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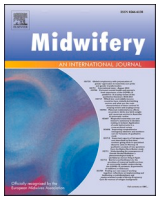

Then they're not there. Women's experiences following admission of their newborn to a neonatal intensive care unit

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ABSTRACT

Background: Gestational diabetes mellitus (GDM) is a complication of pregnancy associated with neonatal morbidities including admission to Neonatal Intensive Care Units (NICU). Previous research highlights a lack of birth satisfaction and trauma for women following admission of their baby. Previously, research has focussed on a pre-term population. This study aimed to explore the experiences of women, diagnosed with GDM, whose babies were admitted to NICU at any gestation.

Methods: A 24-item, fully qualitative online survey was launched through JISC on 28th July 2023, shared through social media and online platforms. Inclusion criteria specified women who had been diagnosed with GDM, lived and received care in the UK and whose baby was admitted to NICU at or shortly after birth. Ethical approval was granted by Bournemouth University.

Results: 18 women participated in the survey. Two primary themes were identified: 'experience' and 'understanding', further separated into five and three sub-themes respectively. A lack of understanding and knowledge was identified, with calls for enhanced education and joint decision making. Women recalled feelings of grief, isolation and stress as a result of the admission. For many, this experience was traumatic with lasting effects. For babies born at term, feelings of surprise and separation were paramount, in contrast to those born pre-term.

Conclusion: There is need to increase education and improve current material to support women who find themselves facing this outcome. Future research should also focus on reducing the incidence of admission to NICU for women who have received a diagnosis of GDM.

Statement of significance

Problem: The prevalence of gestational diabetes mellitus (GDM) is increasing, it may be linked to an increased risk of neonatal intensive care unit (NICU) admission. How women perceive this is yet to be explored in this population.

What is known: NICU admission causes stress for mothers due to separation, impacting mother-baby attachment. Minimising separation is essential for ethical maternity care.

What this paper adds: This online qualitative survey is the first to explore women's experiences of NICU admission following pregnancies complicated by GDM. Women expressed a need for better education about potential NICU admission and desired greater involvement in their care and decision-making.

Introduction

Gestational diabetes mellitus (GDM) is one of the most common maternal morbidities, characterised by hyperglycaemia as a result of carbohydrate intolerance, which first arises in pregnancy (Domanski

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et al., 2018; Keikkala et al. 2020). The prevalence of diabetes is increasing globally; attributed to an ageing population, obesity epidemic and physical inactivity (Zhang et al. 2021). A recent systematic review and meta-analysis determined that GDM is associated with an increased risk of adverse neonatal outcomes including admission to a Neonatal Intensive Care Unit (NICU), respiratory distress, hypoglycaemia and jaundice (Ye et al. 2022). According to NHS Improvement (2017), now NHS England, the four primary reasons for babies born at term being admitted to NICU are asphyxia, hypoglycaemia, respiratory distress and jaundice.

NICU provides a place of care for sick or premature neonates and forms part of a planned approach to care (Malouf et al. 2022). However, the admission of a baby to NICU can be distressing and overwhelming for parents, particularly for women who report high rates of stress and anxiety (Roque et al. 2017; Malouf et al. 2022). Admission to NICU often results in physical separation, which has been proven to be a critical obstacle in the formation of mother-baby relationships and the positive development of attachment (Crenshaw 2019; Wang et al. 2021; Malouf et al. 2022). Women have reported that such separation adds to the trauma of complex birth (APPG 2024). Preventing separation, except for compelling medical indications is an essential part of providing safe maternity services and an ethical responsibility for healthcare professionals (Crenshaw 2019).

Globally the screening, diagnosis and management of GDM remains idiosyncratic with no unanimously accepted criteria, even between high-income countries (Tieu et al. 2017). Previously, GDM was diagnosed based on the likelihood of the women developing type 2 diabetes later in life; however, diagnosis is now based on the potential for adverse outcome in the index pregnancy (Agarwal 2015). Following the Hyperglycaemia and Adverse Pregnancy Outcomes (HAPO) study, the development of the International Association of Diabetes and Pregnancy Study Group (IADPSG) criteria were developed (IADPSG 2010). However, a rapid increase in the prevalence, the associated financial burden, and fears of over medicalising pregnancy without proportional improvement in adverse outcomes have meant that these criteria are yet to be universally adopted (Cundy et al. 2014; Agarwal 2015). In contrast to the IADPSG criteria, the screening, diagnosis and management of GDM in the UK continues to follow National Institute for Health and Care Excellence (NICE 2020) guidance. Global disparities in the defining characteristics of NICU and the classification of care levels makes synthesising international evidence problematic (Malouf et al. 2022). A systematic review suggested that women's experiences involving GDM could be used to inform the content of communication materials both before and after diagnosis (Craig et al., 2020).

Given the increasing prevalence of GDM globally, the increased likelihood of admission to NICU and the known literature evidencing women's experiences, this study aimed to understand the experiences of women, diagnosed with GDM, whose babies were admitted to NICU.

Methods

The researchers adopted an interpretivist approach because of their interest in understanding the meaning behind individual experiences. Since the focus was on the 'emic' perspective (the 'inside view'), it was appropriate to select a qualitative design for the study (Holloway and Galvin 2018). Data in qualitative research is typically collected through close contact with participants such as by interview (individual or focus groups). However, the topic (term admission to NICU) would have made recruitment challenging due to a limited number of potential participants in the geographical area. For this reason, an innovative qualitative method, the qualitative survey (Braun et al. 2021), was used.

Survey design

This was a qualitative online survey of women whose pregnancy was complicated by GDM. Fully qualitative surveys are unusual but offer the researcher the ability to include a more diverse population than would be possible with in-depth interviews without geographical limitation (Braun et al. 2021; Thomas et al. 2024). The anonymity afforded through online surveys can encourage greater participation from individuals who experience anxiety in social interactions or who might have otherwise avoided discussing sensitive or emotional topics in face-to-face settings (Terry and Braun, 2017; Davey et al., 2019; Braun et al., 2021). Online surveys offer participants a degree of autonomy that would not be possible with face-to-face methods, such as interviews or focus groups (Thomas et al. 2024).

Survey content was derived from a recent scoping review (Stedman, 2025) and systematic review (Wang et al. 2021). A 24-item, fully qualitative online survey was designed by the primary researcher LS and hosted on the JISC Online Surveys platform. In line with a qualitative interview approach, questions were open ended enabling participants to respond freely. Questions prompted participants to reflect on their emotional experience, to detail conversations with staff as part of their enhanced care provision, recall education received with regard to NICU and to consider any impact on their overall birthing journey (Appendix 1). Each question was formatted with a large free-text box to enable a full and detailed response. A small amount of demographic data was collected in order to describe the participant population.

The questions were reviewed by an expert midwifery panel which consisted of a professor of midwifery, an associate professor and experienced research academic, and a midwifery lecturer with expert knowledge in the field of GDM. Holloway and Galvin state that "pilot studies are not always used in qualitative research as the research is developmental" (Holloway and Galvin 2018, p88), but interview studies traditionally use the first couple of interviews as a form of a pilot to inform how the questions are asked. Given the online nature of this study, early responses were reviewed to identify any issues with the survey. No issues were found and therefore the survey was not changed.

Ethical approval

Ethical approval was obtained from Bournemouth University in July 2023 (REF 51994), an amendment was accepted in September 2023 following a request to extended advertisement of the survey on social media. Prior to commencing the survey participants were presented with a comprehensive participant information sheet (PIS), which was also available to download. The PIS included details of support groups that participants may find beneficial given the emotive nature of recounting their lived experiences.

Participants

Participants were recruited through a number of mechanisms. The survey was initially advertised through two GDM support groups. Following a limited response, recruitment was extended by using a social media platform (Facebook) and subsequently shared across a multitude of groups including diabetic charities and maternity voice partnerships (MVPs) to ensure breadth of involvement. Women were invited to access the link, but participants only progressed to the survey after consenting to participate and successfully answering the screening questions. Inclusion and exclusion criteria are listed in Table 1.

Participation was voluntary, and those who did not consent were directed away from the survey to a page thanking them for their time. Confidentiality was protected by ensuring the survey did not contain personal, identifiable information such as names, email or IP addresses.

Data collection

The survey was launched through JISC online surveys on 28th July 2023 and was open for 21 weeks. The survey was fully online and able to be completed on a multitude of personal electronic devices. The data were collected and analysed at regular intervals with the survey closed

Table 1
Inclusion and exclusion criteria for the online qualitative survey.

INCLUSION CRITERIA	EXCLUSION CRITERIA
• Screened and diagnosed with GDM in the pregnancy the participant is answering about	• Pre-existing diabetes including type 1, type 2, Maturity Onset Diabetes of the Young (MODY) or any other type of diabetes • Borderline or negative screening for GDM
• Baby/babies admitted to NICU at birth or within 28 days of life	• Routine postnatal care on either postnatal ward or enhance transitional care ward, but not admitted to NICU
• Screening, diagnosis and management of GDM in pregnancy by a healthcare institution in the UK	• Received any part of pregnancy care outside of the UK
• Birth within the last five years	• Birth more than five years ago

once saturation had occurred. Saturation was considered the point at which further data would not lead to discovery of more information (Lowe et al. 2018). To protect anonymity, participant responses (quotes) were recorded and attributed in the JISC Online Survey platform using a numerical code. On completion of data collection, the data were extracted from JISC and transferred to a password protected file on a Bournemouth University encrypted laptop. Data were kept securely in line with general data protection regulation (GDPR).

Data analysis

The findings from the free text questions were descriptively analysed using reflexive thematic analysis (RTA) whereby patterns within the dataset are identified and themes are developed following a systematic process of data coding (Braun and Clake 2022). RTA is flexible, allowing researchers to uncover nuanced insights whilst also considering the impact of their own reflective stance on the themes generated without abiding by rigid guidelines. RTA allows researchers to foster deep and sensitive interpretations which is particularly useful when seeking to understand participant experiences. To do this, the six stages encouraged by Braun and Clarke (2022) were adopted. A number of creative tasks supported the analysis. Once familiarisation with the dataset had been achieved and initial coding had been completed, a Word Cloud (Fig. 1) was used to identify frequently used words and phrases, which then supported the generation of initial themes. By consistently developing and reviewing the themes, more refined areas of interest became apparent which facilitated a deeper understanding of participant experiences.

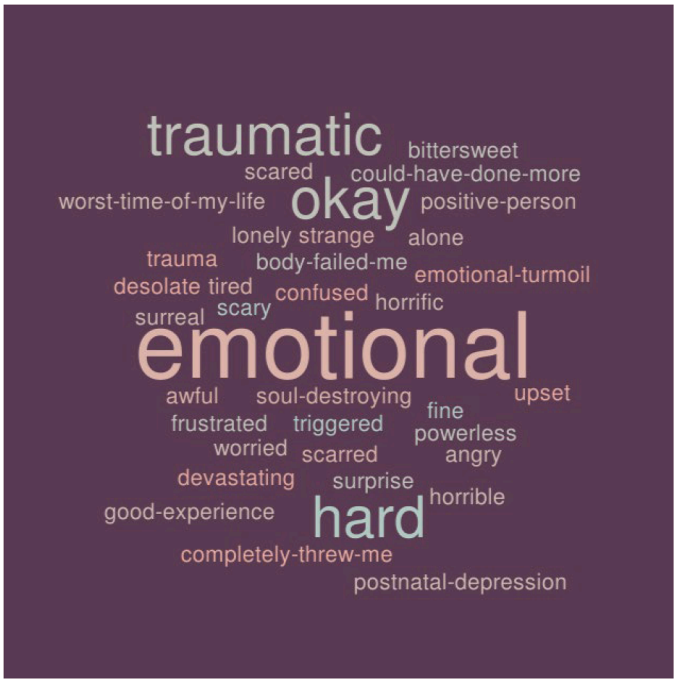

Fig. 1. . Word cloud of frequently used words and phrases.

Reflexivity was critical in ensuring that analysis remained sensitive and ethical, and this is essential in health research, where practitioners may be inclined to adopt professional ways of thinking (Holloway and Galvin 2018). By critically reflected on their own perspectives, the researchers mitigating bias whilst acknowledging their personal values and preconceptions. This in turn helped enhance the transparency of the inquiry and strengthened its credibility. Direct participant quotes have been used within the discussions to demonstrate the veracity of each theme. The closed questions and demographic details were analysed in simple percentages.

Results

A total of 598 people opened the survey and 61 progressed to the consent page (Fig. 2). Nine participants dropped out prior to consenting and a further six before screening was complete. Twenty participants were screened out. Eight participants dropped out following screening, but before completing the survey. In total 18 people completed the survey. Most participants were aged 30–34. Gestation at birth ranged from 28+2 weeks of pregnancy to 39+0 weeks of pregnancy with just over half birthed at a term gestation and the remainder considered preterm at <37 weeks of pregnancy. None of the participants birthed an extremely pre-term infant, defined as below 26 weeks of pregnancy (NICE, 2022). Despite launching the survey UK wide, participants exclusively lived in England, with responses missing from Wales, Scotland and Northern Ireland. Participants differed in educational level, ranging from no qualifications to degree-level or equivalent status. Nearly two-thirds participants considered themselves to be in the latter category. A full account of all participants including codes for future quotation reference is included in Table 2.

Thematic analysis

Two main themes were generated from the data: experience and understanding. As a theme, 'experience' evolved into five further subthemes:

- 'then they're not there';
- then and now: the emotional toll;
- journeying NICU;
- birth experience & great expectations
- infant feeding.

Understanding was further analysed under three sub-themes:

- clinical care;
- informed decision making
- understanding NICU.

There were some important instances of overlap between themes which will be discussed throughout the results, however, for clarity and understanding the themes are presented separately (Figs. 3 and 4).

Experience – 'then they're not there'

Several of the women who participated in the survey shared feelings of loneliness and isolation, often due to visiting restrictions within NICU, their partner being asked to leave or being discharged from the hospital to create bedspaces. As one woman said:

"I was so sad he couldn't meet his big sister and he had to stay for almost a week but I was sent home after 2 days because it was busy

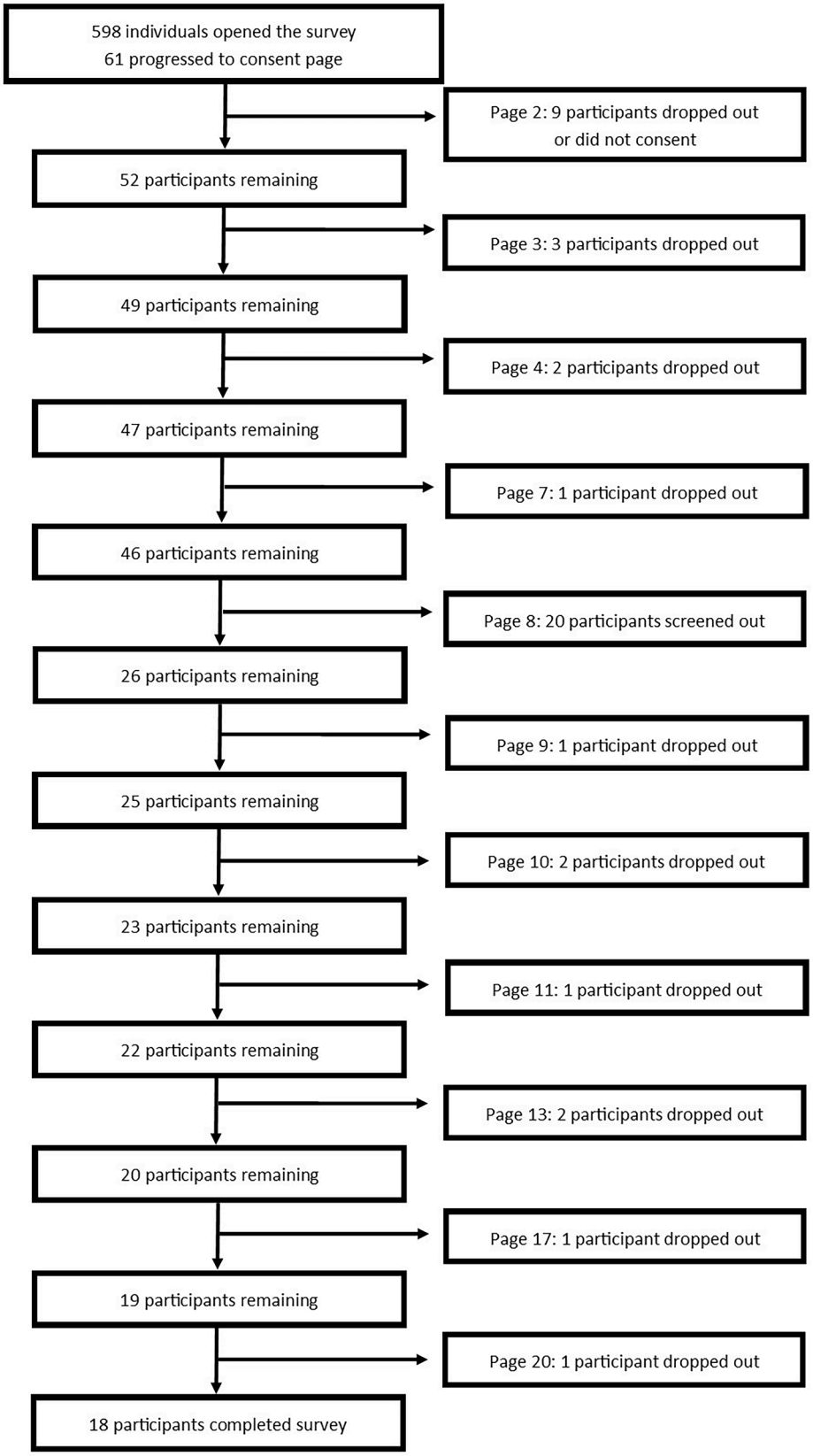

Fig. 2. Survey responses and participant drop out.

Table 2
Participant demongraphics.

Participant Code	Gestate	Gestation at birth	Health Conditions	Treatment	Gender Identity	Age	Ethnicity[1]	Region	Education[2]	Disability
310	Singleton	38+1	None	Combination [metformin (Glucophage) and insulin]	Female	35–39	White	North East	Level 3	None
799	Singleton	37+6	GBS Polyhydramnios	metformin (Glucophage)	Female	30–34	White	South East	None	None
659	Singleton	39+0	Mental Health LGA	metformin (Glucophage)	Female	30–34	White	South West	Level 2	Mental Health
996	Singleton	37+3	None	Diet	Female	24–29	White	South East	Level 4	None
613	Singleton	38+5	None	Insulin	Female	30–34	White	South East	Level 3	Dyslexia
376	Twin	34+5	Pre-eclampsia	Diet	Female	40+	White	East of England	Level 4	Hearing Mental Health
465	Twin	36+0	OC	metformin (Glucophage)	Female	30–34	White	South East	Level 2	None
556	Singleton	38+2	None	Insulin	Female	30–34	White	West Midlands	Level 4	None
437	Singleton	36+2	None	Insulin	Female	30–34	White	Yorkshire & The Humber	Level 2	None
261	Singleton	38+1	None	Insulin	Female	35–39	Asian	London	Level 4	None
302	Singleton	28+2	Erythromelalgia Raynaud's Hyperemesis PGP	Unspecified/Unknown [birthed before treatment]	Female	30–34	White	North West	Level 4	None
402	Singleton	30+2	Pre-eclampsia	Diet	Female	40+	White	North East	Level 4	None
079	Singleton	39+0	None	Diet	Female	40+	White	London	Level 4	None
764	Twin	36+4	Endometriosis	metformin (Glucophage)	Female	40+	White	South East	Level 4	None
436	Singleton	38+2	Previous LSCS	Insulin	Female	35–39	White	South East	Level 4	None
611	Twin	29+6	TTTS	Insulin	Female	35–39	White	Yorkshire & The Humber	Level 4	None
336	Singleton	36+3	Ulcerative Colitis IBD	Unspecified [medication]	Female	30–34	White	Yorkshire & The Humber	Level 3	None
021	Singleton	39+0	None	Diet	Female	35–39	White	South West	Level 4	None

ABBREVIATIONS: GBS – Group B Streptococcus; LGA – Large for Gestational Age; OC – Obstetric Cholestasis; PGP – Pelvic Girdle Pain; LSCS – Lower segment caesarean section; TTTS – Twin to Twin Transfusion Syndrome; IBD – Inflammatory Bowel Disease.

[1] Ethnicity has been recorded as the leading title of each group and may include any of the following in the same category: Asian, Asian British, Asian Welsh (Bangladeshi, Chinese, Indian, Pakistani, Other Asian); White (British, Irish, Gypsy or Traveller, Roma or Other White); Black, Black British, Black Welsh, Caribbean or African (African, Caribbean, Other Black); Mixed or Multiple (White and Asian, White and Black African, White and Black Caribbean; Other mixed or Multiple ethnic groups).

[2] Education is categorised under the following headings: Level 1 and entry level qualifications: 1 to 4 GCSEs grade A* to C, Any GCSEs at other grades, O levels or CSEs (any grades), 1 AS level, NVQ level 1, Foundation GNVQ, Basic or Essential Skills; Level 2 qualifications: 5 or more GCSEs (A* to C or 9 to 4), O levels (passes), CSEs (grade 1), School Certification, 1 A level, 2 to 3 AS levels, VCEs, Intermediate or Higher Diploma, Welsh Baccalaureate Intermediate Diploma, NVQ level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First or General Diploma, RSA Diploma; Level 3 qualifications: 2 or more A levels or VCEs, 4 or more AS levels, Higher School Certificate, Progression or Advanced Diploma, Welsh Baccalaureate Advance Diploma, NVQ level 3; Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma; Level 4 qualifications and above: degree (BA, BSc), higher degree (MA, PhD, PGCE), NVQ level 4 to 5, HNC, HND, RSA Higher Diploma, BTEC Higher level, professional qualifications (for example, teaching, nursing, accountancy); Apprenticeship; No formal qualifications; Other qualifications.

> and they needed the bed back. I know the nurses were looking after him well and it was nice to get photos but I wanted to do that myself and to bring him home to meet all the family" (659).

Even in their personal absence, women would embrace their partner being able to visit the baby and this seemingly brought them comfort. For example:

> "It was good that my husband went to the unit and spent time with our son… amazing that my husband could go there as well any time" (079).

Several of the women felt their baby was "taken" from them, highlighting how this was not perceived as a voluntary choice. Whilst some women could rationalise and comprehend how their own clinical situation or physical restrictions impacted their ability to visit their baby, for some this wasn't enough and manifested as feelings of guilt and heartbreak.

> "The idea of her being somewhere other than with me was heartbreaking, I wasn't very well either because I had sepsis, made visiting very difficult." (261)

For some women this loneliness was exacerbated when considering their wider family unit. Many women felt it caused a separation both emotionally and physically. For one woman, returning home and explaining to siblings why the baby was not there was described as "the hardest bit" (659).

Experience – 'Then and now: the emotional toll'

For women who reflected on the emotional impact, there were generally two perspectives. How they felt initially and how they feel now. Generally, the initial emotions felt were of a negative stance with women using phrases such as, "devastating" (799), "traumatic" (465) and "the worst time of my life" (611).

A few women did not express any particular emotion, instead alluding to a void of emotion as a result of being overwhelmed, tired and surprised. For many who expressed thoughts of sadness, powerlessness and depression, these emotions continue to manifest despite varying

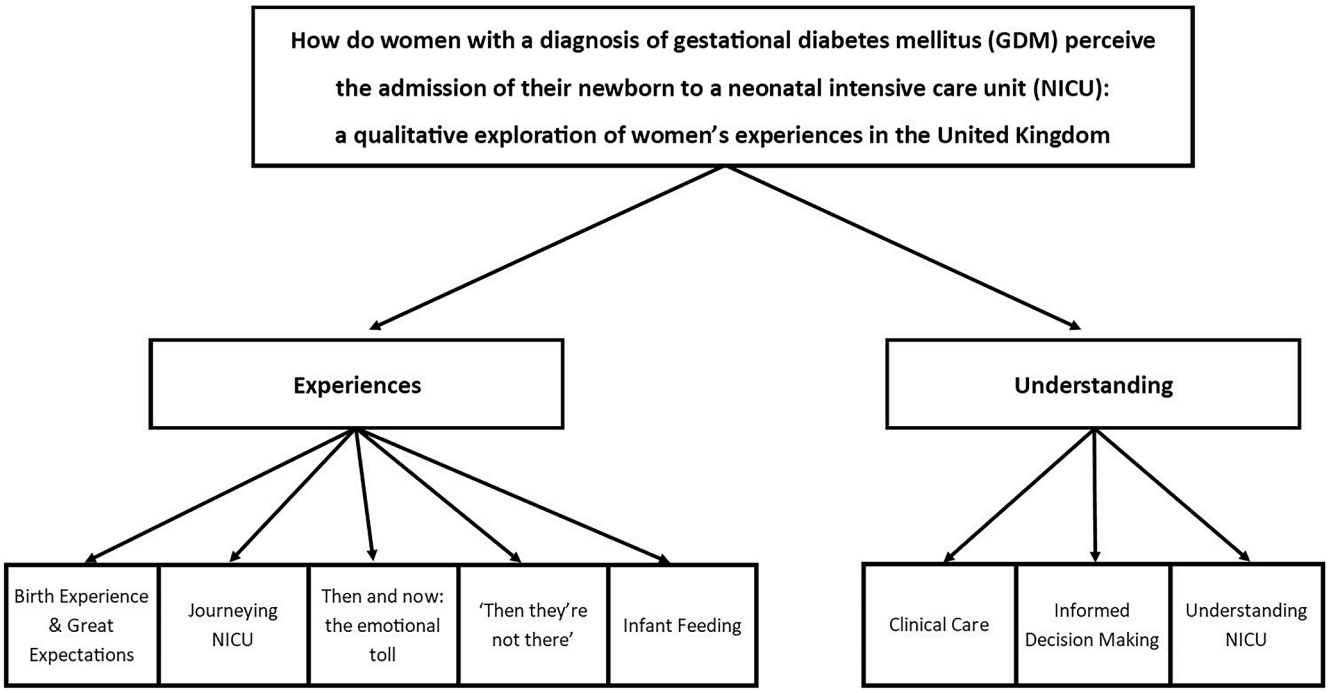

Fig. 3. Themes and sub-themes.

periods of time between births and these accounts. For two women, who birthed three and five years ago respectively, both shared continued recollection and trauma.

> "I couldn't understand why I was not allowed to go in to see her. It was a desolate, soul destroying experience for the first few weeks. Five years later this still affects me hugely." (402)

For others, time and reflection appears to have been more healing with one woman who recalled initially feeling worried and scared, instead now experiencing thoughts of confusion and frustration but "generally ok" (302).

Experience – 'Journeying NICU'

There were two key elements for the women who discussed their 'journey' through NICU: outcomes for their baby and how professional staff influenced their experience. Many of the women shared feelings of apprehension and worry regarding clinical care following admission to NICU. There appears to be a preconception of vulnerability and an association with poor outcomes.

> "I felt powerless. My body had failed me and my daughters. I was so worried I would lose them and terrified about them catching an infection in hospital." (611).

Some women reflected on the equipment being used and how it appeared. The uncertainty and lack of understanding for their new environment evoked further feelings of fear and concern.

> "I was sad that we couldn't be together and seeing all those tubes and wires is scary… There is lots of beeping and noises in the NICU and it would scare me because I thought it was his monitor." (437)

This was also reflected in the sub-theme of 'understanding NICU', which is later discussed. There appears to be a connection between staff relationships and the woman's perceptions of the clinical care provided. One participant sadly recalled the loss of a previous child due to "neglect and not being listened to" (336). But otherwise, there was an overwhelming response highlighting positive relationships with staff and how both physical and emotional aspects of care impacted the women's experiences. Many shared how they felt their baby received high quality, professional care.

> "Highly professional unit, helpful and caring staff with empathy… The advanced neonatal practitioners were expecially amazing. 1 in particular came to see me regularly and offered me so much help and support" (764)

Others recognised how staff went above and beyond to care for them emotionally, recalling feelings of support, reassurance and empathy.

> "They showed me how to dress him and how to breastfeed so it was like I had intense mum lessons there." (079)

> "One nurse recognised I was upset and sent me videos of my baby whilst on the ward." (764)

Almost one-quarter of participants also described an overall priority or goal for their pregnancy, birth and time in NICU. Women almost unanimously shared how the baby's health and welfare took precedence amongst anything else.

> "I'm just glad she is ok." (613)

> "…but like most other mums, my biggest priority was to make sure my baby was ok." (556)

> "…again it doesn't matter in grand scheme he was ok, and he was safe." (996)

Experience – 'Birth experience & great expectations'

There were differences in women's perceptions of their whole birthing experience. Some women felt that they had lost the ability to choose aspects of their care, whilst other women felt their birth no longer aligned with their initial preferences.

> "I didn't have a birth plan as such, that went out the window" (556).

Some women felt that they had a positive experience, but this was mostly with focus on the birth itself. For some women, the difference between what they had expected or envisioned their experience to be like, lead to feelings of grief and loss.

> "I feel like I lost not only my pregnancy experience but also what I envisioned for birth. I grieved the loss of both experiences." (402)

This was also reflected by women who expressed difficulty with

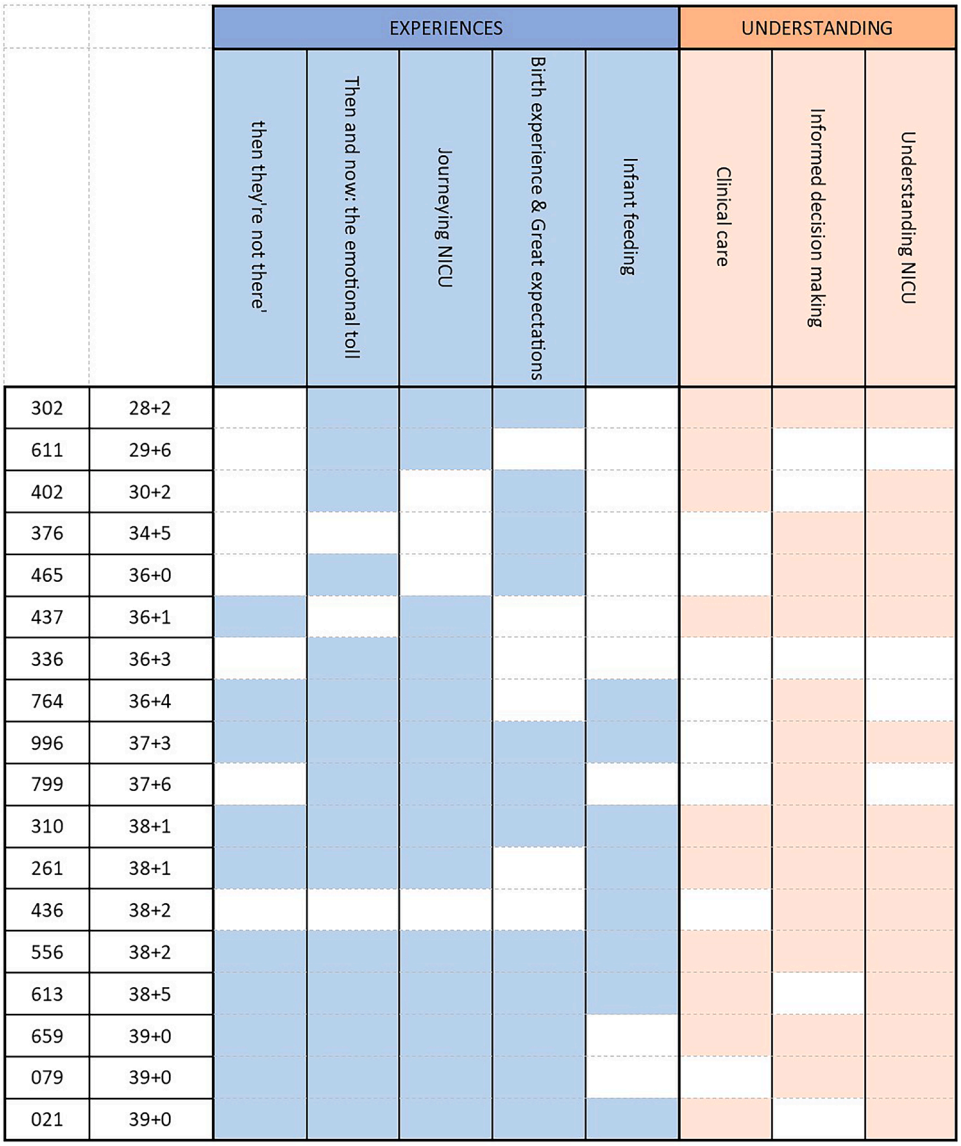

Fig. 4. Theme and sub-themes by gestation.

bonding and attachment as a result of the admission to NICU.

"NICU team were great but it didn't feel like my baby. I wasn't allowed to touch him without washing hands twice etc." (996).

Others shared feeling a lack of consideration from staff at the time of admission. This manifested when some participants reflected on their care following admission.

"After they wheeled him out the team just carried on and I could hear people talking around me but no one really explained what would happen next… In the recovery room the beeping from the machine doing my blood pressure seemed so loud because all the other noise just stopped. For the staff it was an every day event, but this was my first baby and I had no idea if he was even still breathing." (556).

One woman recalled being surrounded by other women who had their babies by their side.

"When he was taken from me I was made to go into the postnatal ward where everyone had their babies. I could hear them crying. My husband was forced to leave because of the covid restrictions and I didn't know what was happening with my baby." (021).

Ultimately, for women with who had not previously experienced birth, making comparisons was more difficult.

"I know no different so can't comment" (376).

Experience – 'Infant feeding'

There were mixed responses in relation to women's accounts and experiences of infant feeding. These were most commonly shared by women who birthed at late pre-term or term gestations (Fig. 3).

Some women recalled feelings of apprehension despite not yet experiencing any problems.

"I understood why they needed to test his sugars but no one really explained what would happen if they were low or how it would work with him being in special care. I was worried I wouldn't be able to breastfeed very well." (310)

Whilst others shared frustrations around the difficulty with expressing breast milk.

"I had always had a really good milk supply and had harvested approx 40mls EBM prior to birth. When my baby was taken to NICU my milk supply seemed to stop and I wasn't able to hand express. I

was told I could not feed my baby directly as it would make him too tired. As soon as my baby was returned my milk came back." (436).

For some women, they experienced more of an emotional barrier to hand expressing. The act of NICU staff providing photos seemed to result in positive experiences, but in relation to supporting feeding, photos were not always beneficial.

"Someone came to remind me every three hours to express my milk for him and it just felt wrong. I have never felt so alone in all my life." (556)

"I was given a photo and I didn't get those warm fuzzy feels… They said to try and express whilst looking at the photo but I felt a bit clueless" (996).

There were some frustrations, particularly when women reflected on the use of formula milk. Whilst some saw the provision of formula as a means of supporting their baby, others were not so accepting and felt this impacted on their breastfeeding journey.

"I feel angry that I wasn't listened to about trying to feed my baby and also that formula was pushed upon us." (436).

The connotation of feeding support also exhibited mixed responses with contrasting perspectives, especially once the women returned home.

"My biggest upset is that he was able to be breast and bottle fed in NICU but when we came home there was no support and he continued being fed NG tube. He now has an aversion and is fully fed by NG tube. Theres no provisions for supporting with feeding at home. Even now there's nothing local and funding isn't approved because of postcode lotteries and the appropriate services being out of area." (021).

Understanding – 'Clinical care'

Almost half of the participants discussed their understanding of how GDM impacted their pregnancy and birth. Some recalled being aware of the clinical implications a diagnosis of GDM entailed including extra scans, glucose monitoring and expediting birth, but discussion was mostly focussed on care throughout pregnancy and rarely extended to postnatal care.

"…the doctors spoke a lot about possible problems for me like needing to be induced early or if she was big and her shoulders got stuck." (613).

When considering understanding in regard to implications for the baby, responses focussed almost exclusively on growth and the impact on mode of birth. One woman raised concern that outcomes for the baby were not discussed.

"I was induced because of the diabetes and I had lots of conversations about if the induction didn't work, if his shoulders got stuck, the potential for bleeding and maybe needing a section but no one ever spoke about the potential outcomes for the baby" (556).

Some of the participants discussed their understanding of professional roles and how this influenced their decisions. For example, one woman stated,

"I understand the doctors are there to protect and advise me…", "doctors said he has to be born early…" (556)

Some responses were not indicative of a shared approach to care. One woman recalled accepting a doctor's recommendation despite it being in contrast to her choice, whilst another felt that her perspective was not being considered.

"Having diabetes meant I had to have lots of extra scans and tests. I got induced too which I didn't want." (310)

"I suspected GDM since 16 weeks gestation due to symptoms I was having but was a battle to get anyone to take me seriously." (302)

Understanding – 'Informed Decision Making'

When asked to describe in detail any conversations about NICU being a potential outcome for the pregnancy, nearly two-thirds did not recall any discussions of this topic taking place. Of those who did recall, one reported that this was through a leaflet and not discussion, one felt it was only after she asked and even then it was "glossed over" (764) and two reported that they were aware but only because they were anticipating a premature birth as a result of a multiple pregnancy.

Over one-third of participants reported a sense of not understanding what was happening and why, or wanting to know more information. Regardless of whether women felt they were aware of NICU being a possibility or not, there was an evident desire for better education both in regard to choices through pregnancy but also in managing daily expectations in NICU. One woman called it a "learn as you go situation" (376).

For many women, they felt the extra information would have influenced their decisions and the impact the admission to NICU would have on their mental health.

"I think I would have considered things differently if information about how it could affect the baby was shared too." (556).

For one respondent in particular, the admission to NICU resulted in feelings of self-blame and questioned if their choices were an influencing factor in this outcome.

"It made me question every decision I had made throughout my labour and birth, I was concerned that maybe something I had done had caused this… I still question my decisions now and think I would handle the situation differently." (261).

A few participants reflected on how knowledge was shared and the impact any previous understanding had. Two perspectives emerged. Firstly, some were grateful for any material regardless of format and believe this education should be mandatory to aid preparation. However, another participant felt "you can never prepare yourself for the NICU" (465).

Understanding – 'Understanding NICU'

Of all 18 participants, only one reported they did not know or understand why their baby was admitted to NICU. Despite this, the overwhelming majority still questioned aspects of care they did not feel they fully understood.

"One doctor talked about how he was really big probably because my sugars were always high so he might need some extra help if his sugars went low but I didn't know that was something that he could be taken away for. When he couldn't breathe properly I didn't know about that." (659).

Whilst some understood the clinical need for intervention, the speed of admission was not something that was anticipated. Participants recalled being surprised by the air of urgency to admit the baby.

"The whole experience from labour to c-section didn't feel like an emergency. And when I did see my son for that brief moment, he seemed 'fine'." (996).

This feeling of uncertainty was echoed by many participants, with some finding it difficult to balance their expectation of parenting with the implications of their baby requiring clinical care. Many participants voiced a struggle in not having exact answers and making future plans.

"I think the worst part was not knowing how long she would need to be there. Every time I asked they just said they didn't know." (613)

Two participants highlighted a common misconception, and a key understanding to why admission to NICU can be so surprising for some women.

"I feel like once you reach the later stages of pregnancy it stops becoming a concern because NICU is associated with premature babies." (261)

"I thought NICU was for premature babies or babies that were really sick so my whole experience was tainted by this thought of 'is he too sick to ever come home" (556)

Discussion

This research explored women's perceptions, opinions and experiences when their pregnancy has been complicated by GDM and their baby is subsequently admitted to NICU.

The emotional impact of separating the mother and baby dyad to facilitate admission to NICU was a key finding in the theme of experience. The negative emotional toll was shared almost unanimously by participants, regardless of gestation at birth (Fig. 3). This echoes findings of three meta-analysis and systematic reviews, all of which indicate increased rates of either anxiety, stress, mental ill health and difficulty in bonding as a result of the admission to NICU (Caporali et al. 2020; Wang et al. 2021; Malouf et al. 2022).

The majority of research to date exploring NICU admission has focussed on preterm babies. However, this study found the perception of unexpected admission was much more prevalent amongst women of babies born late-preterm and term gestation. Parental experiences in the NICU has been well researched, but there appears to be a dearth of literature exploring the experiences for these later gestations. This makes it difficult when looking forward at future suggestions for practice and should be actioned. From this research, it appears that there was an anticipation and acceptance that premature birth goes hand in hand with admission to NICU, however, the same cannot be said for babies born at a later gestation.

There were some findings that interacted between themes. A multitude of responses highlighted the link between a lack of understanding, the impact this had on the overall birth experience, and the overwhelming desire for enhanced education and support.

At the point of initially diagnosing GDM, many women express feelings of self-blame, fear and concern (Craig et al., 2020). Uncertainties around managing the condition, prognosis for the pregnancy and feelings of isolation are a focal point for many women (Craig et al., 2020). He et al. (2020) found women are inclined to focus on interventions and outcomes that promote the wellbeing of their baby, prioritising the needs of the baby over their own, in concordance with the findings of this research. Ensuring informed choice and decision making is an ethical principle in guiding women-centred care (Yuill et al. 2020). However, there are also concerns that promoting autonomy and choice can result in tension between individual preference and professional guidance (Jomeen 2012). To achieve this, women are likely to seek information from professionals, but may also venture outside of the medical sphere, seeking input from social sources such as friend and family (Yuill et al. 2020; He et al., 2020). In this study, several participants were concerned that they were not made fully aware of the potential outcomes for their choices. They reported that clinicians focussed on managing the pregnancy and the immediate concerns, such as growth and induction of labour, rather than involving women in decisions. The impact of this is evident where, on reflection, some participants felt they would have altered their choices or given further deliberation if there had been better communication and shared decision-making. Clinicians recognise that services are likely not currently meeting women's needs with recurring themes around lack of individualised care, disparities in health education and support, and a lack of choice (Van Ryswyk et al. 2014; Craig et al., 2020). Although not directly related to education with regard to GDM, Akca et al. (2017) found that a systematic multidisciplinary birth preparation programme improves birth satisfaction and experience by enabling women to communicate better and participate in decision making. Women have come to expect health professionals to give advice and support their education with appropriate resources (He et al., 2020). In the dominance of a medicalised model of care, women can feel persuaded by professional opinion, valuing their expertise and appreciation for their role (Jomeen 2012). However, there are also concerns that some professionals may restrict information, influenced instead by personal opinion, preference or judgement (Jomeen 2012).

Strengths and limitations

Creating and launching online surveys has become increasingly simple, the flexibility offered by modern online programmes allows researchers to utilise a number of question types, formats, layouts and visual aspects which support inclusivity (Evans and Mathur 2018; Braun et al. 2021). With some countries close to 100 % internet coverage, a significant proportion of people can access the internet via smartphones, allowing researchers to reach potential participants virtually any time (Evans and Mathur 2018). This has meant researchers can now obtain large samples of data, across a greater geographical spread, but at a significantly reduced cost compared to some traditional survey methods (Braun et al. 2017; Evans and Mathur 2018). This survey was confined to a UK population where only 6 % of adults do not have access to the internet, and 17 % of adults only use the internet through their smartphone (Ofcom 2024). As a result, internet access was not considered to be a limitation to this research. The anonymity offered by online surveys can also increase participation from people who find social interaction anxiety induced, or who may have otherwise avoided sensitive, emotive topics in face-to-face situations (Terry and Braun 2017; Davey et al. 2019; Braun et al. 2021). There are, however, some limitations to consider. When distributed electronically, some surveys can be perceived as junk often intercepted by automatic spam filters (Evans and Mathur 2018). Equally, concerns regarding the security of information stored have also impacted rates of participation (Evans and Mathur 2018). If participants are illiterate, struggle to understand the primary language or lack online access or privacy, all could limit rates of participation (Evans and Mathur 2018; Braun et al. 2021).

Although online surveys can support inclusivity through flexible formats and wide accessibility, the sample in this study was predominantly White. This lack of ethnic diversity may limit the transferability of the findings to more diverse communities and settings, and highlights the importance of considering cultural and demographic factors when interpreting the results

Qualitative research typically focusses on achieving a rich understanding and perspective with regard to the topic studied, as opposed to generating a sample that is representative of the whole population (Braun et al. 2021). Because of this, a qualitative survey was used with a series of open-ended questions to harness understanding of issues in this research area (Braun et al. 2021). Fully qualitative surveys are unusual, arguably because of the novel approach, but can be useful in allowing participants to answer freely in their own words, in turn producing a rich and complex account of their experience (Braun et al. 2021). One might argue that this method favours those participants with higher levels of education, however this study found that women felt able to share their experiences in writing irrespective of their education level.

Another critique of the online qualitative survey is the assumption that only "thin textual data" can be collected by this method (Thomas et al. 2024). This is not our experience; indeed, participants provided detailed accounts of their experiences and the impact that NICU admission had on them, enabling a rich understanding of a sensitive topic. Future research might consider following up with online interviews, but this would have required the participants to provide personal, identifiable information and could have affected their willingness to participate so openly on a sensitive subject. Online surveys offer participants the possibility of dropping out at various stages of the survey (nine participants chose to do this), which would not be possible with face-to-face methods, such as interviews or focus groups (Thomas et al. 2024).

Conclusion

This qualitative survey highlights the psychological impact that an admission to NICU brings to parents. Whilst research has previously focussed on preterm populations, this qualitative survey found that admission to NICU at late pre-term and term gestations prompted feelings of trauma, separation and being in the unknown. Concerns for infant feeding were also more common the later the gestation at birth.

A key finding was the desire for education and awareness to aid birth preparation. There is a paucity of literature examining this topic specifically with regard to GDM. Birth trauma is a salient and important topic of discussion. Further research is required to explore ways of firstly improving experiences following admission to NICU, or secondly, reducing the incidence.

CRediT authorship contribution statement

Laura Stedman: Writing – review & editing, Writing – original draft, Visualization, Validation, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Catherine Angell:** Writing – review & editing, Visualization, Supervision, Methodology. **Vanora A Hundley:** Writing – review & editing, Visualization, Supervision, Methodology.

Declaration of competing interest

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

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Supplementary materials

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