020 using EBSCO (ASC, CINAHL, Pubmed/MEDLINE/PMC, SocIndex, PsycARTICLES) OVID/ MIDIRS, PSYCHinfo and Web of Science, with advice from a specialist subject librarian. Grey literature

**Table 1**  
Inclusion and exclusion criteria.

	Inclusion	Exclusion
Time period	Published post 1990- 2021	Published Pre 1990
Setting	High-middle income countries UK analogous healthcare models UK similar socio-cultural demographic	Low-income countries Healthcare model / socio-cultural demographic unlike the UK
Language	English/ Translated into English/ Translatable	Non-English language/ Unable to translate
Participants	>18 years old Primiparous/Multiparous Birth and pregnancy in any setting	<18 years old Partners and Healthcare providers
Study Design	Primary qualitative studies/ including Qualitative methodology Qualitative element of mixed method	Quantitative methodology / RCT/ Open ended questions in surveys
Literature Type	Peer reviewed journal articles, research reports, theses	Secondary research or analysis Opinion and commentary
Study Focus	Views, attitudes, experience, perspectives of choice of non-normative care pathway by women	Views, attitudes, experience of choice of non-normative care pathway by healthcare, partners and others

was sourced using EthOs. Author 1 also undertook author and citation searching, also contacting authors of four papers to elicit further information. A call for literature through the JISCMAIL (Email discussion lists for the UK Education and Research communities) midwifery research group email list was also undertaken.

### Phase 2: inclusion and exclusion criteria, screening and quality appraisal

Inclusion and exclusion criteria were developed by the review team (see Table 1). Papers from 1990 onwards were included in the review to reflect changes following publication of *Changing Childbirth* (DoH et al., 1993) in the UK. 2476 records were identified, 58 papers were included for full text screening with 33 meeting criteria for inclusion (see Fig. 1). Sampling was undertaken within the review team; author two focused on title and abstract screening, author three focused on full text screening to confirm rigour. Ten papers across the sample reported data from four studies (Jackson et al., 2012; Feeley and Thomson, 2016b, 2016b; Jenkinson et al., 2016; Lee et al., 2016c, 2016b, 2016a; Jenkinson et al., 2017; Jackson et al., 2020); they were all included because they reported different data. Broad principles of quality assessment (Walsh and Downe, 2005; Joanna Briggs Institute, 2020) were applied, noting recommendations in the eMERGe reporting guidelines.

### Phase 3: reading studies and extracting data

Data extraction for first and second order constructs was undertaken using NVivo 12 qualitative data analysis software; this enabled a systematic and repeated reading of the studies, using a process of constant comparison (Campbell et al., 2011; Cahill et al., 2018). First order constructs included the phrases, words, metaphors, and key concepts articulated by the original research participants. Second order constructs were extracted by identifying the concepts, themes and interpretations articulated by the authors of the original studies. Details of each study (including aims and objectives, research question, study design and methodology, methods, sampling (size and strategy), data collec-

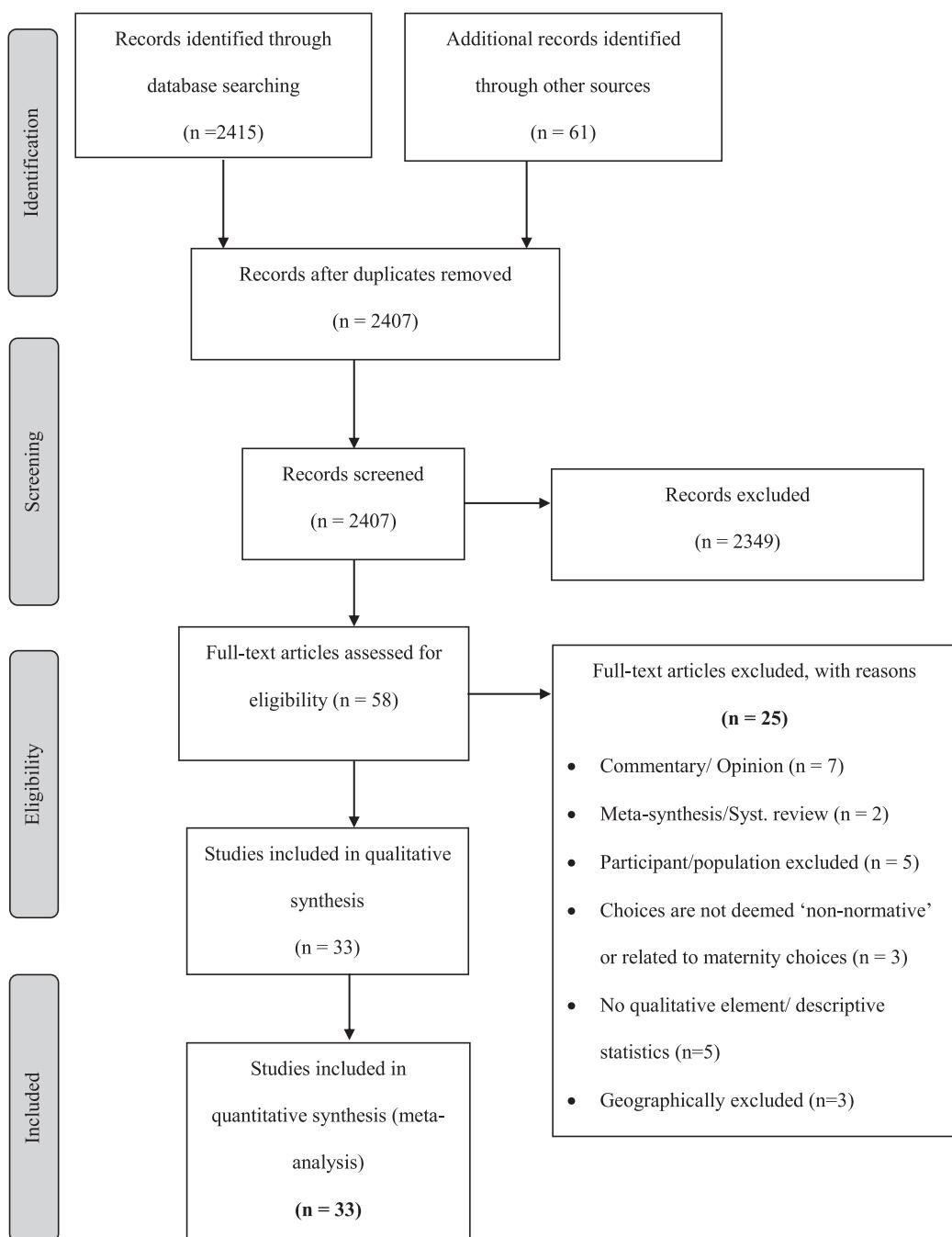


Fig. 1. PRISMA diagram.

tion method and data analysis methods) were recorded to enable comparison (see Table 2).

#### Phase 4: determining how studies were related

Phase 4 involved comparing the characteristic data within and between the included studies. Data collection and analysis methods across the studies included semi-structured interviews, diaries, surveys, and focus groups. Methodological approaches included thematic framework analysis, thematic analysis, grounded theory, phenomenology, and interpretative phenomenological analysis. The research location of the studies included were: United Kingdom (12); Australia (10); Netherlands (4); Sweden (3); Norway (2); Iceland (1); Ireland (1).

Study aims varied. These included:

- Exploring motivations, experiences and decision-making processes for birthing at home in the presence of obstetric or medical risk factors (Lee et al., 2016c, 2016b, 2016a, 2016d; Hollander et al., 2017; Holten et al., 2018)
- Freebirthing (Feeley and Thomson, 2016b, 2016a; O'Boyle, 2016; Plested and Kirkham, 2016; Lindgren et al., 2017; Henriksen et al., 2020)
- A combination of both freebirthing and homebirth in the presence of complex needs (Jackson et al., 2012; Hollander et al., 2017; Rigg et al., 2017, 2020; Jackson et al., 2020)
- Exploring refusal of recommended care including declining discrete routine or recommended interventions or treatment including induction of labour for postdates pregnancy

**Table 2**  
Summary of included studies and characteristics.

	Author and country	Aims and objectives	Sample, Data Collection, Analysis Method
1	Bakkeren et al. (2020) Netherlands	Views and opinions of pregnant women who have made the decisions about whether to accept prenatal screening tests.	19, Semi-structured (SS) interviews, Thematic analysis
2	Crombag et al. (2016) Netherlands	Determine if screening policy and healthcare system influences individual decision-making and uptake	$n = 46$ ( $n = 22^*$ ), Focus group Framework analysis
3	de Zulueta and Boulton (2007), United Kingdom	Decision-making processes and informed consent around routine antenatal HIV testing	$N = 32$ ( $n = 6^*$ ) SS interviews, matrix based thematic analysis.
4	Eide et al. (2019), Norway	Exploration of maternal request for planned caesarean section in the absence of obstetric indication	$n = 17$ , SS interviews, Thematic cross case analysis
5	Feeley and Thomson (2016a) <sup>a</sup> United Kingdom (UK)	Identify and explore influences on women's decision to freebirth.	$n = 10$ , Narrative accounts, SS interviews, Interpretative phenomenological analysis (IPA)
6	Feeley and Thomson (2016b) <sup>b</sup> , UK	Explore conflicts and tensions in freebirth through the views, experiences, and motivations of women who choose freebirth	$n = 10$ , Written narrative accounts, SS interviews, IPA
7	Fenwick et al. (2010) Australia	Describe women's request for caesarean section in the absence of a known medical indication.	$n = 14$ , Interviews and questionnaire, haematic Analysis
8	Gottfreðsdóttir et al. (2009), Iceland	Decision-making to undergo nuchal translucency screening amongst both couples who accept and couples who decline screening	$n = 10$ , SS interviews, thematic framework analysis
9	Henriksen et al. (2020) Norway	Describing motivations and preparations for freebirth	$n = 12$ , SS interviews, Thematic Analysis
10	Hollander et al. (2017), Netherlands	Motivations for high-risk homebirth and unassisted childbirth.	$n = 28$ , SS interviews/field notes Constructivist Grounded Theory
11	Holten et al. (2018), Netherlands	Explore how the choice to birth outside of the system was negotiated in clinical encounters.	$n = 10$ , SS interviews, Descartes phenomenology
12	Jackson et al. (2012), Australia	Explore the perceptions of risk held by women who choose to have a freebirth or a 'high-risk' homebirth.	$n = 20$ , SS interviews, Qualitative interpretative
13	Jackson et al. (2020), Australia	Motivations for birthing outside of the system (high risk homebirth and freebirth)	$n = 20$ , SS Interviews Grounded Theory
14	Jenkinson et al. (2016), Australia	Perspectives of women, midwives and obstetricians after introduction of a formal process to document refusal of recommended care.	$n = 9$ , SS interviews Qualitative interpretative thematic analysis
15	Jenkinson et al. (2017), Australia	Explore experiences of refusal of recommended maternity care.	$n = 9$ SS interviews Feminist thematic analysis
16	Keedle et al. (2015), Australia	Reasons for and experiences of choosing a Home Birth after Caesarean (HBAC)	$n = 12$ , SS interviews Interpretative/ Feminist framework
17	Lee et al. (2016a) <sup>a</sup> , UK	Explore women's decision-making during high-risk pregnancies, half planning high risk homebirth	$n = 26^*$ , SS interviews Thematic Analysis
18	Lee et al. (2016b) <sup>b</sup> , UK	Explore women's perceptions of interactions with obstetricians and midwives during high-risk pregnancies.	$n = 26^*$ , SS interviews Thematic Analysis
19	Lee et al. (2016c) <sup>c</sup> , UK	Examine differences and similarities between women planning to give birth at home or in hospital.	$n = 26^*$ , SS interviews, Thematic Analysis
20	Lee et al. (2016)d	Examine perception of risk amongst women with high-risk pregnancies who were either planning to give birth in hospital, or at home despite medical advice to the contrary. Consider differences and similarities between groups to examine how perception of risk relates to choice of place of birth.	
21	Liamputpong et al. (2003), Australia	Explored women's use of lay information during high-risk pregnancies to examine differences and similarities in the use of information in relation to planned place of birth.	$n = 26^*$ , SS interviews Thematic Analysis
22	Lindgren et al. (2017), Sweden	Reasons for declining prenatal screening and diagnosis	
23	McDonald and Kirkman (2011), Australia	Experiences of unassisted planned homebirth in Sweden	$n = 46^*$ , questionnaire, thematic analysis
24	McKenna and Symon (2014), UK	Accounts from HIV positive women of their use and non-use of treatments for the prevention of mother to child transmission	$n = 8$ , SS interviews Phenomenology
25	O'Boyle (2016), Ireland	Explore the reasons for requesting a water vaginal birth after caesarean and experiences	$n = 16$ SS interviews Thematic framework analysis
26	Plested and Kirkham (2016), UK	Explore the choice to birth unassisted	$n = 8$ SS interview, IPA
27	Rigg et al. (2017), Australia	Examine the lived-experience of women who birth without a midwife or other health-care professional including risk discourse	$n = 4$ , Survey/ Interview, Thematic analysis
28	Rigg et al. (2020), Australia	Explore reasons why women choose to give birth at home with an unregulated birth worker (UBW)	$n = 10$ , SS Interviews, Hermeneutic phenomenology
29	Roberts and Walsh (2018), UK	Explore the experiences and reasoning choosing unregulated birth workers for a homebirth.	$n = 9$ , SS interviews Thematic Analysis
30	Sahlin et al. (2013), Sweden	Explore women's understanding, experience, and balance of risks of prolonged pregnancy and induction.	$n = 82$ , survey, content analysis
31	Tully and Ball (2013), UK	Primigravida experiences of caesarean section in absence of medical indication.	
32	Wätterbörk et al. (2015), Sweden	Examine experiences of operative birth in a UK hospital, explores how women understand and rationalize their birth experiences.	$n = 21$ , SS interviews and focus groups, thematic analysis
33	Weaver et al. (2007), UK and 'Eire	Reasons for declining extended information visit on prenatal screening amongst pregnant women and their partners	$n = 12$ , SS interviews, thematic analysis
		Examine whether, and in what context, maternal requests for caesarean section are made	$n = 115^*$ , SS interviews, thematic analysis
			$n = 8$ , SS Interviews, interpretative thematic analysis
			$n = 64$ (diary), 44 (interview), thematic Analysis

7 canonical phases of meta-ethnography
<ol style="list-style-type: none"> <li>1. Getting Started</li> <li>2. Deciding what is relevant to the initial interest</li> <li>3. Reading the studies</li> <li>4. Determining how studies are related</li> <li>5. Translating studies into one another</li> <li>6. Synthesising translations</li> <li>7. Expressing the synthesis</li> </ol>

**Fig. 2.** 7 Canonical phases of meta-ethnography (Noblit and Hare, 1988).

(Jenkinson et al., 2016; Jenkinson et al., 2017; Roberts and Walsh, 2019)

- HIV treatment in pregnancy (McDonald and Kirkman, 2011);
- Motivations for declining routinely offered screening (Liamputong et al., 2003; de Zulueta and Boulton, 2007; Gottfreðsdóttir et al., 2009; Wätterbörk et al., 2015; Crombag et al., 2016; Bakkeren et al., 2020) and R
- Requesting care outside of current medical recommendations or guidelines such as water vaginal birth after caesarean (McKenna and Symon, 2014).
- Motivation for caesarean section in the absence of clinical indication. (Weaver et al., 2007; Fenwick et al., 2010; Sahlin et al., 2013; Tully and Ball, 2013; Eide et al., 2019)

#### Phase 5: translation of studies into one another

NVivo was used to assist with the process of translating studies into one another, referring to the comparison of data across studies. It allowed author 1 to move back and forth, comparing and translating the data within and between studies. This iterative process of merging and grouping enabled identification of concepts and themes that either shared meaning and represented similarities across studies (reciprocal translation) or demonstrated differences or incongruities (refutational translation) (Toye et al., 2014, p. 31). This process formed the basis for synthesising translations, the next phase of analysis.

#### Phase 6: synthesising translations

Three reciprocal interpretative themes and one refutational interpretative theme were identified by the review; within meta-ethnography these are expressed as third order constructs (Britten et al., 2002).

The three reciprocal themes are:

- *Influences and motivations for a non-normative choice* (exploring individual accounts, justifications, and motivations for making non-normative choices)
- *Barriers and Conflict* (exploring institutional and systemic barriers and conflicts when making or which might influence non-normative choices)
- *Knowledge as Empowerment* (describes how women engaged with and utilised knowledge to assert control and autonomy in making non-normative choices).

Only one significant refutational theme was identified through analysis: '*the middle ground*'. This refers to the way in which facilitative care was experienced by some women.

#### Phase 7: expressing the synthesis

In the final phase of meta-ethnography, data analysis is distilled and expressed as a 'line of argument synthesis' (Noblit and Hare, 1988) representing the similarities and differences between the studies, interpretative relationship between themes, new interpretations and conceptualisations of the data, or the 'storyline' (Campbell et al., 2011; Cahill et al., 2018). The line of argument synthesis is outlined within the Discussion and Conclusion section.

#### Findings

33 papers were included in the review representing 25 studies overall. The following section describes the three reciprocal themes identified across the studies: Influences and motivations for a non-normative choice; barriers and conflict; and knowledge as empowerment and the refutational theme: the middle ground.

#### Reciprocal theme 1: influences and motivations for a non-normative choice

This theme explores accounts, influences, and motivations for making non-normative choices. Five sub-themes were identified in the review and discussed next: Philosophy, values, and beliefs; Socio-cultural influences; Risk interpretation and safety; Ambivalence; and Fear and (re)traumatising choices.

#### Philosophy, values, and beliefs

Many women reported making decisions that accord with a view of birth as a normal, physiological event which "imprints on one's life" (Jackson et al., 2020, p. 7), sometimes adopting a view of pregnancy and birth as a "rite of passage" (Jenkinson et al., 2017, p.4). For many women these views were laden with personal, cultural, religious, and societal significance (Lee et al., 2016a) and, depending on whether their values, beliefs and needs were met, influenced how they came to understand what was a 'safe' maternity experience (Jackson et al., 2020). For some women, this meant an "undisturbed natural birth" (Hollander et al., 2017, p. 5), outside of the institution (Keedle et al., 2015; Lee et al., 2016a; Hollander et al., 2017; Rigg et al., 2017; Holten et al., 2018; Jackson et al., 2020), without a regulated birth worker or obstetrician (Feeley and Thomson, 2016b; O'Boyle, 2016; Plested and Kirkham, 2016; Lindgren et al., 2017; Holten et al., 2018, 2018; Jackson et al., 2020). Some participants placed high value on the emotional and psychological significance of childbirth, rather than on physical birth outcomes. For example, McKenna and

Symon (2014, p. 23) reported that, for women who chose to birth at home after a previous caesarean section, the "psychological benefits were of even greater significance ... than the beneficial physical outcomes". Women also made choices that promoted the physiology of birth, often in response to previous experiences of childbearing. For example, choosing home birth to avoid unnecessary intervention or the need to repeatedly defend their choices (Feeley and Thomson, 2016b; Lee et al., 2016a).

Conversely, some women described feeling emotionally disconnected from the birth process altogether "struggling to articulate any personal meaning" (Fenwick et al., 2010, p. 397), framing the birth as a means to an end in order to obtain a healthy baby. This was particularly noteworthy in relation to studies exploring caesarean birth in the absence of clinical indication, illustrated by a participant who explained "...I don't see the process of birth as some kind of big payoff for me. I'll do anything, c-section or whatever, in order to get a healthy baby" (Weaver et al., 2007, p.35). This is discussed further in the subtheme 'ambivalence'.

### Socio-cultural influences

The influence of societal expectations on women's non-normative choices was seen across studies, most notably in relation to screening. In a study exploring decision-making and Non-Invasive Prenatal Testing (NIPT) (Bakkeren et al., 2020), participants said they felt socially obliged to accept prenatal screening, regardless of their own views.

Socio-cultural influences also impacted on non-normative choices. Some participants were suspicious of, and rejected, the offer of a termination, assuming that it was linked to a societal assumption that 'perfect children' (Bakkeren et al., 2020, p. 117) were the only acceptable outcome. Studies reported that women likened the process to 'playing God' (de Zulueta and Boulton, 2007; Bakkeren et al., 2020, p. 117) and that prenatal screening was a means of 'clearing the human race' (Wätterböök et al., 2015, p. 1235) leading to a rejection of the intervention. Women also declined screening when they rejected the societal imperative to produce 'perfect' babies, emphasising the value of disabled people instead (Liamputong et al., 2003). A healthy baby was a motivator for making non-normative choices, such as declining screening, refusing HIV medication (de Zulueta and Boulton, 2007; McDonald and Kirkman, 2011) or requesting caesarean section in the absence of medical indication (Weaver et al., 2007).

Some participants felt that rejecting vaginal birth was stigmatised, characterised by multiple accounts of being accused of being 'too posh to push' when choosing caesarean section in the absence of clinical indication (Tully and Ball, 2013, p. 106). Participants in Sahlin et al.'s (2013) study reported that they felt subject to an assumption that "a real women will give birth naturally, vaginally" and thus to choose otherwise in the absence of indication could, as the authors suggest, be perceived as being "...unwomanly... not good enough, provocative and a way of cheating" (Sahlin et al., 2013, p. 450).

Participants across most studies felt they must publicly regulate their own opinions and disclosures to some degree to avoid stigmatisation and judgement from the wider community and society. This sometimes forced decision-making and disclosure of non-normative intention underground, for example when intending to freebirth or homebirth in the presence of risk (Keedle et al., 2015; Feeley and Thomson, 2016b, 2016a; O'Boyle, 2016; Lindgren et al., 2017; Henriksen et al., 2020).

### Risk, interpretation and safety

The review suggests that individual perception of risk determined choice of treatment, however discordant or at odds this was

with the risk presented by health professionals. Recognising that pregnancy and birth is not in itself inherently risk free and that complications arise regardless of screening, intervention, examination, or mode/ place of birth was a commonly expressed view in the studies reviewed. Women's individual perception of risk included consideration of the acceptability of material risk. Material risk is defined as one which "a reasonable person in the patients position would be likely to attach significance to" (UKSC, 2015, p. 15) and is an important legal test embedded within UK law. This takes into consideration objective clinical risk and the woman's own personal and social circumstances, which can conflict with recommendations for care (Fenwick et al., 2010; Jackson et al., 2012; Crombag et al., 2016; Feeley and Thomson, 2016a; Lee et al., 2016c; Hollander et al., 2017; Eide et al., 2019).

Studies reported that screening had the potential for anxiety, emotional and psychological distress rather than providing reassurance. Women reported concerns with the potential adverse outcomes of screening, including the physical risks of invasive screening (Liamputong et al., 2003; Gottfreðsdóttir et al., 2009) and the psychological risks of "knowing" the outcome of screening (and potential for a termination). The act of declining screening and related information or treatment can therefore be regarded as psychologically protective behaviour (Liamputong et al., 2003; Crombag et al., 2016; Bakkeren et al., 2020).

Women reported concern about what they perceived as an over-medicalisation of childbearing (Liamputong et al., 2003) believing that unnecessary intervention posed a higher likelihood of harm than the risks or consequences of their choices (Jackson et al., 2012; Lee et al., 2016a, 2016c; Holten et al., 2018). These concerns were reported to lead to rejection of healthcare professionals and services.

The avoidance of iatrogenic harm was a consideration for women exerting non-normative choices (Lee et al., 2016a). Perception of risk and safety is a complex mix of physical and psychological factors. Women expressed the need for psychological and emotional safety in a number of studies, acknowledging that while contemporary maternity care focuses predominantly on physical safety, achieving a positive, fulfilling birth experience was also important (de Zulueta and Boulton, 2007; McKenna and Symon, 2014; Lee et al., 2016a; Plested and Kirkham, 2016; Hollander et al., 2017). The studies did not imply that women were naïve in their decision-making, many expressed the intention to accept responsibility and accountability for the consequences of their choices (Jackson et al., 2012; Lindgren et al., 2017; Rigg et al., 2020).

### Ambivalence

Women may remain ambivalent to choices open to them. This is evident in studies that focused on caesarean section in the absence of medical indication. Some women considered caesarean birth safer than vaginal birth (Sahlin et al., 2013) or were compelled to relinquish responsibility for decisions to their obstetric team, seeking emotional, physical and psychological safety by abdicating their decision-making, as one participant stated, "I trusted them. I handed control of myself over to them. I was completely in their hands" (Fenwick et al., 2010, p. 398). Whilst it might be argued that this is reflective of a technocratic society (Fenwick et al., 2010), women who viewed vaginal birth as hazardous safeguarded their own values and beliefs by choosing caesarean section in the absence of clinical indication in the same way women did so by declining intervention. Women's fear of vaginal birth was reported with some, believing it to be unnatural or unpleasant (Eide et al., 2019), "frightening, unpredictable and dangerous" (Fenwick et al., 2010, p. 396), or describing a sense of "sheer terror" (Ibid. p296). Accounts of fear of vaginal birth was noted to be complex and multi-factorial including family members' traumatic experiences of

childbirth (Weaver et al., 2007; Fenwick et al., 2010), negative experiences of inpatient medical care and, sexual assault (Feeley and Thomson, 2016b).

#### *Fear and (re) traumatising experiences*

A previous traumatic experience was a noteworthy factor influencing non-normative choices whereby women sought to avoid a system that might (re)traumatised them. This featured in studies of caesarean section in the absence of obstetric indication (McKenna and Symon, 2014), water birth after caesarean section (Keedle et al., 2015) and, freebirth and high-risk home birth (Feeley and Thomson, 2016b; Jenkinson et al., 2017; Henriksen et al., 2020; Jackson et al., 2020). These studies describe how women sought to side-step previous poor experiences by making choices about the mode or location of birth and presence (or not) of attendants to avoid "*being back on that butcher's bench*" (Eide et al., 2019, p. 4).

Influences and motivators for deciding to make a non-normative choice were complex and highly individual. This provides important context for how individuals experience asserting choices within their healthcare system and the institutional barriers they encounter.

#### **Reciprocal theme 2: barriers and conflict**

This theme describes institutional and systemic barriers that influence non-normative choices. The sub-themes discussed below are an inflexible, fearful, risk averse system; policy, procedure, and guidelines; and institutional manifestation of fear.

##### *An inflexible, fearful, risk averse system*

Criticisms of the inflexible nature of institutional systems within which maternity care is offered were observed across studies. Routine screening, examinations and interventions intended for the estimation and mitigation of risk were evident in women's reported accounts of dissatisfaction. Estimation of risk was seen to be about standardised rather than individualised care. The application of guidelines that inform estimation of risk and its mitigation are seen as inflexible where choices fall outside particular parameters, limiting the ability of clinicians to support non-normative care choices (Hollander et al., 2017; Rigg et al., 2017).

##### *Policy, procedure, and guidelines*

Inflexible institutional systems manifested in tension between a woman-centred, individualised approach to care and the risk averse, biomedical model of childbirth where compliance and strict application of guidelines was employed by healthcare providers, seemingly to mitigate medicolegal risk and adhere to institutional timetables. Women's distrust was reported to arise from a view that institutions protect clinicians and institutions from litigation and/or regulatory action, above supporting women's choice (Lee et al., 2016b; Plested and Kirkham, 2016; Hollander et al., 2017) as one participant explains: "*It was invasive, intrusive and my wellbeing as a mother was secondary to achieving timelines of the hospitals protocols*" (Rigg et al., 2017, p. 88).

##### *Institutional manifestation of fear*

Women making non-normative choices about their care were reported to be a step too far for institutions (Lee et al., 2016b). Institutions were described as, "*drawing lines in the sand*" (Jenkinson et al., 2017, p. 8), when women did not comply with clinician recommendations (Plested and Kirkham, 2016;

Jenkinson et al., 2017). Example of actions included: women did not feel they were listened to; the misrepresentation or manipulation of risk information; continued and repeated unwanted conversations (Feeley and Thomson, 2016b; Jenkinson et al., 2016; Hollander et al., 2017; Jenkinson et al., 2017; Rigg et al., 2017, 2020; Roberts and Walsh, 2019); and, the phenomena of "*shroud waving*" (Plested and Kirkham, 2015, p30). Shroud waving refers to the likelihood of the death of the baby or mother should recommendations not be followed.

Reports of obstetric violence and threatened assault were noted (Jenkinson et al., 2017). Women gave accounts of interactions with clinicians claiming loss of identity, dehumanisation and infantilisation, being ignored and treated like "*a piece of meat*" (Keedle et al., 2015, p.5), experiencing impersonal, traumatising births (Rigg et al., 2017) and being viewed through the lens of their condition, rather than as an individual (McDonald and Kirkman, 2011).

Studies also noted the questioning of women's capacity to be a fit mother, labelling women as reckless or deviant in their decision-making (C. Feeley and Thomson, 2016a; Roberts and Walsh, 2019). This sometimes resulted in inappropriate referral to social services (Feeley and Thomson, 2016b; Plested and Kirkham, 2016; Hollander et al., 2017).

Interactions with healthcare providers described in this section are defined by Holten et al., p.1) as "*defining moments*", which are influential in determining non-normative choices.

Women employed sophisticated strategies for asserting non-normative choice in the system described above. A central means of doing so was becoming an expert through seeking and operationalising knowledge, empowering them in their choices.

#### **Reciprocal theme 3: knowledge as empowerment**

This theme describes how women engaged with and utilised knowledge to assert control and autonomy in making non-normative choices. There are two sub-themes, discussed below: seeking and evaluating knowledge; and, operationalising knowledge

##### *Seeking and evaluating knowledge*

A key observation across the studies reviewed was women's knowledge seeking to support and rationalise individual choices. Women reported using a variety of sources and strategies to facilitate "*becoming an expert*" (Jackson et al., 2012, p. 9) regardless of the nature of the choice (de Zulueta and Boulton, 2007; Bakkeren et al., 2020). These sources of information were evident alongside or rejecting medical expertise (Hollander et al., 2017; Eide et al., 2019; Roberts and Walsh, 2019; Henriksen et al., 2020).

Women drew upon their own and familial experiences to inform their choices as well as their instinctual and embodied assumptions of their (in)ability to birth. Some used information from previous pregnancies to decide about screening in a current pregnancy, sometimes declining information altogether (Wätterjöök et al., 2015).

Studies reported that some women were engaged in extensive sourcing and interpretation of evidence including the use of medical journals, primary research and social media sources which served to both inform and legitimise their choices. Social media enabled engagement with communities that reflected their own situations and philosophies (Lee et al., 2016; Roberts and Walsh, 2019; Henriksen et al., 2020). Jackson et al. (2020) reported that for some women in their study this was the first time that the range of birthing options became available, as one participant explained "*I just became more informed about my other choices ...*

[and this] just blew open a whole new world for me around another choice" (Jackson et al., 2020, p. 8).

Few studies identified healthcare providers as primary or trusted sources of information, with some women recognising their own embodied knowledge as superior (Hollander et al., 2017). Participants were reported to engage with knowledge seeking behaviour to corroborate or contradict clinical advice, especially in relation to risk, often rejecting what they consider to be unhelpful, or not applicable, in relation to their individual context (Keedle et al., 2015; Lee et al., 2016). Some women were reported to be selective in drawing on information, minimising information that did not accord with their own beliefs, values, and philosophies, or that might create anxiety, preferring to accept and trust lay information that supported their own understanding and approach to birth. This was illustrated by one participant "*If something's made sense to me, and my logic and my beliefs and my kind of philosophy*" (Lee et al., 2016, p. 3). This might appear to represent elements of confirmation bias, a well-documented phenomenon in health information seeking behaviours (Meppelink et al., 2019; Forgie et al., 2021).

### Operationalising knowledge

Planning for interactions with practitioners was reported across studies, to enable women to be armed with knowledge. This involved negotiation and subversion of the system to avoid intrusion, resistance or opposition from healthcare providers (Feeley and Thomson, 2016a; Jackson et al., 2020; Rigg et al., 2020). Studies highlighted how avoidance strategies and tactics were employed, for example in cases of induction of labour (Roberts and Walsh, 2019) or free birthing practices, as one participant explained:

*"...my tactic with the midwives that we called three or so days later was to be very agreeable, be very kind of apologetic... that 'we're not being contrary or irresponsible, it just kind of happened like this and it was all ok and you know, saved the placenta for you to check and do all the checks to show 'we've nothing to hide'"* (Feeley and Thomson, 2016a, p. 19)

Women clearly utilised knowledge in a sophisticated way covering a variety of sources. Not every interaction with healthcare professionals was challenging, with facilitative and supportive episodes of care noted in the following refutational theme.

### Refutational theme: the middle ground

Only one significant refutational theme was identified through analysis: 'the middle ground'. This refers to the way in which the subversive practices, avoidance strategies and tactics utilised by some women were not always necessary. Some participants reported finding a middle ground which enabled clinicians to work with women to facilitate their needs. The middle ground was described in various ways, rooted in valuing the women's journey by reinforcing and enabling values and beliefs and thus supporting non-normative choices (Fenwick et al., 2010; Crombag et al., 2016; Jenkinson et al., 2016, 2017; Rigg et al., 2017; Roberts and Walsh, 2019).

### Discussion and conclusions

This meta-ethnography offers insights into the views, attitudes, perceptions, and experiences of women who make non-normative choices in childbearing. The review drew on a definition of non-normative choices to include three distinct elements which are discussed in turn below:

- Desiring care outside of established guidelines or medical recommendations which would not be offered as a choice.
- Withholding consent to any routinely offered intervention which is offered as a choice
- Moving outside cultural, social, or familial expectations and non-medical 'norms'

#### *Desiring care outside of established national or local guidelines or medical recommendations*

23 of the papers representing the results of 13 studies focus on care outside of guideline or recommendation which are not usually offered as choices within the intrapartum period i.e., freebirth, homebirth in the presence of complexity, maternal request caesarean section or requesting more intervention. As previously discussed, evidence surrounding decision-making processes in pregnancy provide important insights into how and why women make particular decisions, for example choosing homebirth to avoid perceived unnecessary interventions and support choice (Hauck et al., 2020), however as this review has demonstrated, a focus on specific non-normative choices outside the intrapartum period remains largely absent from discussions, potentially reflecting the expectation of compliance with recommendations and care pathways. Data reflecting the incidence, prevalence and outcomes for women who make non-normative choices are limited, although as interest in the subject grows, as does the evidence base (Hollowell et al., 2014; Rowe et al., 2016). The growth of interest and research in this area may be related to increased scrutiny on healthcare providers to support respectful, safe and personalised care planning, with a renewed emphasis on both a human rights framework and national maternity transformation, especially within the UK (Birthrights, 2017; NHS England, 2021a, 2021b). Many studies have focussed largely on facilitative encounters with midwives and the institutional arrangements for supporting choice with growing understandings of how healthcare providers facilitate non-normative choice alongside more normative requests (Madeley, 2018; Feeley et al., 2020; Larner and Hooks, 2020; Price, 2020; Feeley et al., 2021). As this review has demonstrated however, women making non-normative choices do not always regard healthcare providers, including both midwives and obstetricians, as a source of authoritative knowledge (Davis-Floyd and Sargent, 1997). UK data predominantly falls within this definition of non-normative choice with 10 of the 12 overall studies conducted in the UK focusing on care outside of guidance (freebirth, homebirth with complex needs, vaginal birth after caesarean in water, maternal request caesarean section). These fail to address wider experiences beyond non-normative mode or location of birth choices outside incidental reporting of withholding consent or choices which represent moving outside social, cultural, or familial expectations or norms. Moreover, such choices across the wider childbearing continuum are largely absent. It is also unclear if healthcare providers approach to supporting non-normative choices correspond with the needs and preferences of the women themselves and to this end women's voices remain largely under-represented. This is therefore a significant unexplored dimension in the literature as it is vital women's voices underpin further evidence, representing an apparent gap in practical and theoretical knowledge (Muller-Bloch and Kranz, 2014; Miles, 2017).

#### *Withholding consent to any routinely offered intervention, screening, or treatment*

10 of the papers representing the results of 9 studies focus on withholding consent to any routinely offered intervention which are offered as a choice. Some of the included studies also addressed the declining of screening technologies such as testing and

treatment for HIV and prenatal foetal anomaly screening, induction of labour and the declining of interventions such as cardiotocograph monitoring during a planned vaginal birth after caesarean and induction of labour after 42 weeks (Jenkinson et al., 2017; Roberts and Walsh, 2019), however these were not extensively addressed across the entire childbearing continuum. The review suggests that women make decisions such as these to avoid routine interventions, having to repeatedly justify choices and avoid perceived physical and psychological harm. The review noted the overall paucity of evidence concerning the withholding of consent to routinely offered interventions, screening, or treatment, with only 2 situated within the UK; declining induction of labour (Roberts and Walsh, 2019) and decision making in routine HIV screening (de Zulueta and Boulton, 2007). Jenkinson's study in particular (Jenkinson et al., 2016, 2017) provided valuable insights into women's (and healthcare providers) experiences of this element of nonnormative choice and a process of documenting refusal of recommended care, however application of this knowledge in the UK may be limited taking into account the Australian healthcare and sociodemographic context within which the research was situated. Further research is therefore required to bridge a gap in empirical and theoretical knowledge (Muller-Bloch and Kranz, 2014). This should be wide enough in scope to generate insights into the experiences of making choices in the antenatal, intrapartum, and postnatal period, exploring the decision-making processes, personal influences and motivators and the experiences of withholding consent to any routinely offered intervention, screening, or treatment, within the context of the UK maternity system.

#### *Moving outside cultural, social, or familial expectations and norms*

None of the papers explicitly focussed on experiences of moving outside cultural, social, or familial expectations and norms. Where data were available, this was provided either as context or presented as influences and motivators, as described in the theme of the same name. As discussed previously, if there is to be a move away from describing experiences towards more relational, personalised care pathways with clinician application, it is vital that complex biopsychosocial influences, motivators, and wider social processes that contribute to making such choices are understood. This represents both a knowledge and apparent theoretical gap in the prior research. Few of the papers in the review included or reported including women from Black, Asian, and other ethnic and cultural backgrounds representing a population knowledge gap (Miles, 2017). This is noteworthy because whilst perinatal morbidity is improving globally, there are still poorer outcomes for Black, Asian and other ethnic background women compared to their white counterparts (WHO et al., 2019; Knight et al., 2021). Recent reports have linked these outcomes to structural barriers, institutional racism, lack of physical and psychological safety, dehumanisation and a lack of choice, consent and coercion (Birthrights, 2022). Women therefore may make nonnormative choices to avoid these effects, however within the review data and specifically within the UK, this is an underrepresented field of enquiry. It was also unclear from the studies reviewed the extent to which lesbian, bisexual, pansexual, queer, trans gender and non-binary participants contributed to data across studies. It is not clear from the studies reviewed how diversity of any kind influenced non-normative decisions making. This is particularly significant given emerging evidence that, during the Covid-19 pandemic, women from minoritized communities were more likely to consider freebirth (Greenfield et al., 2021). When taking into consideration the overall findings of this review, reveals a gap in knowledge that supports the need for further research.

#### **Summary and line of argument synthesis**

This meta-ethnography suggests that the reality of making non-normative choices is complex, with choices informed by individual and contextual biopsychosocial factors including the degree to which personal significance is attached to pregnancy and birth, control, and bodily autonomy. Women's non-normative choices are influenced by both direct and indirect experiences of maternity care or negative views of health professionals and health institutions. Non-normative choices may also be the result of push back against a risk averse and (re) traumatising system however this is not the dominant motivator. Non-normative choices are rarely arbitrary; women do not make such choices naively understand and retain personal responsibility for the consequences of their actions. The notion that women prioritise birth experience over physical maternal or foetal safety and outcome is unsubstantiated although psychological and emotional wellbeing is also seen as crucial. The institution remains a central source of conflict and resistance because many women believe that the implementation of risk-averse systems and guidelines are prioritised over their needs. Non-normative choice could therefore be viewed as a physical and psychologically protective behaviour.

#### **Strengths and limitations**

This study has strengths and limitations. One strength common to meta-ethnographies of this type is that we have been able to bring together potentially unwieldy amounts of data whilst maintaining overall conceptual quality and richness to provide new insights. Another strength is that the meta-ethnographic approach to systematic and comprehensive search strategy and synthesis has enabled us to make an original contribution to knowledge through the line of argument synthesis. However, a limitation of the study is that we were only able to include papers written in the English language. Also, the studies we have reviewed do not adequately address issues of diversity and inclusion. Traditionally, meta-ethnographies were criticised for a loss of integrity and authenticity in relation to the primary studies included (Sandelowski et al., 1997); we have, however, been guided by the eMERGe reporting guidelines which were developed to address this critique.

#### *Final conclusions*

Despite continued universal aspiration for choice in maternity care, the degree to which choice can be exerted and how these episodes of care are experienced is influenced by complex biopsychosocial factors, especially in the context of non-normative choice. The review has identified evidence gaps in the prior research concerning key areas of empirical and theoretical knowledge relating to the wider childbearing continuum, as well as underexplored population groups (Muller-Bloch and Kranz, 2014; Miles, 2017). The findings of this review suggest that whilst existing literature from a range of high-income countries with similar healthcare systems to the UK have begun to explore non-normative decision-making for discrete episodes of care and choices, a gap exists and therefore future research should explore the experiences and social pressures that influence decision making for non-normative choices across the UK maternity care continuum.

#### **Author contributions and credit roles**

Dr Sally Boyle: Validation, Supervision, writing – review and editing.

## Ethical statement

Ethical approval was not required due to nature of the work being a meta-ethnographic review.

## Review registration

The review protocol for this study was submitted and registered with PROSPERO (The International Prospective Register of Systematic Reviews), registration number CRD42020223097.

## Funding

Funded PhD studentship by the Faculty of Wellbeing, Education and Language Studies (WELS) at the Open University. Other than the roles acknowledged in author contributions, the funding body was not involved in the design, collection, analysis, and interpretation of the data, writing of this report and decision to submit the article.

## Declaration of Competing Interest

The authors declare they have no conflict of interest, known competing financial interests or personal relationships that could have influenced the work reported in this paper

## CRediT authorship contribution statement

**Anna-Marie Madeley:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – original draft, Writing – review & editing, Visualization, Project administration. **Sarah Earle:** Validation, Supervision, Writing – review & editing. **Lindsay O'Dell:** Validation, Supervision, Writing – review & editing.

## Acknowledgments

This review was part of Author 1's PhD, a funded studentship by the Faculty of Wellbeing, Education and Language Studies (WELS) at the Open University. The views expressed are those of the authors and not necessarily those of the Open University. The Authors wish to gratefully acknowledge and thank the peer reviewers of this paper for their kind feedback and suggestions.

## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.midw.2022.103532.

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